

How Parkinson's disease affects the bladder

by Neha Prakash, MD

When we talk about Parkinson's disease, we think mostly of motor symptoms like slowness, stiffness, tremors, trouble walking, and falls. But studies have shown that Parkinson's is more than what meets the eye. It includes a wide spectrum of nonmotor symptoms, like constipation, depression, anxiety, and loss of sense of smell. Bladder dysfunction is one such symptom commonly seen among PD patients. These symptoms' effects on quality of life can be exacerbated by the concurrent motor symptoms.

Why do I have trouble urinating?

Think of the bladder as a tiny elastic bag that stores urine produced by the kidneys. It has two key muscles: the detrusor, which lines the bladder wall, and the sphincter, located at the outlet. Bladder voiding occurs when the brain sends signals to the detrusor to contract and to the sphincter to relax. Vice versa is true to help the bladder store urine. This seemingly simple life process is a result of a complex coordinated neural mechanism involving the brain and the spinal cord. In Parkinson's disease, loss of the dopaminergic cells disrupts the pathways controlling the bladder.

What kind of symptoms can I have?

Symptoms occur due to problems in the storage or voiding phases. Storage symptoms occur due to an overactive detrusor muscle. Nocturia, or waking up multiple times a night to urinate,

is the most common symptom among PD patients. Other symptoms include urgency and incontinence. Voiding symptoms are less reported and occur due to detrusor underactivity and delayed relaxation of the sphincter. Symptoms range from hesitancy to straining to void.

It's important to determine whether symptoms are due to PD or unrelated causes. Discuss your symptoms with your primary care physician and neurologist. A urologist will be involved in your care when appropriate. A number of minimally invasive screenings are available to determine the cause of your symptoms.

What treatment options are available?

Conservative management is usually the first approach, targeted at improving quality of life.

Behavioral modification is the first line of management for bladder symptoms in PD patients. Most patients reduce their fluid intake in order to avoid running to the restroom. This is not advised, however, as it's important that you drink enough fluid to remain hydrated during the day. You can avoid drinks that have diuretic effects, like caffeine and alcohol. Avoid drinking fluids in the evening to reduce nighttime bathroom visits. Maintaining a bladder diary can be helpful; train yourself to void at shorter intervals than usual to avoid urgency. Pelvic floor exercises and biofeedback training can help in cases of incontinence.

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April is Parkinson's Awareness Month

Parkinson's disease is a slowly progressing disorder of the nervous system, marked by slowness of movement, tremor at rest, muscle stiffness, and problems with gait.

- 60,000 people are diagnosed with PD each year
- 1 in 100 people over age 60 have PD
- Men are 1 ½ times more likely than women to have PD
- Exercise is vital in managing PD
- The causes of PD are unknown

Join us in our efforts by

- Getting the latest information about Parkinson's from our center at parkinsons.nm.org or from our partner, the Parkinson's Foundation, at parkinson.org
- Sharing what you've learned with your family, friends, and community
- Making an impact. Donations are gratefully accepted at 312-926-2033. Our representative will ensure your gift is designated to the Parkinson's Disease and Movement Disorders Center.

PARTNERING WITH PF



CENTER OF EXCELLENCE

The Northwestern Medicine Parkinson's Disease and Movement Disorders Center, recognized by the Parkinson's Foundation (PF) as a Center of Excellence, collaborates with the foundation on such events as conferences, professional training, and the annual Moving Day Chicago fundraiser.

Founded in 1957 and located in Miami, PF is a premier international organization that funds research and provides support services, educational outreach, and advocacy for people with PD and their loved ones. Its Centers of Excellence must provide the highest quality in patient care, implement best practices, provide leadership in developing targeted research to extend knowledge of PD, and create innovative models of education, services, and outreach.

Northwestern and PF work together to deliver high-quality patient care, form a united front against Parkinson's, and make a difference.

For more information, visit parkinson.org.

BIOREPOSITORY

The Movement Disorders Center Biorepository collects biological and clinical information, such as blood and tissue samples, and medical and family histories from patients diagnosed with movement disorders.

The information is maintained to be studied in the future to identify factors that either cause these neurological conditions or increase the risk of developing them. Samples collected include a blood sample and a skin biopsy. Participants may donate one or both samples.

Blood samples are tested for proteins and other chemicals that

differ in amount or change at different rates across participant groups. Samples are also analyzed to identify genes that may be related to specific movement disorders.

Fibroblast cells, obtained by skin biopsy, are processed to give rise to neurons, a type of cell found in the brain. These neurons can be analyzed for gene expression and other biomarkers to help us better understand the mechanisms of diseases.

All samples are stripped of any information that can link them to a specific person. To participate, please call 312-503-0755 or email pdclinicaltrials@northwestern.edu.

Physical Activity and Parkinson's Disease

Daily physical activity is an effective tool to manage symptoms of Parkinson's disease as well as a way for patients to actively participate in their treatment. Studies show that the benefits of physical activity include slowing the disease's progression.

The Center for Rehabilitation Outcomes Research (CROR) at the Shirley Ryan AbilityLab (formerly the Rehabilitation Institute of Chicago), along with the Parkinson's Disease and Movement Disorders Center, is studying how motivational interviewing and other strategies can promote a healthy lifestyle, including increased physical activity. Motivational interviewing is a style of counseling and coaching that helps people change behavior by working on goals.

Linda Ehrlich-Jones, PhD, RN, assistant director of CROR, worked with Northwestern University's Center for Behavioral Intervention Technologies to create a web-based application for PD patients to track weekly activity goals. Focus groups last year provided feedback about readily-accessible resources that would be beneficial to the Parkinson's population, and patients tested the application for usability.

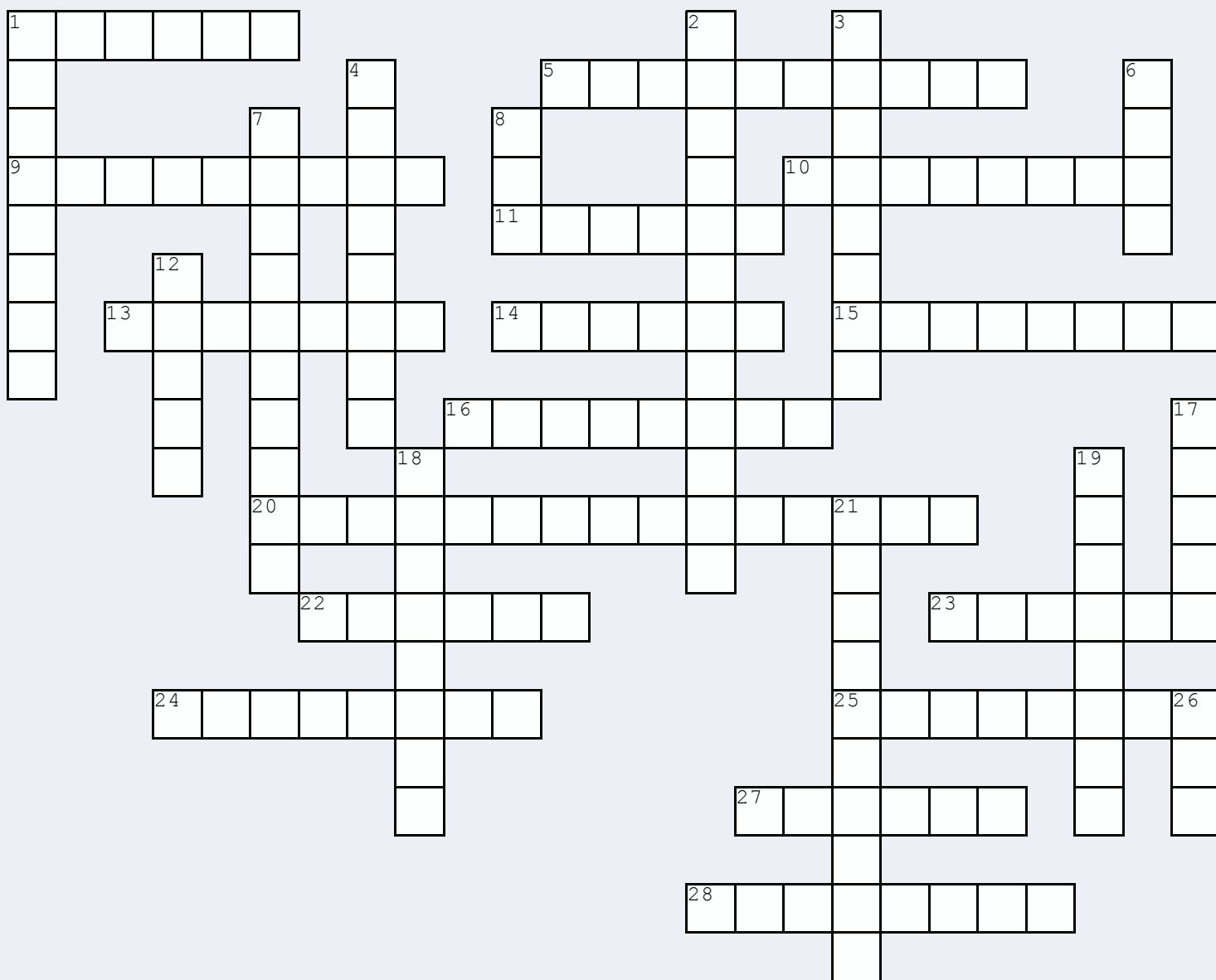


Funded by the National Institute on Disability, Independent Living, and Rehabilitation Research, the **Motivational Interviewing and Physical Activity in Parkinson's Disease** project will investigate how participants in four groups use different strategies to promote activity:

- motivational interviewing
- a web-based application to keep track of physical activity
- a combination of the two
- an educational program on issues related to Parkinson's disease

If you are interested in participating in the study, please call Edeth Engel, Research Assistant, at 312-238-1405.

PD Awareness Crossword



ACROSS

- [Blank] Day, a walk for Parkinson's in local communities to raise funds and awareness about PD
- Center of [blank] is where exemplar patient care is paired with groundbreaking research
- Support groups offer [blank], social contact, and understanding
- The loss of [blank]-producing neurons results in difficulty with movement
- A specialized cell that transmits nerve impulses from one part of the body to another
- PD affects about [blank] per one thousand Americans over age 55
- A main motor symptom of PD is shaking or [blank]
- [Blank] therapists evaluate and treat mobility problems
- Stiffness in a limb or joint
- Exercise facilitates [blank] (brain connectivity)
- To keep your voice strong, take a [blank] before you start to speak
- [Blank] exacerbates the symptoms of PD
- Enemies of restful sleep include alcohol, [blank], and other stimulants
- Trouble with balance is also called [blank] instability
- Exert a degree of control by assuming an [blank] role in your health
- Optimal health includes a [blank] attitude
- Bradykinesia is [blank] of movement
- DBS stands for [blank] brain stimulation
- Exercise should include [blank], aerobic activity, and resistance training
- Fatigue, sweating, or anxiety are called [blank]-motor symptoms
- Substantia [blank] is a region of the brain where cells produce dopamine
- 19th-century British physician named [blank] Parkinson documented key features of PD
- [Blank] is a temporary, involuntary inability to move
- Medical [blank] helps us learn more about PD
- [Blank] PD is used to describe an unknown cause
- Dysarthria is [blank] voice volume

DOWN

- Parkinson's disease is a [blank] disorder
- [Blank] are doctors who specialize in problems with the nervous system
- [Blank] remains the gold-standard treatment for PD

Answers on page 8

Cognitive Behavioral Therapy for Parkinson's

by Danielle Marino, LCSW

Parkinson's disease is more than a movement disorder; over half of people with PD are estimated to also have anxiety or depression. Research shows that it's not movement issues that bother people most; in fact, the strongest predictor of poor quality of life with PD is having anxiety and depression.

// Patients can go from feeling sad and helpless to happy and hopeful by challenging and restructuring their thoughts. //



Depression negatively affects long-term outcomes for patients. It reduces their social connectivity and hinders their motivation to exercise or seek help. However, anxiety and depression are treatable. One form of therapy in particular may be as effective as medication: cognitive behavioral therapy.

What is CBT?

Cognitive behavioral therapy, or CBT, is a type of psychotherapy focused on problem solving and changing unhelpful thought patterns. Treatment is brief, typically requiring 8 to 16 sessions. The widely researched treatment has been found effective for anxiety, depression, insomnia, grief, eating and weight problems, and many more issues. Several comparative research studies have shown that CBT can be as effective and in some cases superior to antidepressant medication.

How can CBT help Parkinson's?

CBT helps Parkinson's patients in three ways: to become more active, to develop solutions to problems, and to balance their thought patterns.

CBT can help people develop strategies to increase their involvement in meaningful, pleasurable social activities, as well as ways to safely increase daily exercise. CBT also helps PD patients maximize control over their reactions to stressful circumstances by developing healthier ways to deal with negative feelings such as sadness, irritability, anxiety, and anger. For example, patients are taught techniques to recognize, label, and restructure negative thoughts. Thoughts of disability, dependency, burden, loneliness, isolation, lack of intimacy, and loss of control are main targets of treatment.

Example of CBT:

Situation: Hand tremor makes it hard to eat.

Patients can go from feeling sad and helpless to happy and hopeful by challenging and restructuring their thoughts. While patients' situations may not change, how patients look at situations does. CBT teaches that how we think about PD—not the disease itself—is what matters.

Automatic thought: "I'm helpless, I can't even eat the soup."
⇒⇒ **Emotions felt:** sad, anxious

Balanced thought: "Even though I struggled, I made the best of the situation by eating handheld foods and using my nondominant hand. I was able to solve the situation."
⇒⇒ **New emotional state:** happy, hopeful

Try CBT:

- Find a therapist providing CBT in your community. Call the number on the back of your medical insurance card to ask about therapists in your area. Be sure to research therapists online or ask if they have experience with CBT.
- Northwestern Medicine will host its first CBT for Parkinson's course this spring. The four-session therapeutic course is free for Northwestern patients (see page 7). If you are interested in joining this course, another in the future, or our other support groups, contact Danielle Marino at danielle.marino@northwestern.edu or 312-695-2168.

Danielle Marino, LCSW, has been a social worker in the Chicago area for the past nine years. She received her BS in psychology from the University of Illinois at Urbana-Champaign and her MSW from Loyola University Chicago. She began her career as a school social worker working with students with disabilities. Ms. Marino began working at Northwestern University in 2015, when she joined the TeleHealth Cognitive Behavioral Therapy depression research study. She now works as a patient navigator and therapist to people with Parkinson's disease and their families in the Parkinson's Disease and Movement Disorders Center. She is trained in structured cognitive behavioral therapy and motivational interviewing and offers both individual and group therapy at the clinic.

Does Parkinson's disease affect my bladder? *continued from page 1*

Pharmacological measures are undertaken when behavior modifications yield little benefit. A multidisciplinary approach involving a urologist is advisable. Effects of Parkinson's medications like levodopa, dopamine agonists, and MAO inhibitors on bladder symptoms are variable and unclear. Medications commonly used for overactive bladder are used cautiously in PD patients due to such side effects as dry mouth, constipation, and cognitive changes. If symptoms are difficult to control with medications, other advanced therapy options are available. Though not specifically studied for PD patients, these options include intravesical botulinum injections and neuromodulation, such as posterior tibial nerve stimulation. Deep brain stimulation may have some benefit on bladder symptoms as well.

RESEARCH PARTICIPATION OPPORTUNITIES AT NORTHWESTERN UNIVERSITY

We need you to participate in research!

Participating in clinical trials brings potential benefits to you and others who have or are at risk of developing Parkinson's. Immediate benefits include playing an active role in your own healthcare; you also contribute to the growing body of knowledge about Parkinson's disease and help future generations who may be affected by the disease.

For more information about Parkinson's disease research at Northwestern, see pages 14 and 15, visit parkinsons.northwestern.edu/research/clinical-trials, call 312-503-0770, or email pdclinicaltrials@northwestern.edu.



LIGHTER SIDE OF PARKINSON'S

by Nettie Brenner

Three years ago, I was diagnosed with Parkinson's disease. When I received my diagnosis, I felt very depressed and isolated, and I feared that my future would now be filled with years of boredom and sadness. However, being affiliated with Northwestern Medicine, I found they had programs for people like me. Slowly I discovered there is a Parkinson's community with a myriad of activities. As a person with Parkinson's, I participate in the Second City improv support group, boxing fitness class, art therapy, yoga, and a Hubbard Street Dance class. Basically, if there is a support or exercise group, I want to be a part of it, and I wish there were more days in the week to accommodate everything. The biggest benefit has been meeting and becoming friends with like-minded people.

PD CROSSWORD ANSWERS

ACROSS

1. Moving
5. Excellence
9. Education
10. Dopamine
11. Neuron
13. Fifteen
14. Tremor
15. Physical
16. Rigidity
20. Neuroplasticity

22. Breath

23. Stress
24. Caffeine
25. Postural
27. Active
28. Positive

DOWN

1. Movement
2. Neurologists
3. Levodopa

4. Slowness
6. Deep
7. Stretching
8. Non
12. Nigra
17. James
18. Freezing
19. Research
21. Idiopathic
26. Low

Support Groups, Programs, and Events

Chicago

Monthly Parkinson's Disease Support Group

251 East Huron Street,
Feinberg Pavilion, Room A
First Tuesday of the month

Dance/Music Therapy and Movement:
10:30 a.m.

Group physical therapy: 11:15 a.m.

Provided box lunch: Noon

Guest speaker: 1 p.m.

Care Partner Support Group

251 East Huron Street,
Feinberg Pavilion, Room A
First Tuesday of the month, noon.
Separate table for facilitated
discussion with box lunch provided.

Art and Yoga

250 East Superior Street,
Prentice Pavilion, Room Q
Second, third, fourth, and
fifth Tuesday of month

Art Therapy: 1–2 p.m.

Yoga: 2–3 p.m.

Parkinson's Disease 101

250 East Superior Street,
Prentice Pavilion, Room P
First Wednesday of month, 3–4:30 p.m.
Registration is required. Contact
Carolyn Taylor, APN, at 312-695-1822.

Second City Improv Group

1616 North Wells Street
March 8–April 26; May 3–June 21
2–3:30 p.m.
Class size is limited and
registration is required.
Contact Pam Palmentera, LCSW,
at 312-503-4397.

“Empowering You through Parkinson's: Cognitive Behavioral Skills for Reducing Anxiety and Depression and Improving Sleep in PD”

250 East Superior Street,
Prentice Pavilion, Room Q
Tuesdays, May 1–22, 3:30–5 p.m.
To register, contact Danielle Marino
at 312-695-2168.

SAFRA - Bernard Horwich JCC

3003 West Touhy Avenue, Chicago

Strength and Balance

Mondays, 3–4 p.m.

Support Group

Mondays, 2–2:50 p.m.
Second Thursday of the month,
1–2 p.m.

Nia

Tuesdays, 10:30–11:30 a.m.

Chair Functional Fitness

Wednesdays, 3–4 p.m.

Yoga for Parkinson's, Levels 3 and 4

Fridays, 2–3 p.m.

Education Event

Women and Parkinson's Disease
presentation by Cindy Zadikoff, MD
Sunday, February 25, 10 a.m.

Suburbs

Fitness Classes

NM Lake Forest Fitness Center,
1200 North Westmoreland Road, Lake Forest

Lindenhurst Health and Fitness Center,
3098 Falling Waters Boulevard, Lindenhurst

Classes are at Lake Forest unless otherwise indicated.
Call 847-535-7000 for more information.

TRX for Parkinson's, Levels 1 and 2

Mondays and Wednesdays, 12:15–1:15 p.m.

Pedal for Parkinson's, Levels 1 and 2

Mondays, 10:30–11:30 a.m.

Tuesdays, 10:30–11:30 a.m. (Lindenhurst)

Wednesdays, 11 a.m.–noon

Thursdays, 10:30–11:30 a.m. (Lindenhurst)

Fridays, 11:30 a.m.–12:30 p.m.

Strength and Balance, Levels 2 and 3

Tuesdays, 12:45–1:45 p.m.

Rock Steady Boxing, All Levels

Tuesdays, 2–3 p.m. and 3:15–4:15 p.m.

Support Group

Second Wednesday of the month, 10 a.m.–noon

Dance for Parkinson's, Levels 3 and 4

Wednesdays, 1–2 p.m.

Functional Fitness, Levels 3 and 4

Thursdays, 2:30–3:30 p.m.

Yoga for Parkinson's, Levels 3 and 4

Fridays, 1–2 p.m.

Pilates for Parkinson's, Levels 2 and 3

Sundays, 11 a.m.–noon

SAFRA - Lustbader Center JCC

Bernard Weinberg JCC, 300 Revere Drive, Northbrook

Punch for Parkinson's

Mondays, 1–2 p.m.

TRX and Cycle Circuit

Wednesdays, 1–2 p.m.

My Experience with DBS

by Dale Moss

I've heard it said that the symptoms of Parkinson's disease are never exactly the same in any two patients. The story of how each patient is diagnosed with Parkinson's is equally unique. Mine started with a slight tremor in my right hand in my early 50s that led my family doctor to refer me to the only neurologist in our small Colorado town. He had a six-month waiting list—so I waited.

When I finally saw him, it took him no more than five minutes of standard neurological examination to reach the conclusion that I had PD. He broke the news by handing me a Parkinson's book. The book was outdated, and he told me that it was his last copy so I needed to return it to his office.

I desired a greater standard of care, the most current information, and the most up-to-date treatments. So within a year, my wife and I came to Chicago, and I became a patient at Northwestern's Parkinson's Disease and Movement Disorders Center. Dr. Onur Melen started me on Sinemet, and I saw immediate improvement in the quality of my life.

While Sinemet is effective in treating PD tremors, it wears off over time, and eventually you have to increase your dose. And with more medicine come more side effects, such as involuntary muscle movements called dyskinesia. Eventually I was up to 10 Sinemet tablets daily, which seems like a lot, but I've heard of patients taking up to 40 a day. Along the way, I participated in a 15-month clinical trial for inhaled levodopa, one of the drugs in Sinemet.

Dr. Melen felt I would be a good candidate for deep brain stimulation (DBS)—a surgically implanted medical device, similar to a cardiac pacemaker. Through electrodes implanted in the brain, DBS constantly stimulates brain tissue affected by PD and offers more consistent control of PD's motor symptoms than that provided by oral medications. I was referred to Dr. Cindy Zadikoff, who also felt I could benefit from DBS. She became my neurologist and began to educate and guide us through the DBS process.



// After DBS, my smile is back //

At Northwestern the DBS surgery is performed by a team led by Dr. Joshua Rosenow. I was scheduled for two surgeries two weeks apart. The first is to place an electrode on the left side of the brain, and the second is for the right side and to implant the neurostimulator device. Throughout both surgeries, Dr. Rosenow and his team's experience and professionalism enabled me, and my family in the waiting room, to stay informed and calm. They even let me choose the music in the operating room—the soundtrack for my DBS surgeries was classic Motown and Stevie Wonder.



In DBS surgery, the patient must be awake for the final positioning of electrodes. As Dr. Rosenow guided me through some arm and hand movements, the surgery team actually listened to the neurons firing in my brain, using the same sound system that had been playing the Four Tops a few minutes earlier. The surgery team was excited, because the sounds generated by my brain indicated the team had found the sweet spot—the position for the electrodes that would yield the best results.

DBS has improved the quality of my life. PD patients are known for having a “frozen face,” and I like to smile and laugh, but my expressionless face didn’t reflect that. After DBS, my smile is back. Friends and family say my voice sounds much stronger on the phone. And I’m down to just four Sinemet tablets per day, so I experience much less troublesome dyskinesia.

My DBS device is produced by Boston Scientific and just recently received FDA approval. This device offers more electrodes than traditional DBS devices and provides programmers with more control over the amount of stimulation delivered to each electrode. Prior to my PD diagnosis, I qualified for and ran the Boston Marathon. I’ve run several 5- and 10K races since my surgery, and my ultimate goal is to return to the Boston Marathon—thanks to my Boston Scientific DBS device.

Meet the Staff

Avram Frait, MD



Frait is finishing a two-year fellowship in movement disorders at Rush Medical University Center. He graduated in 2012 from Rush Medical College, where he completed his neurology residency in 2016. During his fellowship, Frait received a grant from the Dystonia Medical

Research Foundation to investigate the use of telemedicine in evaluating cervical dystonia. This research will serve as the topic of his thesis as he completes coursework for his master’s in clinical research from Rush University’s Graduate College. In August, Frait will join the Northwestern movement disorders team, splitting his time between the Lake Forest and downtown campuses. He has a specific interest in deep brain stimulation as treatment for Parkinson’s disease, essential tremor, and dystonia.

Neha Prakash, MD



After finishing medical school in India, Prakash went on to complete her neurology residency at St. Louis University Hospital. Serving there as chief resident, she participated in a unique blend of education, patient care, advocacy, and administration in a clinical context. In 2017 Prakash began her two-year fellowship at

the Parkinson’s Disease and Movement Disorders Center. She is interested in Parkinson’s disease and hyperkinetic movement disorders.

Try It, You May Like It

by Linda Egan, PT

We live in a society where we are bombarded by a steady stream of statements about the importance of regular exercise. With a background in physical therapy, I am educated in the physical and physiological benefits of exercise. As a practicing clinician for over 25 years, I've recognized how challenging it can be for a person with PD to start or maintain an exercise program. So the question is, how do we achieve a regular exercise program for those with Parkinson's disease?

Recommended exercise guidelines are 2½ hours of exercise per week. People with Parkinson's face obstacles to exercise, including stiffness, feeling unwell, and apathy.

I have found that it is not only the exercise that makes a difference but the environment in which you exercise. I've learned that exercise promotes a positive attitude and improves overall quality of life. I've witnessed PD patients' and caregivers' camaraderie, friendship, motivation, encouragement, and perseverance.

When I walked into the Parkinson's exercise classes at the Lake Forest Health and Fitness Center, they were not what I expected. The instructors and the participants changed my perspective of what makes an exercise class successful—including the best way to persuade someone to exercise. I now understand what drives a group of people to show up day after day, week after week, just to exercise.

Benefits of exercise include increased blood flow, strength, mobility, and flexibility. But are there other benefits to exercise? Benefits that are not usually addressed in research studies are just as important.

When I asked those in the exercise classes how they felt about exercise, here is what I heard:

"Exercise is like a job—at times you don't want to be there. Luckily the people in my class help me fight through the feeling of not wanting to be here."

"Being in the group makes something that seems daunting become fun."

In observing and participating in these classes, I experience firsthand the true meaning of support, friendship, courage, dedication, and strength.

These devoted members show up even when they are tired or hurting. I watch them adjust the seats on their bikes, put on their boxing gloves, or assist others for the task at hand. Despite how they feel at the beginning of class, their determination always kicks in with the start of the first exercise.

During a recent Rock Steady Boxing class, one man was bound and determined to jump rope. He stood there, trying repeatedly, but would swing the rope and miss the jump. He moved back to a starting position and kept working at it. All eyes were on him. Then we heard a repetitive click. He was jumping rope and counting out loud. We joined in, and he reached his goal of 30 jumps. Thunderous applause broke out. He walked away standing taller, with a beaming smile. It was a tremendous sense of accomplishment for all of us, with a positive effect on everyone in that room.

I find that participants arrive early to class. This is not to get the best spot or equipment but to see familiar faces and ask how things are going. If there's a new face in the crowd, it doesn't take long for people to introduce themselves—the sense of community is overwhelming and heartfelt. You may walk into a class by yourself, but you leave with a few more friends and the feeling that you are not alone on your journey. Summing up the uplifting, energy-generating environment, one person explained, "It is a club you don't want to join, but once you are here, you are glad you did."

Linda Egan, PT, is the Parkinson's program coordinator at Lake Forest Hospital.



// Being in the group makes something that seems daunting become fun. //

Engagement: Group exercise classes offer the perfect opportunity to interact with others. As one member explained, “Participation with those facing similar challenges is important. More important than the physical aspects of the classes is the opportunity to meet others facing the unknowns of Parkinson’s.”

Diversity: Lake Forest Health and Fitness offers a variety of exercise classes. No two classes are alike, with different types of workouts offered for all ability levels. “I have done things I would never have tried on my own,” one person told me.

Safety: Classes are led by trained, qualified instructors who take their time to get to know the participants. They are there to guide, support, and supervise everyone. For safety, there is a 10 to 1 ratio of participants to instructors.

I invite you to cast aside any prior notions you have about joining an exercise class. Instead, take a chance. Sign up, pack your gym bag, and get ready for more than just an hour of exercise. You may find that you leave with new friends, a sense of accomplishment, and a supportive community. Join us!

Research Participation Opportunities at Northwestern Medicine

EARLY PARKINSON'S DISEASE

INTRAVENOUS R07046015 (PRX002)

The objective is to determine whether the study drug (R07046015) has an effect on a patient and their Parkinson's disease. This type of drug is called a "monoclonal antibody". Antibodies are proteins produced by the body as part of the immune response. Monoclonal antibodies recognize and bind to a specific type of protein, which has the possibility of slowing the course of PD. The effects of this drug will be compared to that of a placebo, an inactive substance made to look like an active medicine. Participants will either get the study drug or placebo.

GZ/SAR402671

This study will evaluate the possible risks and effectiveness of the study drug called GZ/SAR402671 in PD patients carrying the GBA gene mutation. In addition to evaluating the study-drug for the treatment of GBA-PD, the study aims to improve understanding of the role of GBA as a risk factor in the development and progression of PD. The effects of the study drug will be compared to placebo, an inactive substance made to look like an active medicine. Participants will either get the study drug or placebo.

ADVANCED PARKINSON'S DISEASE

Apomorphine

The objective is to test a new formulation of a marketed drug called APOKYN® (apomorphine hydrochloride injection) to treat the loss of control of body movements in adults with advanced PD. Participants will receive the drug by a continuous infusion through a small needle and pump under the skin of their stomach.

ALL PARKINSON'S PATIENTS

APL-130277

This is a study of the long-term safety, tolerability, and efficacy of a product (APL-130277) under development. APL-130277 is a soluble thin film for sublingual administration. It is designed to deliver apomorphine systemically through absorption from the oral cavity mucosa, thus bypassing the extensive first-pass metabolism associated with gastrointestinal absorption of the compound. The product is intended to be an alternative to the injectable form of apomorphine hydrochloride, which is marketed as APOKYN®.

Droxidopa

This study will test the effects of the drug droxidopa for the treatment of orthostatic dizziness (light-headedness or the feeling that you are about to black out) in patients with a clinical diagnosis of symptomatic neurogenic orthostatic hypertension due to Parkinson's disease, multiple system atrophy, pure autonomic failure, non-diabetic autonomic neuropathy, or dopamine-hydroxylase deficiency. Droxidopa's effectiveness was established in short-term studies lasting 2 weeks but has not yet been demonstrated for longer periods. This long-term study will evaluate the durability of the clinical benefit in NOH patients treated with droxidopa in a randomized withdrawal design (time to treatment intervention) study.

BMS-986168

The objective is to test the long-term safety and tolerability of an investigational drug called BMS-986168. An investigational drug is experimental and has not been approved for use by the US Food and Drug Administration (FDA), but the drug can be used in research studies such as this one. The effects of BMS-986168 will be compared to a placebo, an inactive substance made to look like an active medicine. Participants will either get the study drug or placebo.

Nilotinib

This study will assess the safety and tolerability of the daily oral administration of nilotinib (study drug) in moderate/advanced and early/de novo PD patients. Analysis will be done to compare the observed changes in Parkinson's symptoms between baseline and 6 months.

Motivational Interviewing and Physical Activity in Parkinson's Disease

This study will evaluate ways to increase physical activity in people with Parkinson's disease by increasing motivation to exercise. See page 3 for more details. Participants will be placed in 1 of 4 groups:

- motivational interviewing
- a web-based application to keep track of physical activity
- a combination of the two
- an educational program on issues related to Parkinson's disease.

Attention Bias: Testing a Potential Marker for the Diagnosis of Atypical Movement Disorders

This objective is to determine whether problems with attention lead to abnormal movements. The study involves a few thinking tests to determine if certain patterns of thinking or focusing can be associated with abnormal movements.

Northwestern Movement Disorders Center Biorepository

The Movement Disorders Center Biorepository collects biological and clinical information, such as blood and tissue samples, and medical and family histories from patients diagnosed with movement disorders. The information is maintained to be

studied in the future to identify factors that either cause these neurological conditions or increase the risk of developing them. Samples collected include a blood sample and a skin biopsy. Participants may donate one or both samples. See page 2 for more information.

Biomarkers Discovery in Parkinsonism

Through the use of structural and functional MRIs, blood tests, and behavioral motor and cognitive assessments, this study investigates how the brain and motor behavior change in movement disorders and healthy individuals over time. Participants include people with PD, progressive supranuclear palsy (PSP), or multiple system atrophy (MSA), as well as healthy control subjects.

For more information about Parkinson's disease research at Northwestern, email pdclinicaltrials@northwestern.edu, call 312-503-0775, or visit www.parkinsons.northwestern.edu/research/clinical-trials,

Parkinson's Disease and Movement Disorders Center

710 North Lake Shore Drive, 11th floor
Chicago, Illinois 60611-3006
www.parkinsons.northwestern.edu



Northwestern Medicine's Parkinson's Disease and Movement Disorders Center is proud to be a Parkinson's Foundation Center of Excellence.

CONTACT

312-503-4397 or 312-695-7950

CLINICAL TRIALS

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Please contact us to be added to our mailing or email list or to update your address. We also welcome your comments and letters.

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PATIENT AND FAMILY SYMPOSIUM

Sunday, May 6

8:30 a.m. to 1 p.m.

Bernard Weinger JCC

300 Revere Drive

Northbrook, Illinois

Continental breakfast provided. Sessions include

- Nutrition and Parkinson's Disease with Sabrina Sitoski, RD, LDN, CSG
- New Treatment Pipeline with Cindy Zadikoff, MD, MSC
- Experiential Exercises: yoga and Punch for PD
- Exercise and Parkinson's Disease with Daniel Corcos, PhD
- Questions and answers with Parkinson's Disease experts

RSVP at 312-926-8400