

April 2024

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

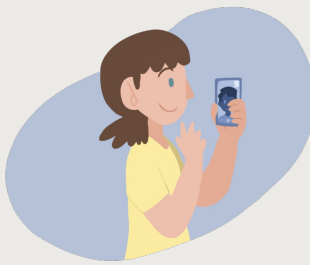
April is Parkinson's Awareness Month!

Around the globe, the PD community takes the month of April to bring awareness to Parkinson's Disease. We take this time to educate others about the complexities of this disease. Many of you have first-hand experience regarding how little most people know about PD. The general public have images of Michael J. Fox or Muhammad Ali and feel that PD is simply a disease where those afflicted experience tremors and involuntary movements. But as we all know, PD is so much more than that.

At the PDMDC, our goal is always to give exceptional PD care to our patients and their loved ones. We recognize that PD care is more comprehensive than writing a prescription for Levodopa or a referral for Physical Therapy. To us, PD care involves creating space for those affected by Parkinson's (both directly and indirectly) where they can come together with others experiencing similar things.

We invite you to check out our various support groups, classes, and programs for PD. We feel there is a little something for everyone. Further down this email, we will highlight some of our upcoming programs.

Thank you to you all for reminding us every day that Parkinson's Disease does not need to divide us. This beautiful Parkinson's Community shows us every day that we can make the experience of PD better by coming together.



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

2nd Wednesday of the
month
2:00 pm – 3:00 pm

Young Onset PD Support Group

4th Wednesday of the
month
6:00 pm – 7:00 pm

PD 101

April 10th and September
18th
4:00pm- 5:30 pm

Dancing w/ Parkinson's

Thursdays 11:30 am- 12:30
pm
March 7th- May 23rd

Music Therapy for PD

Tuesdays 1:00pm -2:00pm
Future dates to be
announced

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

Thursdays 2:00pm - 3:30 pm
Spring: April 18- June 6
Fall: October 3- November
11

PD 201

March 13th and November
13th
4:00 pm- 5:30 pm

Parkinson's Players Ping Pong

Saturdays
11:15am-1:00 pm

Parkinson's Players

Instructional Golf and Tennis

Tuesdays 4:00 pm- 5:00pm
Returning this spring/summer
Future dates to be
announced

For a complete list of our groups and classes, including those

offered at Central DuPage and Lake Forest Hospitals, click
[HERE!](#)



Improv for PD

*Northwestern Medicine, in partnership with The Second City, is happy
to bring you Improv for PD.*

Date: 8 week series on Thursdays

April 18th- June 6th

Time: 2:00-3:30 PM (CT)

Location: The Second City

230 W. North Ave

Chicago, IL 60614

Cost: \$100 for all 8 sessions

Join us for our improvisational group for persons with Parkinson's and their care partners. You don't have to be a professional performer or comedian to learn improv games and have fun!

In this class, you will learn improvisational theatre exercises that benefit emotional, physical, and spiritual wellbeing. We hope that participants find their stress levels decreased and their laugh life increased!

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

Save the date! Back in person!

Parkinson's and Movement Disorders Program Open House

April 10, 2024

Time: 1-3 pm

Location: Shirley Ryan AbilityLab
355 E. Erie, Chicago, IL 60611
10th floor Auditorium A



If you would like additional information regarding programming, have questions, or would like to be removed from our email list, please contact Kaley Brouwer at kbrouwer02@sralab.org

Shirley Ryan
Abilitylab

Please save the date for our annual Parkinson's and Movement Disorders Open House! The event will take place in person at our flagship hospital with a virtual option also available. Research updates, educational presentations, networking opportunities, and community vendor information will be available. Additional details to follow. We look forward to seeing you!

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 2024:
April 10th and September 18th
Time: 4:00-5:30PM (CT)

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



Register here for PD 101

Parkinson's Players: Ping Pong

**Date: Weekly on Saturdays
Beginning on December 9th
Time: 11:30AM- 1:00PM (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 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.

Parkinson's Players Ping Pong has received a great amount of media coverage from local outlets! We are thrilled to see our community embrace this program.

CHICAGO SUN★TIMES

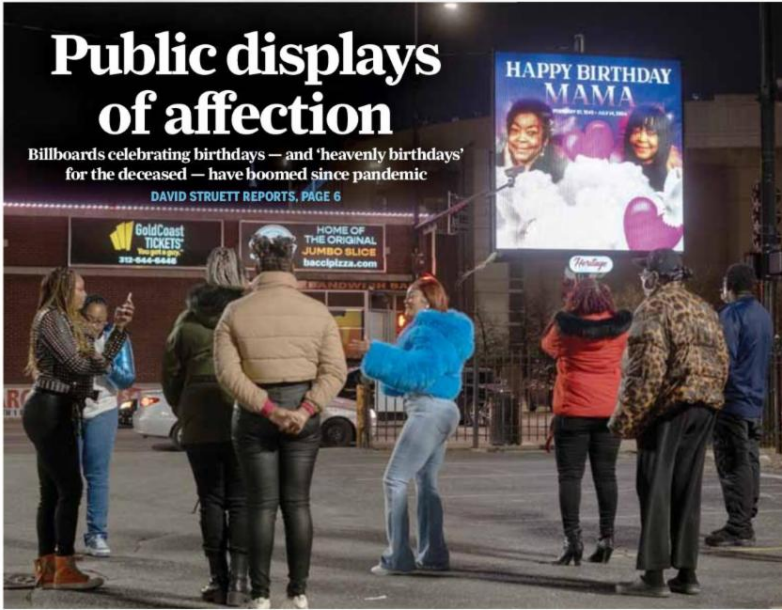
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Edward and Anne Burke

DESPITE CONVICTION, BURKE GETS TO KEEP LAW LICENSE

State Supreme Court — on which Burke's wife recently served — couldn't rule when most justices recused themselves over connections to longtime alderperson **DAVE MCKINNEY & JON SEIDEL REPORT, PAGES 12-13**



Public displays of affection

Billboards celebrating birthdays — and 'heavenly birthdays' for the deceased — have boomed since pandemic

DAVID STRUETT REPORTS, PAGE 6

Tasha Simon gathers with family and friends on March 1 for a balloon release in front of a billboard honoring her late mother's birthday. **JIM VONDERHEKA FOR THE SUNTIMES**

PARKINSON'S PATIENTS FIND VITAL EXERCISE, COMMUNITY WITH PINGPONG

CINDY HERNANDEZ REPORTS, PAGE 10



Mike DeBartolo and Jeff Dohnal concentrate on the ball during the Parkinson's Players pingpong class at Northwestern Medicine Lake Forest Health & Fitness Center. **PROVIDED**

Illinois 'junk fee' legislation calls for price transparency on everything from airline and concert tickets to rent

STEPHANIE ZIMMERMANN REPORTS, PAGE 14

'IT SHOWS US THAT WE'RE NOT ALONE'

Pingpong class helps Parkinson's patients find community, support brain function

BY CINDY HERNANDEZ,

STAFF REPORTER
cbernandez@suntimes.com | @CindyH_7

Mike DeBartolo was an avid runner before he began noticing loss of balance and loss of coordination in his stride.

Then seven years ago, the Winnetka resident was diagnosed with Parkinson's disease.

Though he continued to stay as active as possible, he soon realized there weren't many spaces available for people with his condition where they could continue to do the things they enjoyed.

After his diagnosis, he began helping with a fundraiser that raised awareness and funding for research for a cure. But he began thinking of ways to do more.

"It occurred to me that as good as fundraising is, it wasn't necessarily touching people with Parkinson's immediately," DeBartolo said. "I wanted to create something that's helping people in the here and now."

That is how he came up with Parkinson's Players, a free program that helps patients connect exercise with play.

The Parkinson's Players kick started last summer. In the warmer months, participants played golf or tennis, but as temperatures dropped they needed an indoor activity that would still allow them to get moving during the colder months.

"I'm play-oriented, and I think most of us are," DeBartolo said. "There's many fitness centers that have some focus on Parkinson's, but what I hadn't seen was play-based, activity-based exercise."

For people with Parkinson's, ex-

ercise is vital in helping slow the progression of the disease, which is a neurodegenerative condition that results in a loss of brain cells in particular parts of the brain at faster rates than normal aging that pertain in large part to movement. It also leads to cognitive issues such as memory problems and slow thinking.

Pingpong, or table tennis, is a game most people played during their younger years. What many probably don't realize is how beneficial it can be to helping brain function, said Linda Egan, Parkinson's program coordinator at Northwestern Medicine Lake Forest Hospital.

"Research shows exercise is the only thing available that may slow progression of Parkinson's," Egan said. "Pingpong is beneficial because it addresses strength, balance, eye-hand coordination and motor planning, all of which are affected by Parkinson's."

While there are medications that can help treat physical and motor symptoms, experts say there is evidence that shows exercise and rehab may be able to slow down those changes in the brain.

Involvement in a regular pingpong program may actually improve quality-of-life scores and movement scores," said Dr. Neil Shetty, movement disorders specialist at Northwestern Medicine. "I have a number of patients who play regularly and they kind of characterize it as an instrumental part of their exercise, and that they can see benefits that are mirrored in their day-to-day balance and coordination skills."

More than 30 people have par-



Patients play pingpong as a part of the Parkinson's Players program at Edgewater Fitness Center in March.



Instructor Robert Owens helps a patient with her technique during a pingpong class.

ticipated since the pingpong class started in late December. On any given day, there are at least 12 people in a class, which takes place on Tuesdays and Thursdays at Northwestern Medicine Lake Forest Health and Fitness Center and Saturdays at the Edgewater Fitness Center.

Robert Owens, who has been instructing the group since the summer, said a patient can feel motivated when they see themselves getting better at something.

"These people come out and play

table tennis, and they can see themselves get better at something," Owens said. "It's a small sport, but it's an easy sport to get better at, more than tennis and some others, so you get a sense of progress."

Though exercise is vital to helping patients with Parkinson's, social interaction is just as important. Patients can often experience depression and anxiety when they are diagnosed, so social interaction can help improve patients' mood. Pingpong allows the group to build connections with each other and

improve their skills at the game, Egan said.

"Parkinson's can be a very isolating disease, and we really want to get individuals with Parkinson's in a social group," Egan said. "Whether it's an exercise class or pingpong, just something where they feel comfortable being with others and that gives them the opportunity to build friendships with people who are going through similar experiences."

DeBartolo has experienced that firsthand.

"The friendship-making is what I've found to be even more important in this program," DeBartolo said. "The program just started last summer, and it's growing very nicely. I certainly didn't know this many with Parkinson's before this program began."

DeBartolo said the Parkinson's Players has created the community he was hoping for.

"Community enables you to empathize, and it enables you to relate to people who have a similar condition to you. It shows us that we're not alone," he said. "It's not that we want other people to have Parkinson's, but since people do, it's important to socialize with each other because we can relate ... we can share perspective."

In honor of Parkinson's Awareness Month, here are the ABCs of Parkinson's Disease—from The Parkinson's Foundation

Know the ABCs of PD

All you need to know about Parkinson's disease — from A to Z.



This April is Parkinson's Awareness Month and we're partnering with Mitsubishi Tanabe Pharma America to help people understand the complexity of **Parkinson's disease (PD)** and recognize its symptoms.

A	<u>Anxiety</u>	Parkinson's symptoms not related to movement are often more troublesome and disabling than movement symptoms. These symptoms can include anxiety, depression, vertigo and more.
B	<u>Balance</u>	More than half of people with Parkinson's will experience a fall in the next year. There are many tips and ways to prevent falls.
C	<u>Care Partner</u>	Like Parkinson's, there are several stages of the care partner journey. Explore free articles, tools and courses designed for you.
D	<u>Diagnosis</u>	Finding out you have Parkinson's can be a lengthy process. A diagnosis is made through a combination of in-office tests and diagnostic tools.
E	<u>Early Signs</u>	From small handwriting and loss of smell and trouble sleeping, know the 10 early signs of Parkinson's.
F	<u>Fitness</u>	People with PD who exercise for 2.5 hours per week experience a slowed decline in quality of life. Find the exercise that works for you.
G	<u>Genetics</u>	12.7% of participants in our study have a genetic tie to Parkinson's. PD GENERation is a global initiative that provides genetic testing and counseling to people with PD, at no cost.
H	<u>Hospital Safety</u>	People with Parkinson's are at a higher risk of hospitalization and longer hospital stays. Know how to prepare and advocate for yourself with our Hospital Safety Guide.
I	<u>Incidence</u>	Nearly 90,000 people in the U.S. will be diagnosed with Parkinson's this year.
J	<u>Job</u>	"How long will I be able to work with Parkinson's?" This question is especially important to people with young-onset PD.
K	<u>Knowledge</u>	Find the information you need now — from tools that help you work alongside your care team to resources that empower you.
L	<u>Lewy body dementia</u>	Robin Williams brought awareness to the life-changing, prevalent disease known as Lewy Body Dementia, a progressive brain disorder where cognitive decline is an early symptom.
M	<u>Motor Fluctuations</u>	Also known as "on-off" times, motor fluctuations are changes in the ability related to medications. "On" times are when you have good symptom control. "Off" times are when medications wear off.
N	<u>Neurologist</u>	Neurologists (and specialized neurologists called movement disorders specialists) diagnose and treat Parkinson's.
O	<u>Occupational Therapy</u>	Rehabilitation therapies — occupational, physical and speech therapies — can slow disease progression, address symptoms and enhance mental health.
P	<u>Parkinsonism</u>	Parkinsonism is the collection of signs and movement symptoms associated with several conditions — including Parkinson's disease.
Q	<u>Questions</u>	Our bilingual Helpline answers Parkinson's questions, provides referrals to health professionals and local resources. Call us at 1-800-4PD-INFO (1-800-473-4636) in English or Spanish.
R	<u>Research</u>	Parkinson's research can lead us to breakthroughs in treatment and care at any moment. Explore our currently funded research and how to join a PD study.
S	<u>Stages</u>	Parkinson's symptoms and progression are unique to each person. Knowing the stages of Parkinson's can help you cope with changes as they occur.
T	<u>Tremor</u>	70-90% of people with PD experience a tremor. While most common in the hands, tremors can also occur in the lower lip, jaw, leg or internally.
U	<u>Urinary incontinence</u>	People with Parkinson's may experience bladder problems. The most common is a frequent and urgent need to urinate.
V	<u>Vertigo</u>	Dizziness (feeling faint, weak or unsteady) and vertigo (the false sense that you or your surroundings are spinning) are common signs of Parkinson's.
W	<u>Wellness Wednesday</u>	Access at-home resources through weekly online events. PD Health @ Home offers events that focus on wellness, exercise and mental health.
X	<u>X</u>	Join our online Parkinson's community. We're on X, and all social media channels!
Y	<u>Young-Onset Parkinson's</u>	Young-onset Parkinson's occurs in people who are 50 years of age or younger, who often experience a different set of challenges.
Z	<u>Zen</u>	Stress can make PD symptoms worse. Maintaining emotional health is essential to living well with Parkinson's and can help manage symptoms.

[Click here to learn more about the ABCs of Parkinson's](#)

Survey about Parkinson's Education

At the PDMDC, we always want to make sure we are providing educational programming and content that is of interest to our patients and their loved ones. We have received feedback from a

variety of folks asking to learn more about certain topics. A survey was composed to determine what areas are of most interest. Please complete the survey below. It is only 8 questions and takes less than 5 minutes to complete.

[Survey Link](#)

Thank you in advance!

Research Corner

Do you have Parkinson's disease and are interested in research?

You may be eligible for the Voice-PD study that aims to objectively quantify severity of vocal and speech related symptoms associated with Parkinson's Disease.



You qualify for the study if you are ...

- > Diagnosed with PD, or
- > Prodromal PD, or
- > Age-matched healthy control

What is involved if I participate?

- > Study duration: 10 weeks
- > 7 study visits of combined televisits and at-home assessments
- > Speech tests, PD clinical assessment, and short questionnaires

Participant Resources:

- > Reimbursement will be provided for your time during on-site and telehealth visits.

If you are interested in participating or want to learn more, please contact

Max Galarce

max.galarce@northwestern.edu

Telephone: (312) 503-4270

This study is in need of participants who are in more advanced stages of Parkinson's Disease, as well as people who do not have Parkinson's Disease. Please email Max Galarce at max.galarce@northwestern.edu if interested.

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](https://www.parkinson.org/PDHealth)

[Mindfulness Mondays: Mindfulness of The Breath- April 1st](#)

Join us every Monday as our expert speaker leads you in guided relaxation techniques to help boost brain power and reduce stress.

[Register Virtual](#)

[Expert Briefing: Research Update: Working to Halt PD- April 10th](#)

Learn about current research that is taking various approaches to develop a treatment that may significantly slow PD's progression.

[Register Virtual](#)

[Expert Briefing: Exploring Longevity and Progression- April 17th](#)

During this webinar we will explore why people with Parkinson's progress differently, how to live well in the marathon of PD, and how treatment and care needs may change over time.

[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 Guide](#)

[Medical Alert Card](#)

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

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

[Hospital Safety Guide](#)

[Podcasts](#)

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