

On The Move >>>

Northwestern University Feinberg School of Medicine

Fall 2023 Vol. 36

Dancing with Parkinson's

By Carly Liegel and Katie Fagan, MSW, LCSW



Dance for PD® started in New York as a collaboration between the Brooklyn Parkinson's Project and the Mark Morris Dance Center. In its 20+ years, Dance for PD® has branched out across the U.S. and the world to train teachers, inspire students and invite dance in as an accessible art form for everyone.

I completed the introductory Dance for PD® training in the summer of 2019 with David

Leventhal in New York. After training, I co-led a Dance for PD®-based class in Bloomington, IN, for two years while completing my degree. Upon moving to Chicago, I noticed an absence of classes for those with different abilities and those over age 55. Once I joined the Community Engagement Department at The Joffrey Ballet, I knew I had the perfect opportunity, support and community to kickstart a new class. Dancing with Parkinson's has been a wonderful partnership between The Joffrey Ballet and Northwestern Medicine. We're excited for this class to branch out across Chicagoland and become a consistent presence.

Growing up, I never saw a body over age 40 actively





dancing outside my dance teachers and the occasional family wedding. I decided to become a teacher because I knew how much joy, freedom and connection I gained from dance and wanted to share that with others. However, I wanted the opportunity to teach all ages and abilities, which I rarely saw offered growing up. Dance should be an accessible art form for anyone at any age, and I'm thrilled to put this passion into our Dancing with Parkinson's classes.



Dance is often placed into two isolated boxes: an athletic endeavor or an art form. I've always believed it's not one or the other but both. It's a way to connect your movement to your mind, to invite expression and exploration where you haven't allowed it before: how moving your body in conjunction with others, with space, with music evokes creativity and connection. Everyone should have a chance to experience the unique, beautiful art form of dance, regardless of age or ability.

There is a perception that once a person has Parkinson's disease (PD), there is a lot that a person cannot do. So often, our society associates illness with restrictions and limitations. However, just because a person



has PD does not mean they cannot dance or move. Just the opposite is true! If you are reading this newsletter, you probably know that exercise and movement are integral to managing the symptoms of PD. Dance is a method of exercise that can help with that and is one of many reasons we are so happy to offer this class.

The benefit of Dancing with Parkinson's extends beyond the physical health benefits. In the first few classes we have held so far, it has become clear that one of the greatest benefits is togetherness and socialization. After being isolated and apart for so long, seeing people coming together has been so moving. Multiple participants have expressed, "It's so nice to be together." Some participants have even met virtually, and after years of talking through Zoom, they are now meeting each other in person for the first time. PD itself can be a very isolating illness. It can be isolating for the person with Parkinson's and their care partner. Combating isolation is a core focus of this program.

It has been such an honor to offer this program. It is so

powerful and heartwarming to see a room full of people who choose not to be defined by limitations of their age, disease, etc. Instead, they choose to come together, move together, laugh and smile together.

We look forward to continuing to offer and expand this program, spreading movement and social connection throughout the Chicagoland area.



In its 20+ years, Dance for PD® has branched out across the U.S. and the world to train teachers, inspire students and invite dance in as an accessible art form for everyone.



Join Us for Our Annual Parkinson's Disease Patient and Family Symposium

Saturday, October 7

Presented by Northwestern Medicine Parkinson's Disease and Movement Disorders Center and the Parkinson's Foundation Midwest Chapter



This virtual conference is designed for people affected by Parkinson's disease, their caregivers and families, and community members.

The event will feature experts talking about the advances in Parkinson's disease research, and dementia and cognition in dementia. There will also be a discussion on synuclein biomarkers, a newly discovered tool that is highly accurate at identifying Parkinson's disease, even before diagnosis. There will be a Q&A at the end of the presentation.

If you have any questions about this event, please email movementdisorders@nm.org.

Symposium speakers



Rizwan Akhtar, MD, PhD



Tanya Simuni, MD, FAAN



Michael Mercury, PhD

Register Now

There is no cost to attend, but you must register for the event.

Please register at: parkinson.org/northwestern2023

Annual Parkinson's Disease Patient and Family Symposium

Saturday, October 7

10 am-1 pm (CT)

Location: Zoom



CENTER OF EXCELLENCE

Donor Spotlight:

Meet Linda Kinzelberg

Linda Kinzelberg was born and raised on Chicago's north side. She taught 3rd grade at an elementary school in Evanston while raising her family on the north shore.

Now that her two sons are grown with successful careers and families of their own, Linda enjoys time spent with her four beautiful grandchildren. While she now lives in the city, her sons have chosen to raise their families on the north shore—in Wilmette and Winnetka.

Linda has always been interested in supporting others, saying, "I am fortunate enough to have had a beautiful life and have always felt blessed and grateful, and I want to give back." She

enjoys supporting causes serving the less fortunate, like the Chicago Food Depository, Thresholds and the doctors at our wonderful Chicago hospitals. She is also passionate about research for Parkinson's disease (PD) and dementia and supports Parkinson's research at Northwestern Medicine, Rush and the Michael J. Fox Foundation.

Linda has witnessed firsthand the impact of PD and dementia on her father's side of the family. Her father was diagnosed with PD with Lewy Body Dementia at age 60 and rapidly declined before passing away at age 72, which was difficult for Linda and her family. His brother, her uncle Ben, also had PD, his daughter has been diagnosed with dementia and Linda's sister is currently experiencing difficulties with short-term memory and word recall. Her family's history and genetic components seem strong. From the day of her father's diagnosis, she became interested in preventative measures and supporting work to understand PD better, develop

more effective treatments and ultimately find a cure.

Linda's father's rapid decline made it too hard for him to stay home, and the difficult decision was made to place him in nursing care. He slipped away at such a young age; Linda was in her 20s with her two very young sons. It was hard knowing they would never get to know their grandfather how she knew him. The disease disrupted the family and was especially difficult for Linda's mother. During the 1970s-80s, treatment options were fewer and much different.

They eventually moved her parents to the Los Angeles area, closer to Linda's sister, to take advantage of the warmer weather.

Linda's family history makes her and her

sons keenly aware that they could eventually be diagnosed. She lives a healthy lifestyle, staying active, eating well and exercising her brain. Linda lives a full life and tries not to dwell on what might come. Additionally, she stays abreast of current research and discoveries while supporting work at Northwestern Medicine and elsewhere to develop better diagnostics and treatments for the disease.

Linda's biggest motivation is to support the incredibly talented physicians and teams working daily to treat – and hopefully cure – PD, not only for herself but for her sons, grandchildren and all those affected by this disease. PD and dementia are topics of concern for her age group. It seems that Parkinson's disease and dementia are on the rise, and while Linda does what she can to prevent it in her own life, there is always the concern that it just might not be enough. The investment she makes here at Northwestern Medicine is another way she can contribute to the fight against PD and dementia and help others.

"I am fortunate enough to have had a beautiful life and have always felt blessed and grateful, and I want to give back."

Employment Services for People with Movement Disorders

By Miriam Rafferty and Paulo Aco

Being diagnosed with a movement disorder presents many challenges to completing daily activities. These challenges can be physical, cognitive and/or emotional. Career-related challenges can occur in all three domains, though they have not been investigated thoroughly for individuals with movement disorders.

People with movement disorders may choose to or need to exit the workforce earlier than those without them. However, early exits from the workforce may impact an individual's financial stability as they near retirement. Leaving the workforce early may also make preserving existing healthcare coverage or attaining new insurance more difficult. That is why having the right conversations with the right professionals early will help you get the support you need to leave the workforce in the best possible circumstances.

You want to ensure you have help with necessary accommodations in your workplace, as you prepare to request disability if needed and as you make retirement arrangements.

Here are some of the different health professionals and how they can help address employment challenges:

Neurologist: Help manage movement disorder symptoms and provide referrals to other specialists who could help with job-related issues. They may also offer carefully worded documentation to support requests for accommodations or disability.

Physical Therapist: Help with walking, balance, endurance, pain or stiffness.

Occupational Therapist: Provide strategies for hand coordination for work-related activities such as computer use, handwriting, energy conservation for fatigue, and provide ergonomic advice for office setup and develop adaptive strategies for completion of any work-related activity.

Speech Language Pathologist: Provide strategies to improve voice control for phone calls, public speaking and concentration at work.

Article continues on page 6 >>>

Parkinson's Works

Shirley Ryan
Abilitylab.

Join us for a free, virtual Peer Support Group for people with Parkinson's disease seeking counsel and/or community support as you navigate, looking for work, or work-life balance.

SEE PAGE 7 FOR MORE INFORMATION >>>

Assistive Technology:

Could work with vocational rehabilitation, occupational therapy or speech-language pathology to learn about technology that can help with productivity in the workplace. It can also provide education on computer and mouse use for ongoing independence, even when symptoms are present.

Social Worker:

- **Support:** Help find community resources, discuss workplace changes and provide stress management strategies.
- **Educate:** Share information about employment-related policies, problem-solve and make referrals regarding difficulties at work.
- **Guide:** Provide guidance on issues related to Medicare, Insurance, Social Security and Disability.

Vocational Rehabilitation Counselor:

- **Navigate:** Help work through the decision to disclose movement disorder status to an employer or colleagues, guide through job search, changing roles, or returning to work, and facilitate benefits for FMLA to an employer.
- **Accommodate:** Recommend strategies to assist with organization and concentration, physical accessibility at work, transportation, or travel.

A study being conducted by investigators at Shirley Ryan AbilityLab is tackling employment challenges. The employment study is a



three-year observational study to help researchers track which clinical employment support services are accessed and to monitor employment changes over time in people with early Parkinson's disease (diagnosed < 5 years with PD). The study is led by Miriam Rafferty, PT, DPT, PhD, who serves as the Director of Implementation Science at Shirley Ryan AbilityLab. Dr. Rafferty and her team aim to expand their knowledge on how greater attention to employment concerns early in the disease may benefit people with PD. This study has completed recruitment. In the summer of 2024, the research team will be able to share more about how healthcare professionals are currently being used specifically to address employment challenges. This study will help us determine if/where quality improvement efforts are needed.

One study participant stated their desire to prolong the longevity of their employment, saying, "I'm not ready to go on disability. I enjoy working, but it's

so difficult to navigate options on your own."

If you have employment challenges you would like to discuss, please visit <https://www.sralab.org/services/vocational-rehabilitation>. In addition, Shirley Ryan AbilityLab hosts a 'Parkinson's Works' peer support group moderated by a vocational rehabilitation counselor. Individuals from all over the country find a sense of community with others sharing similar work and life experiences. Guest discussants attend periodically to cover topics of interest with participants, such as mental health, social security benefits, nutrition and rehabilitation. Other resources related to employment and technology, employment accommodations, social security and disclosure are on the employment study webpage on the Shirley Ryan AbilityLab website. For information, visit <https://www.sralab.org/research/labs/Disability-Employment/projects/parkinsons-disease-intervening-early-concerning-employment-piece>.

Parkinson's Works

Join us for a free, virtual Peer Support Group for people with Parkinson's disease seeking counsel and/or community support as you navigate, looking for work, or work-life balance.

PURPOSE

The purpose of the "Parkinson's Works" Peer Support Group is to develop a sense of community among people with Parkinson's who may share similar experiences in the workplace or job-searching process. The group's mission is to provide a safe environment where the physical, emotional, and cognitive challenges of living and working with Parkinson's can be shared with a community of supportive peers with early-stage PD.

These Peer Support Groups are moderated by a Certified Rehabilitation Counselor who specializes in Vocational Rehabilitation at the Shirley Ryan AbilityLab. The group is conducted via a confidential web-based videoconference platform.

MEETINGS

The Group meets twice per month, on the 1st and 3rd Fridays of each month from 4:40pm-5:40pm CST. Guest discussants will be present approximately bi-monthly. Refer to the following dates from September 2023 to August 2024:

End of 2023	Beginning of 2024
September: 1 st & 15 th	January: 5 th & 19 th
October: 6 th & 20 th	February: 2 nd & 16 th
November: 3 rd & 17 th	March: 1 st & 15 th
December: 1 st & 15 th	April: 5 th & 19 th
	May: 3 rd & 17 th
	June: 7 th & 21 st
	July: 19 th
	August: 2 nd & 16 th

Who can participate?

You can participate in this group if you:

- Live in the United States
- Have Parkinson's disease
- Are currently working or looking for work
- Have access to internet via computer, phone, tablet, etc.

To register or for more information, please contact Paulo Aco
paco@sralab.org or (312) 238-7275

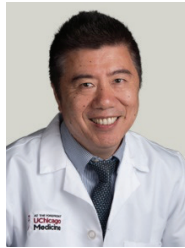


curePSP®
UNLOCKING THE SECRETS OF BRAIN DISEASE®

Dr. Padmanaban



Dr. Xie



Dr. Fleisher



Dr. Akhtar



The Greater Chicago Alliance for the Support and Education of Progressive Supranuclear Palsy (PSP), Corticobasal Degeneration (CBD), and Multiple System Atrophy (MSA) presents a virtual educational series for affected patients and caregivers. Topics vary from week to week as seen below with corresponding dates and will take place from 6:30-8:00 PM (CST).

Session Number	Topic	Experts/Affiliation
1: 8/3	Introduction to PSP, CBS, MSA: Natural history, symptoms, prognosis	M. Padmanaban/ University of Chicago
2: 8/10	Disease Mechanisms and neuropathology	R. Akhtar / Northwestern University
3: 8/17	Current Symptomatic Treatment for PSP, CBS, MSA	T. Xie/ University of Chicago
4: 8/24	Prescription for Hope: Palliative Care	A: J. Fleisher (Rush University) B: H. Leeper (U of C)
5: 8/31	Planning ahead: What to Know and Do after your diagnosis	Social Workers from all 3 institutions
6: 9/7	Clinical trials in PSP, CBS, MSA	T. Xie/ University of Chicago (PSP) R. Akhtar/ Northwestern (CBS, MSA)
7: 9/14	Cognitive/Behavioral	J. Mastrianni (Cognitive)/ University of Chicago A. Corcoran (Psychiatry)/ Northwestern
8: 9/21	Practical strategies for daily living	J. Fleisher/ Rush University
9: 9/28	GI & Nutrition issues in PSP, CBS, MSA	Keshavarzian and K. Gustashaw/ Rush University
	Neuro-ophthalmology	J. Nichols/ University of Chicago
10: 10/5	PT/OT/ST/Yoga/Dance	D. Palmer (ST)/ University of Chicago J. Roy (PT/OT)/ Rush University Yoga/Dance

To sign up and receive the Zoom link, please email Nicole.reidy@uchicagomedicine.org



AT THE FOREFRONT
**UChicago
Medicine**



“I did not know that Parkinson’s could be so funny.”

By Herbert Wennink

After my Parkinson’s diagnosis almost nine years ago, I did not know what to do.

There is no cure, and the available pharmaceuticals only treat the symptoms, not the actual disease. I was at a loss. Sitting at home, watching TV and waiting for my Parkinson’s to slowly take over my life was not something I was looking forward to. So I went to Wikipedia, my trusted internet encyclopedia. If you look up Parkinson’s, you get this picture of a bent-over, wrinkled old man who looks like he could drop dead any minute. I did not want to be that guy.

So, I started collecting information from several organizations that help people with Parkinson’s:

- **The Parkinson’s Foundation**
- **The Michael J. Fox Foundation for Parkinson’s Research**

I recommend watching his latest movie: “Still, a Michael J. Fox Movie,” on Apple TV

- **The Davis Phinney Foundation for Parkinson’s**
- **The Northwestern Medicine Parkinson’s Disease and Movement Disorders Center**
- **Parkinson Voice Project**



Besides the organizations listed, several others share the common goal of wiping out Parkinson’s.

There may not be a cure, but there is a very effective drug that slows down Parkinson’s progress. According to the National Institute of Health, the universal prescription for Parkinson’s disease is exercise.

Dr. Bastiaan Bloem, a well-known Parkinson’s authority from the Netherlands, once told me that it does not really matter what kind of exercise you do as long as it gets your heart rate up and is done twice a week or more.

Local heroes of the Exercise = Medicine lifestyle

are American Ninja Warrior Jimmy Choi and Coast to Coast walker Bill Bucklew.

Nowadays, there are numerous tailor-made programs, live or via ZOOM, for people with Parkinson's to exercise their brain and body: Rock Steady Boxing is one of my favorite programs. Others are golf, tennis, tango, yoga, pilates, dancing, nordic walking, etc.

All these programs cater to people with Parkinson's, so there is no excuse for being a couch potato; get up and do something.

One innovative program, Improv for Parkinson's, exercises the brain. Northwestern Medicine's PDMDC organizes it with The Second City, "The World's Premier School of Comedy." Just walking around the hallowed halls of comedy, with pictures of Second City alums like Dan Aykroyd, Jim & John Belushi, Chris Farley, Steve Carell, Shelley Long and many others makes you funnier.

Improv for Parkinson's started several years ago. It was moved from live to ZOOM during the pandemic but is now back to live-in-person.

The one-and-a-half-hour class is led by an experienced (and funny!) Second City teacher who leads a group of approximately 10 PD-ers with games like "Yes and" and "Five things," forcing participants to think on their feet and be funny at the same time. Of course, not everybody is ready to star on "Saturday Night Live," but you will be surprised how funny PD-ers can be!

A season of 8 weekly classes costs only \$100, and there is no need for boxing gloves, golf clubs, walking sticks or other accessories. Just bring your funny self. The class goes by fast, and the best part is that spending some time at The Second City makes you forget you have Parkinson's.



M

Parkinson's Disease

SIGNS AND SYMPTOMS

Four major symptoms of Parkinson's disease

- TREMORS
- STIFFNESS
- POSTURAL INSTABILITY
- SLOWED MOVEMENT

There's more to Parkinson's disease than what you see on the surface

WHAT YOU CAN SEE

Tremors

WHAT YOU HAVE TO LOOK CLOSELY TO NOTICE

- Change in balance
- Weakness in voice
- Postural instability: posture may become stooped and shoulders may become rounded
- Bradykinesia: slowed movement
- Mask-like expression
- Micrographia: small, cramped handwriting
- Difficulty with fine motor movement: picking up change, buttoning a shirt
- Gait changes: shuffling or taking smaller steps

WHAT YOU CAN'T SEE

- Stiffness and muscle rigidity
- Constipation due to the slowing of involuntary muscular movement
- Change in sleep patterns
- Pain due to muscle rigidity
- Loss of smell
- Depression
- Anxiety
- Bladder problems
- Memory loss
- Changes in vision: blurred or double vision, trouble reading, decreased sensitivity to color and brightness, hallucinations
- Dizziness

Sources:
<https://www.parkinson.org/understanding-parkinsons/non-motor-symptoms>
<https://parkinsonsnewstoday.com/2017/04/13/eleven-facts-about-parkinsons-disease/>
<https://www.parkinson.org/Understanding-Parkinsons/Treatment/Exercise/Neuroprotective-Benefits-of-Exercise>

Visit nm.org/parkinsons-support for more information about "Improv for Parkinson's Disease" and other support classes.



M Northwestern Medicine
Feinberg School of Medicine

Huntington's Disease Patient and Family Symposium

Saturday, November 11



Woodwind Conference Space
Lavin Family Pavilion
259 East Erie Street, 18th Floor, Chicago

Please call 877.926.4664 (TTY: 711) to register.



Agenda

- 8:30 am Check-in and light breakfast
- 9:00 am Welcome
- 9:10 am Nutrition and HD
Emily Kuettel, MS, RD, LDN
- 10:00 am Clinical Research Updates
Danny Bega, MD, MSCI
- 11:00 am Break
- 11:10 am Palliative Care
Emily Zivin, LCSW
- 11:30 am Panel Discussion: Difficult Conversations
- 12:30 pm Adjourn
- 1:00 pm Support group

This event is funded by the Huntington's Disease Society of America with support from Genentech, Teva, uniQure, Neurocrine Biosciences, PicnicHealth, PTC Therapeutics and MassMutual SpecialCare.



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Meet the Team

Juan Deliz Gonzalez, MD

Juan Deliz Gonzalez, MD's hometown is San Juan, Puerto Rico and he attended Washington University School of Medicine. After volunteering as a medical interpreter while in college in New York City, he decided to become a doctor. Dr. Gonzalez then worked as a clinical research coordinator for two years before going to medical school, where he was president of the local chapter of the Latino Medical Student Association. Dr. Gonzalez completed his Neurology residency at Northwestern, where he is staying for a Movement Disorders fellowship.



Mariana Hernández González-Monje, MD, PhD

Mariana Hernández González-Monje, MD, PhD, was born and raised in the beautiful Canary Islands, Spain. Her academic journey began at Universidad Autónoma de Madrid, Spain, where she obtained her medical degree. During her time there, she developed a strong interest in Neuroscience, leading her to pursue a PhD in Neuroscience focused on studying the dopaminergic innervation of the thalamus in a non-human primate model of Parkinson's disease.



Benjamin Friedman, MD

Benjamin Friedman, MD, is the new Medical Director of the Parkinson's Disease and Movement Disorders (PDMD) Program at the Shirley Ryan AbilityLab (SRALab). Dr. Friedman has extensive experience evaluating and caring for the rehabilitation needs of Parkinson's patients and others with movement disorders in outpatient and inpatient settings. He is an Assistant Professor of Physical Medicine and Rehabilitation at the Northwestern University Feinberg School of Medicine. Dr. Friedman completed Medical School at Finch University of Health Sciences, The Chicago Medical School in 2002 and his Residency in Physical Medicine and Rehabilitation was completed at the University of Chicago Network at Schwab Rehabilitation Hospital in 2006. Before joining the SRALab in 2018, Dr. Friedman was the Chairman of the Department of Physical Medicine and Rehabilitation and Medical Director of the Acute Rehabilitation Unit at St. Joseph Hospital in Chicago. As Medical Director of the PDMD program, Dr. Friedman will join an interdisciplinary team in assuring the highest quality care for our patients with Parkinson's disease and other movement disorders and oversee our rehabilitation services in this area. He will continue to see outpatient PDMD patients and other general/neurological conditions and care for inpatients on Nerve, Muscle and Bone, and the Brain Innovation Center's units.



While on her residency in Neurology at the Hospital Universitario Clinico San Carlos in Madrid, Spain, she worked closely with the movement disorders unit, where she gained some experience in advanced therapies. Additionally, Dr. Hernández González-Monje furthered her knowledge by spending three months as a clinical observer in the esteemed Sobel Department of Movement Neuroscience at the Institute of Neurology, UCL, London, UK.

Afterward, Dr. Hernández González-Monje undertook a clinical and research fellowship at HM-CINAC in Madrid, Spain, to enhance her expertise in movement disorders. Throughout this fellowship, she honed her skills in various areas, including focused ultrasound, kinematic evaluations and the utilization of cutting-edge technologies to assess patients with movement disorders.

In late 2020, she joined Northwestern University as a postdoctoral scholar, driven by her desire to expand her body of research and get trained in cell biology at the Krainc lab; an activity she will combine with the movement disorders fellowship.

While Dr. Hernández González-Monje's path has been firmly rooted in her passion for the brain, she must admit that if circumstances were different, she would have eagerly pursued her hobbies as a wine connoisseur or archaeologist, backpacking across the world.

Around the Network



In this segment, we feature updates from the PDMDC sites outside of downtown.

Central DuPage Hospital:

Upcoming Program Announcement:

"Continuing the Conversation: Perspectives on Deep Brain Stimulation" - Meeting in person on October 17 from 4-6 pm - Central DuPage Hospital, Inpatient conference rooms 1 and 2. Registration required by calling 630.933.4234

Lake Forest Hospital:

The Parkinson's Program at Northwestern Medicine Lake Forest Hospital offers a patient-centered approach to the management of Parkinson's disease, providing rehabilitation, wellness and supportive services. We offer a comprehensive team approach to those living with Parkinson's. The clinical team includes movement disorder specialists, general neurologists, cognitive/behavioral specialists and an experienced rehab team- including PT, OT and SLP.

Our community program includes exercise specialists, a Parkinson's specific exercise class and a monthly in-person support group. There are nine different Parkinson's exercise classes offered multiple times during the week. The classes focus on aerobics, strength training, balance/agility/multitasking and stretching. Additional programming includes therapeutic horseback, Saturday morning walk/run and weekly instructional golf and cardio tennis clinics.

For information on the Parkinson's programs offered at Northwestern Medicine Lake Forest Hospital, please contact Linda Egan at linda.egan@nm.org

Palos Hospital:

Introducing Dr. Kapur: I am Dr. Sachin Kapur, and I joined Northwestern Medical Group at Palos Hospital within the last year. I trained at UIC downtown for Neurology residency and did two years of Movement Disorder fellowship at Rush downtown.

I consider the clinic a community Movement Disorders clinic where the focus is on patient care, diagnosis and management of movement-related issues. I pride myself on being able to form a good rapport with patients and their families so that they feel comfortable early on. I want patients to feel open enough so there is no hesitation if something that may be questionable or even embarrassing is affecting the patient's symptoms. The goal is to improve the patient and family's ability to perform ADLs and overall quality of life, if possible.

I'm proud to act as an extension of the downtown Northwestern Neurology Movement Disorders department. I will be offering patients the opportunity to be involved with the studies and clinical trials that the department is offering.

Glenview:

Dr. Shetty is in the Glenview office on Mondays and is able to provide a wide variety of services from this location, including advanced therapeutics. At this time, he has very limited availability of appointments at this location.

Movement Disorders Support Groups and Programs

Central Region: Northwestern Memorial Hospital

General Parkinson's Disease Support Group

Date: First Wednesday of the Month

Time: 2 pm - 3 pm (CT)

Location: This is a virtual/online group. Once registered you will be given information to join the group.

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

Parkinson's Disease Care Partner Support Group

Date: Second Wednesday of the Month

Time: 2 pm - 3 pm (CT)

Location: This is a virtual/online group. Once registered you will be given information to join the group.

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

Young Onset Parkinson's Disease Group

Date: Fourth Wednesday of the Month

Time: 6 pm - 7 pm (CT)

Location: This is a virtual/online group. Once registered you will be given information to join the group.

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

Women and Parkinson's Disease Support Group

Date: Second Wednesday of the Month

Time: 11 am - 12 pm (CT) >>>>>

Location: This is a virtual/online group. Once registered you will be given information to join the group.

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

Chair Yoga

Date: Second, third, fourth and fifth Tuesday of the Month

Time: 2 pm - 3 pm (CT)

Location: This is a virtual/online group. Once registered you will be given information to join the group.

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

Therapy Tuesday Exercise Class

Date: First Tuesday of the Month

Time: 11 am - 12 pm (CT)

Location: This is a virtual/online group. Once registered you will be given information to join the group.

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

Parkinson's Disease 101

About: This informational class is designed to provide an overview of Parkinson's disease, including the history, causes, symptoms and treatments.

Date: November 15

Time: 4:00 pm - 5:30 pm (CT)

Location: This is a virtual/online group. Once registered you will be given information to join the group.

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

**Movement Disorders Support Groups and Programs
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Parkinson's Disease 201

About: This informational class is designed to provide a deeper understanding of the medications, treatments and advanced therapies available in the management of Parkinson's disease.

Date: TBD

Time: 4:00 pm - 5:30 pm (CT)

Location: This is a virtual/online group. Once registered you will be given information to join the group.

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

Art Therapy

Date: Third Monday of the month

Time: 10 am - 11 am (CT)

Location: This is a virtual/online group. Once registered you will be given information to join the group.

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

Dancing with Parkinson's

Date: TBD

Location: The Joffrey South Loop Studios, 1920 S. Wabash Chicago, IL 60616

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

Parkinson's Players (Cardio Tennis and Instructional Golf)

Date: Tuesdays through September

Times: Instructional Golf 5:00 pm - 5:50 pm (CT)
Cardio Tennis 6:00 - 6:50 pm (CT)

Location: Diversey Driving Range and Tennis Courts, 141 W. Diversey Pkwy Chicago, IL 60657

Cost: Free

Contact: For more information and to register, email movementdisorders@nm.org

Improv for PD

Date: Thursdays, October 12 - December 7

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

Location: The Second City - 230 W. North Ave. Chicago, IL 60614

Cost: \$100 for 8-week series

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail movementdisorders@nm.org

General HD Support group:

Date: January/March/no group in May due to Mother's Day July/September/November - 2nd Sunday of the month at 2:30 pm (CT)

Location: Logan Square Library, 3030 W Fullerton Ave, Chicago

Huntington's Disease Caregiver Support Group:

Date: February/April/June/August/October/December

Location: Winnetka Library
768 Oak Street, Winnetka, lower-level community room

Contact: Due to library scheduling, meeting dates are set 2 months in advance. If you want to be added to the caregiver email list, please email emily.zivin@northwestern.edu

Atypical Parkinson's Support Group

About: This support group is designed for people with Multiple System Atrophy (MSA), Corticobasal Degeneration (CBD) and Progressive Supranuclear Palsy (PSP), as well as their caregivers.

Date: Second Thursday of the month

Time: 4 pm (CT)

Location: This is a virtual/online group. Once registered you will be given information to join the group.

Cost: Free

Contact: For more information, please e-mail Emily Zivin, LCSW at emily.zivin@northwestern.edu

Wilson's Disease Support Group

Date: Last Thursday of the month January/April/July/October

Time: 7:00 pm - 8:30 pm (CT)

Location: This is a virtual/online group. Once registered you will be given information to join the group.

Cost: Free

Contact: For more information, please e-mail Emily Zivin, LCSW at emily.zivin@northwestern.edu **Continues on Page 16**

Central Region: Shirley Ryan Ability Lab

Virtual Peer Support Group for People with Parkinson's Disease Who are Working

Date: The group meets two Fridays per month

Time: 4:40 pm - 5:40 pm (CT)

Location: This is a virtual/online group. Once registered you will be given information to join the group.

Cost: Free

Contact: For more information, please contact Paulo Aco at paco@sralab.org or 312.238.7275

PWR! Circuit (Virtual)

Date: Tuesdays and Thursdays

Time: 10 am (CT)

Location: This is a virtual/ online group. Sign up here for the information and session link: www.sralab.org/services/adaptive-sports-and-fitness-program

PWR! Circuit

Date: Mondays, Wednesdays and Fridays

Time: 9:45 am (CT)

Location: SRALab Adaptive Sports and Fitness Center

Contact: 312.238.5001 or www.sralab.org/services/adaptive-sports-and-fitness-program

Nordic Poles Agility

Date: Seasonal class offered April-October, Thursdays

Time: 9 am (CT)

Location: 808 N. Lake Shore Park Drive

Contact: 312.238.5001 or www.sralab.org/services/adaptive-sports-and-fitness-program

PD PWR! Circuit Training

Date: Tuesdays and Thursdays

Time: 4:30 pm - 5:15 pm (CT)

Location: 7600 County Line Road Burr Ridge, IL 60527

Cost: There is a \$220 fee to join this 11-week class

Contact: Shirley Ryan AbilityLab Fitness Center 312.238.5003

Yoga

Dates & Times: Gentle Chair is Fridays at 9 am (CT)
Mat Yoga is Wednesdays at 8:45 am (CT)

Location: SRALab Adaptive Sports and Fitness Center
541 N. Fairbanks Ct. Mezzanine Level

Contact: Shirley Ryan AbilityLab Fitness Center 312.238.5003

The Goldman Functional Fitness Program

Date: Mondays-Fridays

Time: 6:15 am - 4:00 pm (CT)

Location: In-person and virtual telefitness coaching sessions available

Contact: Shirley Ryan AbilityLab Fitness Center 312.238.5003

ProACTIVE PD Exercise Class

Date: Thursdays

Time: 8:15 am - 9:00 am (CT)

Location: SRALab Adaptive Sports and Fitness Center

Cost: There is a \$110 fee to join this 11-week class.

Contact: 312.238.5003

Adaptive Pilates

Date: Tuesdays

Time: 2 pm (CT)

Location: SRALab Adaptive Sports and Fitness Center

Contact: Shirley Ryan AbilityLab Fitness Center 312.238.5003

Chair Based Dance

Date: Fridays

Time: 10:45 am (CT)

Location: SRALab Adaptive Sports and Fitness Center

Contact: Shirley Ryan AbilityLab Fitness Center 312.238.5003

Movement Disorders Support Groups and Programs Continue on Page 17

North Region: NM Lake Forest Hospital

NM Lake Forest Health & Fitness Center

1200 N. Westmoreland Rd. Lake Forest, IL 60045

In Person Exercise Classes:

Pedal for Parkinson's Levels 1 & 2
Seated Cardio Levels 3 & 4
Moves in Motion Levels 1 & 2
Strength & Balance For All Levels
Flexibility Fitness for Parkinson's Levels 3 & 4
Rock Steady Boxing For All Levels
Yoga for Parkinson's Levels 1 & 2
Stride and Strength Levels 1 & 2
Parkinson's Wellness Recovery (PWR! Moves) For All Levels

Please call 847.535.7060 regarding class information and registration.

Outpatient rehab services: including PT, OT & SLP

Monthly Support Group: Second Tuesday of the month
10:30 am - 12:30 pm (CT)

Contact: Linda Egan, PT at legan@nm.org or 847.535.8244

West Region: Central DuPage Hospital

Parkinson's Support Group

Date: Second Thursday of the month

Time: 10:30 am - 11:30 am (CT)

Location: This is a hybrid group. Some group members are come to the meeting online and some come in person. Once registered you will be given information to join the group.

Contact: For more information and to register, please call 630.933.4234.

Memory Caregiver Support Group

Date: First Thursday of the month the group is virtual and third Thursday of the month the group meets in person

Time: 10:00 am - 11:30 am (CT)

Location: Once registered you will be given information to join the group.

Contact: For more information and to register, please call 630.933.4234

JOIN A
SUPPORT
GROUP
TODAY!

STAY
ACTIVE!

CONNECT
WITH
OTHERS!

LEARN
& GROW!

EXERCISE
YOUR MIND!

BE
PROACTIVE!

Research Participation Opportunities at Northwestern Medicine

For more information call 312.503.0755
or email: pdclinicaltrials@northwestern.edu

For more information about Movement Disorders research at Northwestern, visit our website at: <https://www.neurology.northwestern.edu/divisions/movement-disorders/clinical-trials.html>

Research Study Title: Northwestern Movement Disorders Center Biorepository

Clinical Trial Description: The Movement Disorders Center Biorepository (MDC-Biorepository) is a registry aimed to collect biologic and clinical information from patients diagnosed with a movement disorder. The purpose is to identify factors that either cause these neurologic conditions or increase one's risk for developing them.

Clinical Trial Eligibility Criteria:

- Disease subjects and family members
- Diagnosis of a movement disorder

Research Study Visits: 1 visit (can be conducted during a regular clinic visit, includes blood or saliva sample)

Coordinator Contact: Rachel Lewandowski, T 312.695.0508, rachel.lewandowski@northwestern.edu

Research Study Title: The Parkinson's Progression Markers Initiative - Establishing a Deeply Phenotyped PD Cohort (PPMI 2.0)

Clinical Trial Description: The overall goal of PPMI 2.0 is to identify markers of disease progression for use in clinical trials of therapies to reduce progression of PD disability.

Clinical Trial Eligibility Criteria:

- Diagnosis of PD 2 years or less -OR-
- PD with genetic mutation < 2 years duration -OR-
- Prodromal and Healthy Control

Research Study Visits: Annual visits with DatScan, MRI, Lumbar Puncture and blood sample

Coordinator Contact: Sophia Melton, T 312.503.8229, sophia.melton@northwestern.edu or Demetrius Harvell, T 312.503.6819, demetrius.harvell@northwestern.edu

Research Study Title: Parkinson's Foundation PD-GENeration: Mapping the Future of Parkinson's Disease (PD-GENE)

Clinical Trial Description: The purpose of this study is to evaluate how offering certified genetic testing for PD genes to patients with Parkinson's impacts clinical care and potential enrollment in clinical trials.

Clinical Trial Eligibility Criteria:

- Willingness to undergo genetic tests
- No hematologic malignancies such as lymphoma or leukemia
- Have not received a blood transfusion within the past 3 months of study visit or had a bone marrow transplant within the past 5 years

Research Study Visits: Initial visit, genetic counseling session and online surveys

Coordinator Contact: Max Galarce, T 312.503.4270, max.galarce@northwestern.edu

Research Study Title: The Fox Bionet ECV 004 Study

Clinical Trial Description: The overall goal of this study is to identify reliable markers of LRRK2 activity in human CSF. This study is looking for non-manifesting LRRK2 mutation carriers, LRRK2+ Parkinson Disease (PD) participants, idiopathic PD (iPD) participants and healthy control (HC) participants.

Research Study Visits: 1 visit

Coordinator Contact: Sophia Melton, T 312.503.8229, sophia.melton@northwestern.edu or Demetrius Harvell, T 312.503.6819, demetrius.harvell@northwestern.edu

Research Study Title: Study in Parkinson Disease of Exercise Phase 3 Clinical Trial (SPARX3)

Clinical Trial Description: The primary objective of this study is to determine whether the progression of the signs of PD is attenuated at 12 months in non-medicated people with PD when they perform moderate vs. high-intensity endurance treadmill exercise.

Clinical Trial Eligibility Criteria:

- Diagnosis of PD 3 years or less and 40-80 years of age at screening
- Not expected to start PD meds least 6 months from baseline
- Currently exercising less than 2 hours of moderate intensity exercise per week within last 6 months >>>

Research Study Visits: 2-year study with 10 clinic visits and regular exercise training visits (Datscan required)

Coordinator Contact: Max Galarce, T 312.503.4270,
max.galarce@northwestern.edu

The Research Study Title: A Novel Measurement Concept To Objectively Quantify Severity of Vocal and Speech-Related Symptoms Associated With Parkinson's Disease (Voice-Pd)

Clinical Trial Description: The overall goal of this study is to objectively quantify severity of vocal and speech-related symptoms associated with Parkinson's disease. You will be provided with an iPhone to complete assessments at home.

Clinical Trial Eligibility Criteria:

- Diagnosed with PD on standard of care -OR-
- Prodromal participants - as identified via clinician-determined predictive criteria -OR
- Healthy age and sex matched controls

Research Study Visits: 10 weeks with 1 in-person visit and 3 remote visits

Coordinator Contact: Max Galarce, T 312.503.4270,
max.galarce@northwestern.edu

Research Study Title: A Phase 2b, Multicenter, Randomized, Double-Blind, Placebo-Controlled Study to Determine the Efficacy and Safety of BIIB122 in Participants with Parkinson's Disease (LUMA)

Clinical Trial Description: The primary objective of this study is to evaluate the efficacy of BIIB122 225 mg compared with placebo by time to confirmed worsening in MDS-UPDRS Parts II and III combined score over the treatment period.

Clinical Trial Eligibility Criteria:

- Diagnosis of PD 2 years or less and 30-80 years of age at screening.
- MDS-UPDRS Parts 2+3 OFF score ≤ 40 at screening
- 30-80 years of age
- 80% untreated or treated with PD meds for at most 30 days with last dose at least 60 days prior to screening OR
- 20% Treated with stable dose (MAO-B or LD) for minimum 90 days and on PD treatment for less than 1 year AND
- Not expected to start or change PD meds for at least 48 weeks from time of enrollment
- Positive DAT within 2 years

Research Study Visits: minimum 50 weeks and maximum 146 weeks

Coordinator Contact: Monika Szela, T 312.503.2693,
monika.szela@northwestern.edu

Research Study Title: Phase 1 Single- and Multiple-Ascending-Dose Study to Assess the Safety, Tolerability, and Pharmacokinetics of BIIB094 Administered Intrathecally to Adults with PD (REASON)

Clinical Trial Description: The primary objective of this study is to evaluate the safety and tolerability of multiple doses of BIIB094 administered via intrathecal (IT) injection to participants with Parkinson's disease (PD).

Clinical Trial Eligibility Criteria:

- Between 35 to 80 years of age who have a clinical diagnosis of PD with and without LRRK2 mutations
- Diagnosis of PD within 7 years without motor fluctuations or dyskinesias
- Treatment naive or on stable medication for at least 8 weeks prior to screening

Research Study Visits: 47 weeks total with up to 11 weeks screening, 4 monthly doses of study drug and 24-week follow-up

Coordinator Contact: Monika Szela, T 312.503.2693,
monika.szela@northwestern.edu

Research Study Title: A Phase 2, Randomized, Double-Blind, Placebo-Controlled Study to Evaluate the Efficacy, Safety, Tolerability, Pharmacodynamics, and Pharmacokinetics of BIA 28-6156 in Subjects With Parkinson's Disease With a Pathogenic Variant in the Glucocerebrosidase (GBA1) Gene

Clinical Trial Description: To assess the efficacy of BIA 28-6156 in delaying meaningful clinical motor progression in subjects with Parkinson's disease (PD) who have a pathogenic variant in the GBA1 gene (GBA-PD).

Clinical Trial Eligibility Criteria:

- Between 35 and 80 years of age who have a clinical diagnosis of PD ($H\&Y \leq 2.5$)
- On stable medication for at least 30 days prior to screening
- Known GBA-Pd risk-associated variant

Research Study Visits: 78-week treatment period with 35 days screening

Coordinator Contact: Justine Houseman, T 301.503.2128,
justine.houseman@northwestern.edu

Research Study Title: Web-based Automated Imaging Differentiation of Parkinsonism

Clinical Trial Description: The purpose of this study is to test the performance of the wAID-P algorithm in differentiating different types of diseases including Parkinson's disease (PD), multiple system atrophy parkinsonian variant (MSAp) and progressive supranuclear palsy (PSP). Each site will perform >>>

imaging, clinical scales and diagnosis. The clinical diagnosis will be blinded to the diagnostic algorithm and the imaging diagnosis will be compared to the movement disorders trained neurologist diagnosis.

Clinical Trial Eligibility Criteria:

- All subjects will be in the age range of 40-80 years at baseline evaluation
- For PD- symptom duration of 5-9 years and either H+Y 2 or 3 on medication at baseline
- For MSAP and PSP, subjects can be included in the study initially with a possible or probable diagnosis

Research Study Visits: 2 visits

Coordinator Contact: Max Galarce, T 312.503.4270,
max.galarce@northwestern.edu

Research Study Title: A Randomized, Double-blind Placebo-controlled Study to Evaluate the Effects of SAGE-718 in Parkinson's Disease Cognitive Impairment

Clinical Trial Description: This is a randomized, placebo-controlled double-blind study to evaluate the effects of SAGE-718 in PD mild cognitive impairment.

Clinical Trial Eligibility Criteria:

- Between 50 and 75 years of age
- Meet criteria for PD-MCI (MDS task force criteria for MCI in PD)
 - Level 1 PD-MCI with MOCA b/w 20-25
 - Level 2 PD-MCI with MOCA b/w 18-25
- Stable on meds for at least 4 weeks prior to baseline

Research Study Visits: Up to 14 weeks

Coordinator Contact: Nicholas Bobbitt, T 312.503.1999,
nicholas.bobbitt@northwestern.edu

Research Study Title: A 17-week, Phase 2, Randomized, Double-blind, Placebo-controlled, Flexible-dosing, Parallel-group, Multicenter Study of the Efficacy and Safety of Suvecaltamide in the Treatment of Moderate to Severe Residual Tremor in Participants with Parkinson's Disease (Jazz-PD)

Clinical Trial Description: This is a randomized, placebo-controlled double-blind study to evaluate the effects of Suvecaltamide in PD tremor.

Clinical Trial Eligibility Criteria:

- Between 40 and 80 years of age
- Diagnosed with PD within 5 years
- Moderate to severe residual tremor despite treatment with medication
- Stable on meds for at least 6 weeks

Research Study Visits: Up to 23 weeks

Coordinator Contact: Nicholas Bobbitt, T 312.503.1999,
nicholas.bobbitt@northwestern.edu

Join the Mailing List / Questions?

If you would like to be added to the On the Move mailing or email list—or if you have public questions you would like to pose to our collaborative care team (including physicians, social workers, physical and speech therapists or our research team) for our bi-annual newsletter FAQ section—please email jessenia.erickson@nm.org.

Please make sure all questions are general and not related to your personal care; for medication and appointment-related questions, please contact your care team.

Partnerships

Northwestern University is proud to be affiliated with a number of patient advocacy organizations.



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