PARKINSON'S DISEASE AND MOVEMENT DISORDERS CENTER

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

Please join us for PD 101: A recently Diagnosed Workshop on May 21st!

Parkinson's 101: Recently Diagnosed Parkinson's Workshop

An introduction to Parkinson's disease, including diagnosis, common motor and non-motor symptoms, treatment and interventions. 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: May 21st and November 19th Time: 4:00-5:30PM (CT)

E-mail Katie Fagan at **movementdisorders@nm.org** to register.



Register here

Join us for the Michael J. Fox Foundation's Run/ Walk Series



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

and foster friendship with those facing similar challenges.

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.

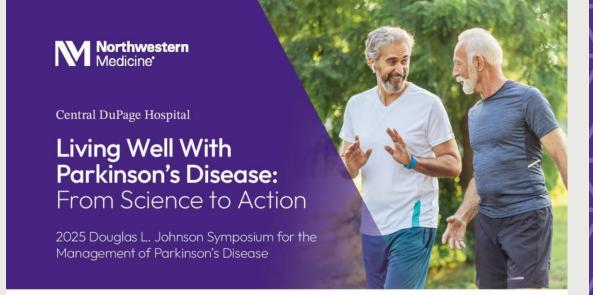
The program is at no cost for participants. Paid parking is available.

Space for the group is limited. RVSP Required.

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

Email to Register

Central DuPage Hospital's Living Well with Parkinson's Disease: From Science to Action Symposium will be Tuesday, June 10th



Northwestern Medicine Parkinson's Disease and Movement Disorders Center at Central DuPage Hospital invites you, your family members and care partners to learn about the latest approaches to living well with Parkinson's disease (PD).

This event will give you valuable insights, answer your questions and help guide you in your PD journey. Our specialists will present on the science behind well-being, and expert facilitators will help participants develop personalized action plans.

We encourage you to attend in person, but a virtual option is available.

Event details

Tuesday, June 10 1:30 – 4:30 pm

From 1:30 to 2:30 pm, the event will be available in person and virtually.

From 2:30 to 4:30 pm, the event will be available in person only.

Northwestern Medicine Central DuPage Hospital 25 North Winfield Road, Winfield Inpatient Pavilion, Conference Rooms 1, 2 and 3

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

Northwestern Medicine Central DuPage Hospital

Call **630.933.4234** (TTY: 711) to register to attend. Or you can register online at **nm.org/pd-symposium**.

There is no cost to attend, but you must register for each individual person attending. Valet parking will be available. Please register at least 48 hours before the event.

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



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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!

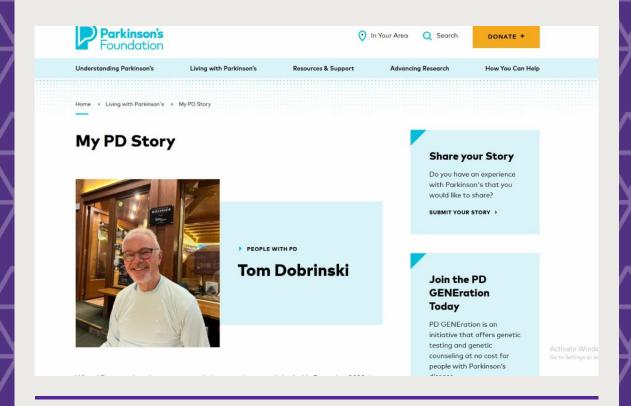
For questions you may reach out to the Research Study Coordinator- Grace Jones. Her email address is gracejones@northwestern.edu.

Click here for registration information.

Northwestern Medicine patient featured on the Parkinson's Foundation's website!

Tom Dobrinski and his wife, Shari Wolf, are featured

on The Parkinson's Foundation's website, showcasing their journey with Parkinson's. Tom and Shari have embodied a philosophy of tackling Tom's diagnosis head-on. We hope you read Tom's My PD Story and feel as inspired by his courage and positive outlook as we do! Click below to read their story.



Chair Yoga for Parkinson's has moved to a new time!





Chair Yoga for Parkinson's

Northwestern Medicine, in partnership with Paul Weitz, certified yoga instructor, is happy to bring you Chair Yoga for Parkinson's.

This program is virtual.

Date: 2nd, 3rd, 4th, and (5th) Wednesday of each month

Time: 11:00-12:00 PM (CT)

Location: Zoom Cost: Free



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

Shirley Ryan Ability Lab's New Tai Chi Class!

Join Our Tai Chi Class



Experience the benefits of Tai Chi, led by certified instructor, Aisling Holt. This class is designed for older adults and individuals with neurological or orthopedic conditions. Whether you are managing parkinson's disease, multiple sclerosis, stroke recovery, arthritis or balance concerns, Tai Chi offers a safe and effective workout to improve movement and confidence.

This class offers:

- Better coordination and body awareness
- Boosted mood and mental focus
- Improved balance and fall prevention
- Increased flexibility and joint mobility
- · Reduced muscle spasticity
- Stamina and endurance

This class benefits adults living with:

- Arthritis or joint conditions
- Balance or coordination issues
- Multiple sclerosis
- Parkinson's disease
- Stroke recovery
- Other orthopedic or neurological diagnoses



Tuesdays, 1-1:45 pm

\$110 for 11-week session or \$15 for drop-in class \$45 registration fee for new members (includes orientation and assessment)

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

To register, please contact the fitness center at 312.238.5001 or email Aleks Gebska at agebska@sralab.org

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

contact@sanogenetics.com | sanogenetics.com

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 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



At-home genetic test



Genetic counseling



Results



Receive notifications about other opportunities 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 mee 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 sellue sample and gand it to be 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.







alve sample

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

<u>Therapy Tuesdays Exercise Class</u> 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

March 27-May 29

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 11:30am- 12:30pm February 27th- May 8th 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 April 22 - June 24

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- Kindness- May 5th

Many of us would like more kindness in our lives. Through meditation we can cultivate this most beneficial quality of the heart. This session will focus on the psychological and physical benefits of cultivating kindness, as well as offer a guided kindness meditation. Register Virtual

Parkinson's 101- May 7th

This program offers an introduction and basic overview of Parkinson's disease (PD). PD varies from person to person and changes over time. Discover its causes, common symptoms, available treatments and effective strategies for managing them. Learn practical daily living tips to empower you to take

charge of your health and to navigate the challenges of living with PD.

Register Virtual

Expert Briefing-Managing Nighttime Interruptions in Parkinson's Disease- May 14th

Sleep disturbances are a common and often challenging symptom of Parkinson's disease (PD). This program explores three prevalent nighttime interruptions—Restless Legs Syndrome (RLS), REM Sleep Behavior Disorder (RBD), and insomnia—that can affect individuals with PD and their care partners. This session will provide an in-depth look at the causes, symptoms, and practical management strategies for these sleep disorders. 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

<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

<u>Tips for How to Prepare for a Telemedicine Appointment</u> Aware in Care Kit

Podcasts

PARKINSON'S DISEASE AND MOVEMENT DISORDERS CENTER

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