

## REM Behavior Disorder and its Link to Parkinson's Disease

by Danielle Larson, MD and Hrayr Attarian, MD



### What is REM Behavior Disorder?

REM Behavior Disorder (RBD) is a sleep disorder characterized by acting out of one's dreams or dream-enactment behaviors (DEB). Normally, during Rapid Eye Movement (REM) sleep, voluntary muscles are mostly paralyzed to prevent us from acting on our dreams. In RBD, this muscle paralysis is lost, so the dreamer can act out their dreams manifesting behaviors such as talking, kicking or punching. Individuals may notice their bed sheets in disarray or find themselves falling out of bed or hitting their bed partners.

RBD affects roughly 2% of people over the age of 60. The average age at diagnosis is 60-70 years. RBD is formally and definitively diagnosed with video polysomnography, also known as a "sleep study."

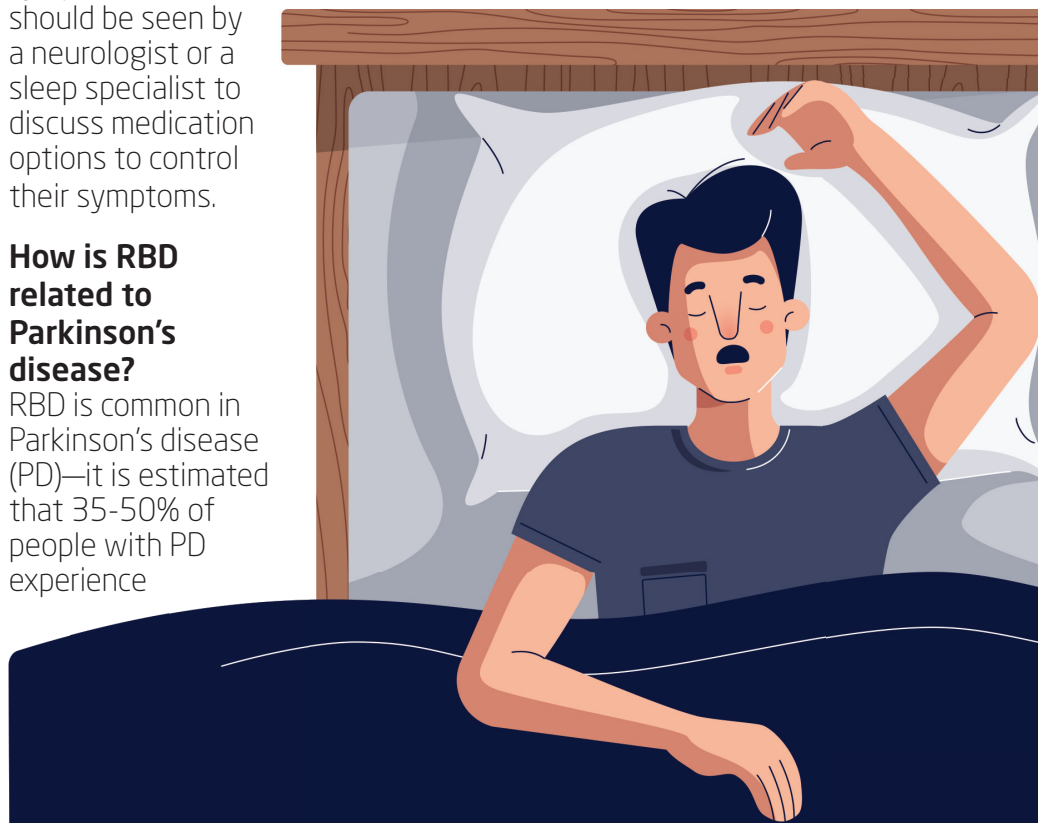
People with symptoms of RBD should be seen by a neurologist or a sleep specialist to discuss medication options to control their symptoms.

### How is RBD related to Parkinson's disease?

RBD is common in Parkinson's disease (PD)—it is estimated that 35-50% of people with PD experience

RBD. RBD is even more common in the rare Atypical Parkinsonian Syndromes of Multiple System Atrophy (MSA) and Dementia with Lewy Bodies (DLB),

**It is estimated that 35-50% of people with Parkinson's Disease experience REM Behavior.**



occurring in 80% of individuals with these syndromes. What these three conditions have in common is progressive degeneration of certain parts of the brain, hence they are known as neurodegenerative conditions. This is related to abnormal brain accumulation of the protein alpha-synuclein.

RBD symptoms occur years to decades prior to the onset of parkinsonian motor symptoms of tremor, slowness in movement and stiffness in movement. Therefore, RBD is thought of as a “prodromal” feature of PD, MSA and DLB. In a large research study of over 1000 patients with RBD, the annual rate of developing one of the above three disorders was 6%. Within 12 years of RBD diagnosis, 74% had developed either PD, DLB or MSA.

**What does “Prodromal Parkinson’s Disease” mean?**  
“Prodromal Parkinson’s disease” is when an individual has

symptoms associated with a high likelihood of developing parkinsonian motor symptoms and being diagnosed with PD, or the rarer conditions DLB or MSA. RBD is one of these symptoms, along with constipation, a decreased sense of smell or a specific genetic mutation.

### **The Parkinson’s Progression Marker Initiative (PPMI) Study**

The PPMI Study is a large international study funded by the Michael J. Fox Foundation to observe and collect blood and spinal fluid samples and imaging of PD patients and people at risk for PD. The study’s goal is to identify biomarkers (such as blood or imaging tests) that would accurately detect or diagnose PD at an early stage, potentially even before motor symptom onset.

Individuals at risk for PD included in this study are those with RBD and/or a decreased sense of smell. Studying people with these risk factors may uncover

clues about early changes in people eventually diagnosed with PD—which would enable us to diagnose and treat the disease earlier and eventually develop strategies to prevent the disease.

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**To learn more about the PPMI Study visit the website:**  
[www.ppmi-info.org](http://www.ppmi-info.org)

**Take a survey to see if you can participate in the research study on the website:**  
[www.michaeljfox.org/ppmi](http://www.michaeljfox.org/ppmi)

### **Reference**

Postuma et al. (2019). Risk and predictors of dementia and parkinsonism in idiopathic REM sleep behaviour disorder: a multicentre study. *Brain*, 142(3): 744-759. [10.1093/brain/awz030](https://doi.org/10.1093/brain/awz030)

## **Parkinson’s Foundation Expert Briefings Webinars**

Whether you are a person touched by Parkinson’s disease (PD) or a health care professional, the Parkinson’s Foundation’s online Expert Briefings offer a course for you. Learn more about PD symptoms, progression, treatments and management during our live slideshow presentations.

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**Expert Briefing: Understanding Gene and Cell-Based Therapies in Parkinson’s**

**Date:** Wednesday, October 5 • **Time:** 12 pm (CT) • **Cost:** Free

**Location:** This is a virtual/online group. Once registered you will be given information to join the group.  
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**To sign up and to find more information:** <https://www.parkinson.org/Living-with-Parkinsons/Resources-and-Support/PD-ExpertBriefings-Webinars>.



# Parkinson's Disease Patient and Family Symposium

Presented by Northwestern Medicine  
Parkinson's Disease and Movement  
Disorder Center



Join us for our annual Parkinson's Disease Patient and Family Symposium. This conference is for people affected by Parkinson's disease (PD), their caregivers and families and community members.

The event will feature experts talking about:

- Advances in PD research
- Therapies for PD
- PD nutritional requirements
- Psychological aspects of PD and interventions for mental health and overall well-being

**There will be a Q&A at the end of the presentation.**

If you have any questions about this event, please email [erin.cecchi@nm.org](mailto:erin.cecchi@nm.org).

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## Event Information

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### **Annual Parkinson's Disease Symposium**

Saturday, October 8

10 am - 12:30 pm (CT)

Location: Zoom

There is no cost to attend, but registration is required. Please register at: [parkinson.org/northwestern](https://parkinson.org/northwestern). You will receive an email with more information regarding the event after your register.

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# TIPS FOR CARE PARTNERS

by Erin Cecchi, MSW, LCSW - with contributions from care partners like you!

**Being a care partner is no easy feat. Whether it is a role assumed quickly or gradually over time, know that you are not alone. Help and support are available. Below are recommendations from current and past care partners to provide you with guidance, hope and connection.**

**Attitude is Everything.** “We fight this disease together.” While only one person has the disease, Parkinson’s, Huntington’s, ataxias and all movement disorders also affect those who identify as and take on the role of a care partner. Taking on an attitude of us against the “disease” can help with bonding, coping and symptom management.

**Laugh!** Maintain a sense of humor. Try to laugh every day. Get goofy. Dance. Sing. Joke. Whatever brings a chuckle, just do it!

**Prioritize your needs.** Care partners need to prioritize their mental, physical and spiritual health and overall well-being. Taking care of your own needs does not mean that you are neglecting others. It is in line with the notion that you must first take care of yourself in order to help and be present for others.

**Here is a metaphor to help further show the importance of self-care:** *Imagine that you have a glass of water. The level of water in the glass represents the amount of emotional, physical and spiritual energy you have available. If you exclusively care for others, the water will drain from your cup without the opportunity to refill. If you do not practice self-care, your glass will be empty, which means that others may have to fill it for you through positive affirmations and other forms of care. This can create an unhealthy cycle. Giving yourself permission to pause and refill your own cup will improve your quality of life and allow you to be a stronger care partner.*

**Be patient with yourself and others.** Being a care partner requires an extraordinary amount of patience. It’s a difficult skill to learn, but one that is worth the effort. Try not to get down on yourself when you “lose your cool.” We are human and our patience will be tested at times. Developing this skill will help ensure a better quality of life for you and your loved ones in the long-run and in times of increased stress.

**Acknowledge loss and grief.** At some point, each of us will experience grief and loss. Those of us caring for loved ones with a chronic and/or progressive illness know a very particular kind of loss. Acknowledging and naming this pain can help us to process and understand our feelings. It may not change the realities we face, but by approaching our emotions with curiosity, mindfulness and self-awareness, we can be more accepting of our current circumstances.

**Be together.** Chronic/progressive diseases can be isolating for care partners and care recipients alike. When we consciously spend time together—hold each other, affirm each other and celebrate being in each other’s company—we create meaningful moments, maintain and strengthen bonds. This may be difficult to do at times due to stress, competing priorities or as an illness progresses, but spending time together can be an important source of healing.

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**Keep records.** Keeping records for the person you are caring for is helpful for you, their medical providers and any other individuals involved in the person's care. It may seem like an overwhelming task to compile all important documents into one central place, but this can save you time in the long run. It also can be important for the person's health and well-being, as accurate record keeping can ensure everyone involved in the person's care is aware of their health history, medications and future wishes.

#### **Maintain records of:**

- **Identifying Information:** A list of commonly requested information such as height and weight, date of birth, address and important phone numbers; copies of identification cards; copies of insurance cards; any important legal papers, including any durable power of attorney documents
- **Medical History:** A list of all health/medical conditions; family health history; immunizations; surgeries and procedures; emergency room visits and hospitalizations; falls and near falls, along with a description of the circumstances; all physician contact information including last visit
- **Medication Information:** A list of prescription and over the counter medications, (including dosage, time when medication should be taken and prescribing provider); a list of changes in any medications, bothersome symptoms; changes in behavior or in the person's condition
- **Allergies:** A list of allergies or special conditions that might prevent someone from receiving certain treatments, undergoing certain procedures or taking specific medications
- **Questions:** A running list of questions you want to address with your neurologist and other health care providers

**Agree to disagree.** While an admirable goal, it may not be possible or realistic for a care recipient and care partner to agree on everything. Third party care, for example, is a common source of disagreement among care partners and care recipients. Care recipients often push back against the introduction of third party care, due to feelings of embarrassment, discomfort, or a lack of understanding of the care partner's emotional state. As uncomfortable as it can be, it's important for care partners to make their needs known before burnout strikes. In these situations, it's okay to say "This isn't about you. This is about me." Tending to your needs as a care partner supports the well-being of the care recipient and protects the relationship as a whole. These situations require us to recognize and respect the needs and safety of all involved. Flexibility and balance are two important factors when we "agree to disagree". It is about finding the sweet spot that balances the

care partner's needs, the care recipient's needs and the relationship's needs.

#### **Getting to know the diagnosis.**

Receiving a chronic/progressive illness diagnosis can be difficult for care recipients and care partners alike. Some people need time to process, others immediately learn everything they can about the diagnosis, while others prefer to learn as they go. However you and the one you are caring for approach familiarizing yourselves with the diagnosis, below are few recommended pieces of information to gather:

**Learn the basics:** Study the condition. Get to know its symptoms, treatments, and care approaches; track trends and monitor disease progression

**Get to know your healthcare resources:** Learn about all the different healthcare professionals that can help, what services they offer and what costs are associated. For example, are services such as occupational therapy, physical therapy, speech therapy, social work, driving rehabilitation or palliative care, available?

**Understand your insurance coverage:** Learn about what your insurance will and will not cover. Many people are surprised to find out that Medicare doesn't pay for long-term care in the home. While Medicare covers skilled nursing or rehabilitation services in the home, this service does not provide the one-on-one care and supervision that many require.

**Talk about and make arrangements for the future:** Planning for loss is a tender and sometimes anxiety-provoking subject. Nevertheless, individuals often find a weight lifted off their shoulders when they start talking and making plans. Having a conversation about the future earlier on, can also ensure that everyone's voices are heard. This can alleviate emotional and logistical burdens as care partners know they are following the wishes of their loved one.

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The information shared in this article is not exhaustive. There are endless other tips, tricks and strategies to share. The most important takeaway is to know that help and information are available when you want to seek it. You are always in charge of how much you want to know, when you want to learn it and how you want to move forward.

Call the Parkinson's Disease and Movement Disorder Center at 312.695.7950 with any questions or to be connected with a member of your healthcare team.

# Lewy Body Dementia and Occupational Therapy: Home Safety and Equipment

by Lena Menkes, OTD, OTR/L, Shirley Ryan AbilityLab

## What do Occupational Therapists do?

Occupational therapists help individuals participate in their desired occupations, or their meaningful day-to-day activities. While many may think that “occupations” refer to people’s work or employment, these “occupations” are really the everyday activities that we do—ranging from getting dressed and bathed, eating, performing hobbies, enjoying leisure activities as well as working.

When working with clients with Lewy Body Dementia (LBD), occupational therapists may assist with maintaining independence with daily routines, as well as modifying tasks and environments to allow continued safe participation in meaningful roles and activities. LBD is an umbrella term that includes two similar conditions—namely Parkinson’s disease with dementia and Dementia with Lewy Bodies.

Occupational therapists have a unique viewpoint on the interdisciplinary team to provide education on home safety, as well as recommending appropriate equipment to support this continued engagement across disease progression.

## Home Safety

Many factors can impact safety in the home environment and put an individual with LBD at a higher risk for falls or injury. When working with an occupational therapist or having a home evaluation completed, they may assess the following:

### Regular check-ins with your doctor or medical team

Keeping up with your doctors’ appointments will help ensure that your medications are appropriate and up to date and limiting any medication-related effects on cognition. Having your vision checked regularly will also help ensure improved safety with mobility at home.



### Home set-up

Checking that your home and hallways are clear of throw rugs and cords on the floor and other objects such as children’s toys, pet toys, among others can reduce fall risk. Having appropriate lighting in the home can also help limit falls while walking.

### Having appropriate supervision

When balance becomes affected in LBD and other movement disorders, there may be a role for direct supervision and physical assistance when moving around. This guidance can help prevent falls at home, and it may be important to also work with a physical therapist on the team. When cognition becomes affected, supervision may also become necessary for safety with household activities such as cooking, managing finances, managing medications and considerations for driving safety.

### Regular exercise

Participating in regular exercise will help keep muscles strong and maintain balance. There are many ways to exercise and opportunities to work with occupational therapists, physical therapists, exercise physiologists and exercise professionals.

## Equipment Use

A variety of different equipment exists to assist with both the physical and cognitive aspects of LBD. >>>

## Bathroom equipment

Many different seating options and grab bars exist to promote safety when using a shower, tub or toilet to promote energy conservation and support balance. An occupational therapist can help recommend the most appropriate option.

## Equipment for mobility

Use of an appropriate mobility device, such as a walker, cane or wheelchair, may be appropriate to support an individual with LBD as the disease progresses. (A physical therapist can assist with assessing the most appropriate device.)

## Bedroom equipment

Guardrails can be added to a standard bed to prevent rolling off of the bed while sleeping. Bed alarms can be utilized to ensure that a family member or caregiver can be alerted if an individual with LBD is getting up and may need assistance with mobility.

## Kitchen safety

Knob covers can be placed onto oven and stove knobs to ensure no accidental use in kitchen, as well as locks for drawers containing knives and other sharp objects.

## General safety

Use of an emergency alert system can assist in case of emergency. Smart phones and watches can also be programmed with fall detection software, to alert a caregiver in case of a fall.

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If you are a person with LBD or a care partner for someone with LBD, you are invited to join **Shirley Ryan's Lewy Body Dementia (LBD) Education and Support Group**. This is a monthly meeting held to increase awareness and education about a variety of topics encountered in the journey with LBD, as well as an opportunity to connect and share experiences. See details below.

## Lewy Body Dementia (LBD) Education and Support Group

**Date:** Fourth Thursday of the month

**Time:** 1 pm–2 pm (CT)

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

**Sign up here for info and session link:**

[http://bit.ly/SRALAB\\_LBD](http://bit.ly/SRALAB_LBD)

# PD CAREGIVER BOOT CAMP SERIES

**NORTHWESTERN UNIVERSITY**  
DEPARTMENT OF NEUROLOGY

Parkinson's disease caregivers are invited to participate in a PD Caregiver Boot Camp Series, to be held virtually via Zoom. This is a program (PF-CORE-856793) by Danny Bega, MD, MSCI, Linda Egan, PT and Erin Cecchi, MSW, LCSW at Northwestern University and is supported by a Centers of Excellence CORE grant from the Parkinson's Foundation.

## Who is Eligible?

- Individuals aged 18 or older
- Individuals who are taking care of or have taken care of someone with Parkinson's disease



## What will you be asked to do?

- You will be asked to participate in a consecutive weekly series of interactive webinars; each webinar session will be 60-90 minutes
- You will be asked to complete a survey of perceptions of the program, effects on your wellbeing, satisfaction with the program and recommendations for improvement

## Group Details

**About:** The goal of the group is to reduce caregiver burnout, improve mood and provide insights and coping tools to better support you as an individual and a care partner.

**Date:** Winter 2022-2023

**Time:** TBD

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

To participate in the group or if you have any questions, please e-mail Linda Egan, PT at: [linda.egan@nm.org](mailto:linda.egan@nm.org)





**We Care. We Fight. We Move.  
TO BEAT PARKINSON'S**

# Moving Day Chicago

## A Walk for Parkinson's

### Sunday, October 16, 2022

#### Soldier Field - South Lot

Join our team or make a donation:

**Our team name is:**  
NORTHWESTERN UNIVERSITY



AT MOVING DAY, A WALK FOR PARKINSON'S, we're honoring loved ones, raising funds, fighting Parkinson's disease and celebrating movement - proven to help manage Parkinson's symptoms. Whether you take part on a team, as a sponsor or volunteer, join hundreds of supporters in-person or virtually who share a common goal - to make an impact in our community and beat Parkinson's. We hope you will be a part of the movement.

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# Meet the Team

## Sarah Brooker, MD, PhD

Sarah Brooker, MD, PhD, started her Movement Disorders Fellowship at Northwestern in July 2022. She is originally from Minnesota and completed her undergraduate education at Yale University in 2010. She then joined the Medical Scientist Training Program at Northwestern, where she earned her master's degree and doctorate. Her PhD research focused on signaling pathways modulating adult hippocampal neurogenesis. She stayed at Northwestern for her neurology residency and was selected as one of the chief residents. During her fellowship she will be working on a research project with Dmitri Krainc, MD, PhD, investigating genetic and inflammatory mechanisms of Parkinson's disease. Outside of medicine she enjoys figure skating and exploring the Chicago food scene.



## Ignacio Juan Keller Sarmiento, MD

Ignacio Juan Keller Sarmiento, MD, started his Movement Disorders Fellowship at Northwestern in July 2022. Ignacio was born in Argentina and grew up in Italy. His desire to become a neurologist has been growing ever since he studied Freud in high school. He graduated from medical school in 2015 and started his neurology residency in Milan, Italy. Ignacio decided to spend his last year of residency at Northwestern, where he conducted post-doctoral research performing whole-exome sequencing of cases affected by movement disorders of likely genetic etiology. Ignacio also became a member of the Global Parkinson's Genetic Project (GP2), where the goal is to shed light on the genetic architecture of Parkinson's disease. In his free time, he enjoys traveling to the rainforest, practicing Brazilian jiu-jitsu and learning about different cultures.



## Maryellen Lajeunesse, MSW, LCSW

Maryellen Lajeunesse, MSW, LCSW, is a clinical social worker and former nurse who joined the Parkinson's Disease and Movement Disorders Center in July 2022. In this role, Maryellen provides care coordination and counseling. Maryellen graduated from Northwestern's School of Continuing Studies in 2013 with a Bachelor of Psychology. She continued her education and graduated from Loyola Chicago University in 2015 with a Master of Social Work degree. She has previous experience working in an outpatient oncology center and has a part-time private counseling practice that focuses on women experiencing life transitions. Maryellen was born and raised in Chicago and is a mother of two adult children. She is thrilled to be a part of the Movement Disorders team.



# Meet the Team

## Meghan Couch, PT, DPT, NCS, MBA

Meghan Couch, PT, DPT, NCS, MBA, has joined The Shirley Ryan AbilityLab Parkinson's Disease and Movement Disorders (PDMD) program as the new Program Manager working with Jennifer Goldman, MD, MS, and the PDMD team at Shirley Ryan AbilityLab. Meghan is a neurologic certified specialist in physical therapy and has worked across multiple practice settings, including inpatient rehabilitation, outpatient and acute care in Indiana. Her primary emphasis is working with neurologic patient populations including Parkinson's and movement disorders, but she also has experience treating orthopedic, cardiopulmonary, ICU and wound care populations. She earned her bachelor's degree and doctorate from Indiana University and graduated from the neurologic physical therapy residency program at A.T. Still University in Mesa, AZ. She has been involved in mentoring students as a clinical instructor throughout her time as a clinician and is a PWR!Moves® certified therapist. Meghan also recently graduated with a master's degree in business administration (MBA) from the University of Notre Dame with concentrations in strategy and business analytics. She can be reached at Shirley Ryan AbilityLab and 312.238.PDMD (312.238.7363)



## Leo Verhagen Metman, MD, PhD

Leo Verhagen Metman, MD, PhD, is a board-certified neurologist and a Professor of Neurology and Neurological Surgery at Northwestern University. Dr. Verhagen joined the Parkinson's Disease and Movement Disorders Center in July 2022, bringing decades of experience and knowledge with him. He specializes in the medical and surgical management of patients with Parkinson's disease and other movement disorders such as essential tremor and dystonia. Dr. Verhagen earned his medical and doctorate degrees from the University of Leiden in the Netherlands in 1983. After coming to the United States in 1985 to work in the Division of Artificial Organs at the University of Utah, he decided to pursue his interest in the neurosciences and accepted a fellowship in the Division of Restorative Neurology and Human Neurobiology at Baylor College of Medicine in Texas. Subsequently, he completed a neurology residency at Thomas Jefferson University Hospital in Philadelphia, PA. Upon completion in 1992, he accepted a fellowship at the National Institutes of Health in the Experimental Therapeutics Branch of the National Institute of Neurological Disorders and Stroke. After completing this fellowship in 1994, he stayed at the NIH for another 5 years, first as Visiting Associate, later as Visiting Scientist. The Branch's main focus was on pharmacological studies of motor response complications in Parkinson's disease. In 1999 he joined the Movement Disorder Section of the Department of Neurological Sciences at Rush University Medical Center. He most recently held the position of Associate Professor at Rush Medical College, and the Medical Director of the Neurosurgery Program for Movement Disorders, at Rush University Medical Center. Dr. Verhagen is multilingual, speaking English, French, Dutch and German.



# NEW SERIES COMING PRÓXIMA SERIE NUEVA

## IDEAS en Español



### Information for the Educational Development and Social Support of Community Members Affected by Parkinson's

The Shirley Ryan AbilityLab Parkinson's Disease and Movement Disorders (PDMD) program is excited to launch a new Parkinson's series entitled, IDEAS en Español.

This program, directed by doctors Jennifer G. Goldman, MD, MS and Susanna Miranda, DNP along with the Shirley Ryan AbilityLab team, will focus on ways for you to learn about Parkinson's disease, its symptoms and management – whether you are newly diagnosed or have had Parkinson's for a number of years. This program will be offered in Spanish.

We will highlight topics that are important to one's physical and mental health as well as proactive strategies to enhance one's well-being. The sessions will include speakers and instructors who will lead interactive and engaging sessions on topics such as physical exercise, nutrition, dance and more. This program also includes an optional research portion that will involve filling out online surveys including basic demographics, knowledge questions, Parkinson's and caregiver-related questions and program feedback evaluations.

Stay tuned for the eight live, virtual sessions in Spanish that will focus on key topics in PD regarding the importance of mental health, strategies for navigating one's diagnosis and PD motor and non-motor symptom management and the role of non-pharmacological therapies for PD symptoms and mental wellbeing. Expert speakers and instructors will guide these sessions with talks, activities and question and answer panels. Sessions will also be available as recorded webinars for viewing.

This series is supported by a Parkinson's Foundation Community Grant. **For more information, please contact [dmerklich@sralab.org](mailto:dmerklich@sralab.org) or 312.238.7363.**

### Información para el Desarrollo Educativo y Apoyo Social en la comunidad afectada por Parkinson

El programa Shirley Ryan AbilityLab Parkinson's Disease and Movement Disorders (PDMD) se complace en lanzar una nueva serie de Parkinson titulada IDEAS en Español.

Este programa, dirigido por las doctoras, Jennifer G. Goldman, MD, MS y Susanna Miranda, DNP, junto con el equipo de Shirley Ryan AbilityLab, se enfocará en las formas en que usted puede aprender sobre la enfermedad de Parkinson, sus síntomas y su manejo – si le han diagnosticado recientemente o que ha tenido Parkinson durante muchos años. Este programa será ofrecido en español.

Destacaremos temas que son importantes para la salud física y mental, así como estrategias proactivas para mejorar el bienestar. Las sesiones incluirán oradores e instructores que dirigirán sesiones interactivas y atractivas sobre temas como el ejercicio físico, la nutrición la danza y más.

Permanezca atento a las ocho sesiones virtuales en español que se centrarán en temas clave de la EP en relación con la importancia de la salud mental, las estrategias para navegar por el diagnóstico y el manejo de los síntomas motores y no motores de la EP, y el papel de las terapias no farmacológicas para los síntomas de la EP y el bienestar mental. Los expertos conferenciantes e instructores guiarán estas sesiones con charlas, actividades y paneles de preguntas y respuestas. Las sesiones también estarán disponibles como seminarios web grabados para su visualización.

**Para obtener más información, comuníquese con [dmerklich@sralab.org](mailto:dmerklich@sralab.org) o al 312.238.7363.**

**Shirley Ryan**  
**Abilitylab®**



# PD Support Groups and Programs

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## 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](http://nm.org/parkinsons-support) or e-mail Erin Cecchi, LCSW at [erin.cecchi@nm.org](mailto:erin.cecchi@nm.org)

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### 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](http://nm.org/parkinsons-support) or e-mail Erin Cecchi, LCSW at [erin.cecchi@nm.org](mailto:erin.cecchi@nm.org)

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### 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](http://nm.org/parkinsons-support) or e-mail Erin Cecchi, LCSW at [erin.cecchi@nm.org](mailto:erin.cecchi@nm.org)

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### 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](http://nm.org/parkinsons-support) or e-mail Erin Cecchi, LCSW at [erin.cecchi@nm.org](mailto:erin.cecchi@nm.org)

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### 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](http://nm.org/parkinsons-support) or e-mail Erin Cecchi, LCSW at [erin.cecchi@nm.org](mailto:erin.cecchi@nm.org)

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### 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](http://nm.org/parkinsons-support) or e-mail Erin Cecchi, LCSW at [erin.cecchi@nm.org](mailto:erin.cecchi@nm.org)

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### 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:** Wednesday, November 16

**Time:** 4 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](http://nm.org/parkinsons-support) or e-mail Erin Cecchi, LCSW at [erin.cecchi@nm.org](mailto:erin.cecchi@nm.org)

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## Central Region: Shirley Ryan AbilityLab

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

**Date:** The group meets twice per month, on the second and fourth Fridays of each 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 Sydney Achler at [sachler@srilab.org](mailto:sachler@srilab.org) or 312.238.6825

### Lewy Body Dementia (LBD) Education and Support Group

**Date:** Fourth Thursday of the month

**Time:** 1 pm - 2 pm (CT)

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

**Sign up here for info and session link:**  
[http://bit.ly/SRALAB\\_LBD](http://bit.ly/SRALAB_LBD)

## North Region: NM Lake Forest Hospital

### NM Lake Forest Health & Fitness Center

#### Exercise Classes:

Strength and Balance

Pedal for Parkinson's

Stride and Strength

Rock Steady Boxing

Yoga for Parkinson's

**Support Groups:** PD Care Partner and Women and PD group

**Location:** 1200 N. Westmoreland Rd., Lake Forest, IL 60045

**Contact:** For more information regarding the Parkinson's exercise classes or virtual support group meetings, please contact Linda Egan at [Linda.Egan@nm.org](mailto:Linda.Egan@nm.org) or 847.535.8244, or visit [www.lakeforesthfc.com/services/medical-fitness/parkinsons](http://www.lakeforesthfc.com/services/medical-fitness/parkinsons)

## West Region: Central DuPage Hospital

### Parkinson's Support Group

**Date:** Third Thursday of the month

**Time:** 10:30 am - 11:30 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, please call 630.933.4234

### Memory Caregiver Support Group

**Date:** First Thursday 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, please call 630.933.4234





# Research Participation Opportunities at Northwestern Medicine

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For more information call 312.503.0755  
or email: [pdclinicaltrials@northwestern.edu](mailto: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>

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## 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](mailto:rachel.lewandowski@northwestern.edu)

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## 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:** Heidi Friedeck, T 312.503.1519, [heidi.friedeck@northwestern.edu](mailto:heidi.friedeck@northwestern.edu)

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## 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](mailto:max.galarce@northwestern.edu)

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## 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:** Heidi Friedeck, T 312.503.1519, [heidi.friedeck@northwestern.edu](mailto:heidi.friedeck@northwestern.edu)

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## 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](mailto:max.galarce@northwestern.edu)

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**Research Study Title: A double-blind, placebo-controlled, randomized, Phase 2a study with oral UCB0599 in study participants with early Parkinson's Disease**

**Clinical Trial Description:** The primary objective of the study is to demonstrate the superiority of UCB0599 over placebo with regards to clinical symptoms of disease progression over 12 and 18 months in this patient population. Oral UCB0599 capsules or matching placebo capsules will be administered twice per day.

**Clinical Trial Eligibility Criteria:**

- Diagnosis of PD 2 years or less from baseline visit and 40-70 years of age at screening.
- Not expected to start PD meds least 6 months from baseline

**Research Study Visits:** 18-month study with 10 clinic visits and 6 televisits (Datscan required)

**Coordinator Contact:** Justine Houseman, T 312.503.2128, [justine.houseman@northwestern.edu](mailto:justine.houseman@northwestern.edu)

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**Research Study Title: A novel measurement concept to objectively quantify severity of vocal and speech related symptoms associated with Parkinson's Disease**

**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. Participants 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:** Natasha Maria Cabigon, T 312.503.0510, [natasha.cabigon@northwestern.edu](mailto:natasha.cabigon@northwestern.edu)

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**Research Study Title: A Phase 2b study, randomized, double-blind, placebo-controlled, multicenter study to evaluate the efficacy and safety of intravenous prasinezumab in participants with early Parkinson's Disease**

**Clinical Trial Description:** This is a multicenter, randomized,

double-blind, placebo-controlled study that will evaluate the efficacy and safety of intravenous (IV) prasinezumab versus placebo in participants with early Parkinson's disease (PD) who are on stable symptomatic PD medication.

**Clinical Trial Eligibility Criteria:**

- Diagnosis of PD for at least 6 months to maximum 3 years at screening and between 50-85 years of age
- On symptomatic PD medication for at least 6 months, with a stable dose for 3 months prior to baseline
- No dyskinesia or motor fluctuations (i.e., MDS-UPDRS Part IV = 0)

**Research Study Visits:** at least 76 weeks of monthly infusion with optional lumbar puncture

**Coordinator Contact:** Justine Houseman, T 312.503.2128, [justine.houseman@northwestern.edu](mailto:justine.houseman@northwestern.edu)

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**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**

**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 35-80 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, 312.503.2693, [monika.szela@northwestern.edu](mailto:monika.szela@northwestern.edu)

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**Research Study Title: A Phase 1/2a Open-Label Ascending Dose Study to Evaluate the Safety and Effects of PR001A in Patients with Parkinson's Disease with at Least One GBA1 Mutation**

**Clinical Trial Description:** PR001 is being developed as a potentially disease-modifying, single-dose gene therapy for patients with Parkinson's disease with GBA1 mutations (PD-GBA) and neuronopathic Gaucher disease.

**Clinical Trial Eligibility Criteria:**

- Between 40-75 years of age who have a clinical diagnosis of PD (H&Y 3-4)

- On stable medication for at least 8 weeks prior to baseline
- At least 1 GBA mutation

**Research Study Visits:** 5-year study duration with 45 days screening, 12 months of primary safety/efficacy visits, and 4 years follow-up

**Coordinator Contact:** Cynthia Poon, T 312.503.8216, [cynthia.poon@northwestern.edu](mailto:cynthia.poon@northwestern.edu)

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### **Research Study Title: A Dose Selection Trial of Light Therapy for Impaired Sleep in Parkinson's Disease**

**Clinical Trial Description:** The primary aims of this trial are to determine whether once- or twice-daily bright-white light therapy (BWLTL) improves sleep in Parkinson's disease (PD) and, if so, to select the superior dose frequency. This is a 16-week trial in participants with PD and sleep disruption.

#### **Clinical Trial Eligibility Criteria:**

- Age 45 or above with a diagnosis of idiopathic PD
- PD Hoehn and Yahr stage 2 - 4
- A score of 2 (mild) or above on the Sleep Problems question of the MDS-UPDRS Part 1
- Stable dose of all PD medications for at least 30 days prior to randomization

**Research Study Visits:** 5 visits over 16 weeks

**Coordinator Contact:** Monika Szela, T 312.503.2693, [monika.szela@northwestern.edu](mailto:monika.szela@northwestern.edu)

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### **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:** Destiny Gomez, T 312.503.2778, [destiny.gomez@northwestern.edu](mailto:destiny.gomez@northwestern.edu)

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### **Research Study Title: Phase 3, Randomized, Double-Blind, Placebo-Controlled Study to Assess the Efficacy, Safety and Tolerability of Valbenazine for the Treatment of Chorea Associated with HD**

**Clinical Trial Description:** The present study is to evaluate the efficacy, safety and tolerability of valbenazine administered once daily for the treatment of chorea in adult subjects with HD.

#### **Clinical Trial Eligibility Criteria:**

- Age 18-75 years, inclusive
- Diagnosis of motor manifest HD
- Genetic dx of HD with CAG repeat  $\geq 37$
- TMC score  $\geq 8$  and TFC score  $\geq 5$

**Research Study Visits:** Up to 104 weeks (2 years)

**Coordinator Contact:** Zsa Zsa Brown, T 312.503.4121, [zsazsa.brown@northwestern.edu](mailto:zsazsa.brown@northwestern.edu)

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### **Research Study Title: A Randomized, Placebo-Controlled, Double-Blind Study to Evaluate the Effect of SAGE-718 on Cognitive Function in Participants with Huntington's Disease**

**Clinical Trial Description:** The primary purpose of this study is to evaluate the effect of SAGE-718 oral capsules on cognitive performance and functioning in participants with premanifest or early manifest Huntington's disease (HD).

#### **Clinical Trial Eligibility Criteria:**

- Between 25-65 years of age
- HD CAG > 36, UHDRS-TFC b/w 6 and 13
- MOCA < 26 at screening

**Research Study Visits:** Up to 136 days

**Coordinator Contact:** Zsa Zsa Brown, T 312.503.4121, [zsazsa.brown@northwestern.edu](mailto:zsazsa.brown@northwestern.edu)

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### **Research Study Title: TeleHD: Feasibility, validity and value of telemedicine for motor and non-motor assessments in patients with Huntington's Disease (HD)**

**Clinical Trial Description:** To establish the feasibility, validity and value of utilizing telemedicine to conduct remote clinical visits and complete the Composite Unified Huntington's Disease Rating Scale (cUHDRS). Feasibility of televisits for HD patients will be determined by completion of study visits.

#### **Clinical Trial Eligibility Criteria:**

- Between 18-70 years old
- Diagnosis of HD with MOCA > 21

**Research Study Visits:** 2 in-person clinic visits and 2 telemedicine visits.

**Coordinator Contact:** Destiny Gomez, T 312.503.2778, [destiny.gomez@northwestern.edu](mailto:destiny.gomez@northwestern.edu)

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### **Research Study Title: Development of the Virtual Unified Huntington's Disease Rating Scale (vUHDRS)**

**Clinical Trial Description:** To assess the reliability of virtual administered UHDRS compared to the in-person administration of the UHDRS to establish the use of the vUHDRS for clinical trial and regulatory purposes.

#### **Clinical Trial Eligibility Criteria:**

- 18 years or older with motor manifest HD
- Able to maintain stable medication for 30 days following initial visit
- Able to obtain internet connection at home or designated location

**Research Study Visits:** Up to 6 weeks study duration

**Coordinator Contact:** Destiny Gomez, T 312.503.2778, [destiny.gomez@northwestern.edu](mailto:destiny.gomez@northwestern.edu)

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### **Research Study Title: Clinical Study of UX701 AAVMediated Gene Transfer for the Treatment of Wilson Disease**

**Clinical Trial Description:** The primary objectives of this study are to evaluate the safety of single IV doses of UX701 in patients with Wilson disease, to select the UX701 dose with the best benefit/risk profile based on the totality of safety and efficacy data and to evaluate the effect of UX701 on copper regulation.

#### **Clinical Trial Eligibility Criteria:**

- Patients  $\geq$  18 years of age
- Confirmed diagnosis of WD by Leipzig score  $\geq$  4 and clinical impression of WD
- Ongoing copper chelator and/or zinc therapy for at least 12 months at screening, with no medication or dose changes for at least 6 months at screening
- Stable WD as evidenced by lab values

**Research Study Visits:** 41 study visits over 2 years

**Coordinator Contact:** Zsa Zsa Brown, T 312.503.4121, [zsazsa.brown@northwestern.edu](mailto:zsazsa.brown@northwestern.edu)

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### **Research Study Title: A Phase 2b, 12-week, Double-blind, Placebo-controlled, Randomized, Parallel-group, Multicenter Study of the Safety and Efficacy of JZP385 in the Treatment of Adults with Moderate to Severe Essential Tremor**

**Clinical Trial Description:** This is a 12-week, double-blind, placebo-controlled, randomized, parallel-group, multicenter study of the safety and efficacy of JZP385 in the treatment of adult participants with moderate to severe ET.

#### **Clinical Trial Eligibility Criteria:**

- 18-80 years old with diagnosis of ET

- Moderate to severe disability associated with tremor (per scored assessments)

**Research Study Visits:** 21 weeks

**Coordinator Contact:** Monika Szela, T 312.503.2593, [monika.szela@northwestern.edu](mailto:monika.szela@northwestern.edu)

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### **Research Study Title: A Phase 3, Long-term, Randomized, DB-PC Trial of BHV4157 in Adult Subjects with Spinocerebellar Ataxia**

**Clinical Trial Description:** The purpose of this clinical trial is to compare the efficacy of BHV-4157 versus placebo on ataxia symptoms in subjects with spinocerebellar ataxia (SCA).

#### **Clinical Trial Eligibility Criteria:**

- Age 18-75 years of age
- SCA 1-3, SCA 6-8 and SCA 10
- SARA score  $\geq$  8; score of  $\geq$  2 on gait subsection

**Research Study Visits:** Up to 64 weeks

**Coordinator Contact:** Natasha Cabigon, T 312.503.0510, [natasha.cabigon@northwestern.edu](mailto:natasha.cabigon@northwestern.edu)

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### **Research Study Title: Clinical Trial Readiness for SCA1 and SCA3**

**Clinical Trial Description:** The investigators plan to fill the gap between the current state of clinical trial readiness and the optimal one for SCA1 and SCA3, which are fatal rare diseases with no treatments. Through US-European collaborations, the investigators will establish the world's largest cohorts of subjects at the earliest disease stages, who will benefit most from treatments, validate an ability to detect disease onset and early progression by imaging markers, even prior to ataxia onset, and identify clinical trial designs that will generate the most conclusive results on treatment efficacy with small populations of patients.

**Research Study Visits:** 1 visit

**Coordinator Contact:** Natasha Cabigon, T 312.503.0510, [natasha.cabigon@northwestern.edu](mailto:natasha.cabigon@northwestern.edu)

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## **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](mailto: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.

curePSP<sup>®</sup> | CENTER OF CARE

Huntington's Disease Society of America  
**Centers of Excellence**

**WDA**  
WILSON DISEASE ASSOCIATION

**Parkinson's Foundation**  
CENTER OF EXCELLENCE

**PSG**  
PARKINSON STUDY GROUP

**NAF**  
National Ataxia Foundation



## 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

**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

- 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
- 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://parkinsonstoday.com/2017/04/13/eleven-facts-about-parkinsons-disease/>  
<https://www.parkinson.org/Understanding-Parkinsons/Treatment/Exercise/Neuroprotective-Benefits-of-Exercise>