PARKINSON'S DISEASE AND MOVEMENT DISORDERS CENTER

On The Move »»

Northwestern University Feinberg School of Medicine

Spring 2023 Vol. 35

Parkinson's Exercise Guidelines: Key Takeaways and Resources

by Kevin Smaller and Miriam Rafferty, PT, DPT, PhD

Shirley Ryan AbilityLab's team of physical therapists and other rehabilitation providers work with people with Parkinson's disease (PD) and other movement disorders to encourage exercise as a critical part of their treatment plan. Years of research show the potential for regular exercise to slow declines in mobility and quality of life. However, developing and maintaining a comprehensive exercise routine is a challenge. Thankfully, the Parkinson's Foundation and the Academy of Neurologic Physical Therapy, with the involvement of Shirley Ryan AbilityLab faculty, are creating resources for people with PD and their physical therapists. Below, we summarize the key takeaways.

The Parkinson's Foundation developed Parkinson's-specific exercise guidelines in collaboration with the American College of Sports Medicine and a group of exercise and rehabilitation experts. (Their infographic fact sheet can be seen on page 3.) The recommendations say that individuals with PD should try to get about 150 minutes of moderate intensity aerobic exercise (at least three days per week), with at least two days a week of strengthening exercise. The recommendations also

include two to three days per week of two additional types of exercise: stretching and balance, agility and multitasking. Blending these exercises into a comprehensive but manageable weekly program is where skilled exercise professionals, Parkinson's-specific group exercise programming or a physical therapist can help.

The American Physical Therapy Association's clinical practice guidelines (summarized below) support the Parkinson's-specific exercise guidelines. The guidelines state that physical therapists should include appropriately dosed exercise interventions, including aerobic, resistance and balance training. Flexibility training is recommended as a part of the warm-up and cool-down activities. Physical therapy interventions that have been shown to improve motor disease severity include aerobic, resistance, task-specific and gait training. Physical therapy interventions that can improve walking and mobility outcomes (e.g., walking speed, walking endurance, freezing of gait, transfers, balance confidence and fall risk) include gait and balance training, and external cueing. The guidelines are written for physical therapists (make sure to ask your therapist about them), but the Academy of Neurologic Physical Therapy is developing a toolbox with educational resources for clinicians and the people with PD they treat.

Creating a comprehensive plan from these guidelines can feel overwhelming. You may feel like you have the "what" without the "how." Working with your rehabilitation team to develop a personalized exercise plan may help you with the improvements you are seeking.

If you need help finding local resources, ask your neurology center coordinator, physical therapist, or in the absence of a local care team the Parkinson's Foundation helpline – you can call 312.238.7363 (PDMD) or sralab.org/parkinsons.

Key Takeaways from the American Physical Therapy Association's Clinical Practice Guidlines for Management of Parkinson's Disease

Motor Symptom Severity
Unified Parkinson's Disease Rating Scale

Aerobic Exercise | Gait Training | Resistance Training | Integrated Care | Community-Based Exercise

Functional Mobility
Moving from one spot to another

Aerobic Exercise | Resistance Training | Community-Based Exercise | Task-Specific Training

Walking
Step length, speed, and endurance

Gait Training | Balance Training | External Cueing

Balance
Steadiness, agility, and fall risk

Balance Training | Gait Training | Telerehabilitation

Non-motor Symptoms
Cognition, depression, anxiety, and sleep

Resistance Training | Integrated Care | Community-Based Exercise

Quality of Life
Overall wellbeing and percieved health status

Balance Training | Resistance Training | Community-Based Exercise | Behavior Change Approach | Integrated Care

https://www.neuropt.org/practice-resources/anpt-clinical-practice-guidelines/pt-management-of-parkinson-disease

Parkinson's Exercise Recommendations

Parkinson's is a progressive disease of the nervous system marked by tremor, stiffness, slow movement and balance problems.

Exercise and physical activity can improve many motor and non-motor Parkinson's symptoms:

Aerobic Activity

3 days/week for at least 30 mins per session of continuous or intermittent at moderate to vigorous intensity

TYPE: Continuous, rhythmic activities such as brisk walking, running, cycling, swimming, aerobics class

CONSIDERATIONS: Safety concerns due to risks of freezing of gait, low blood pressure, blunted heart rate response. Supervision may be required.

Strength Training

2-3 non-consecutive days/ week for at least 30 mins per session of 10-15 reps for major muscle groups; resistance, speed or power focus

TYPE: Major muscle groups of upper/lower extremities such as using weight machines, resistance bands, light/moderate handheld weights or body weight

CONSIDERATIONS: Muscle stiffness or postural instability may hinder full range of motion.

Balance, Agility & Multitasking

2-3 days/week with daily integration if possible

TYPE: Multi-directional stepping, weight shifting, dynamic balance activities, large movements, multitasking such as yoga, tai chi, dance, boxing

CONSIDERATIONS: Safety concerns with cognitive and balance problems. Hold on to something stable as needed. Supervision may be required.

Stretching

>2-3 days/week with daily being most effective

TYPE: Sustained stretching with deep breathing or dynamic stretching before exercise

CONSIDERATIONS: May require adaptations for flexed posture, osteoporosis and pain.

See a physical therapist specializing in Parkinson's for full functional evaluation and recommendations.

Safety first: Exercise during on periods, when taking medication. If not safe to exercise on your own, have someone with you.

It's important to **modify and progress** your exercise routine over time.

Participate in **150 minutes** of moderate-to-vigorous exercise per week.

AMERICAN COLLEGE of SPORTS MEDICINE LEADING THE WAY

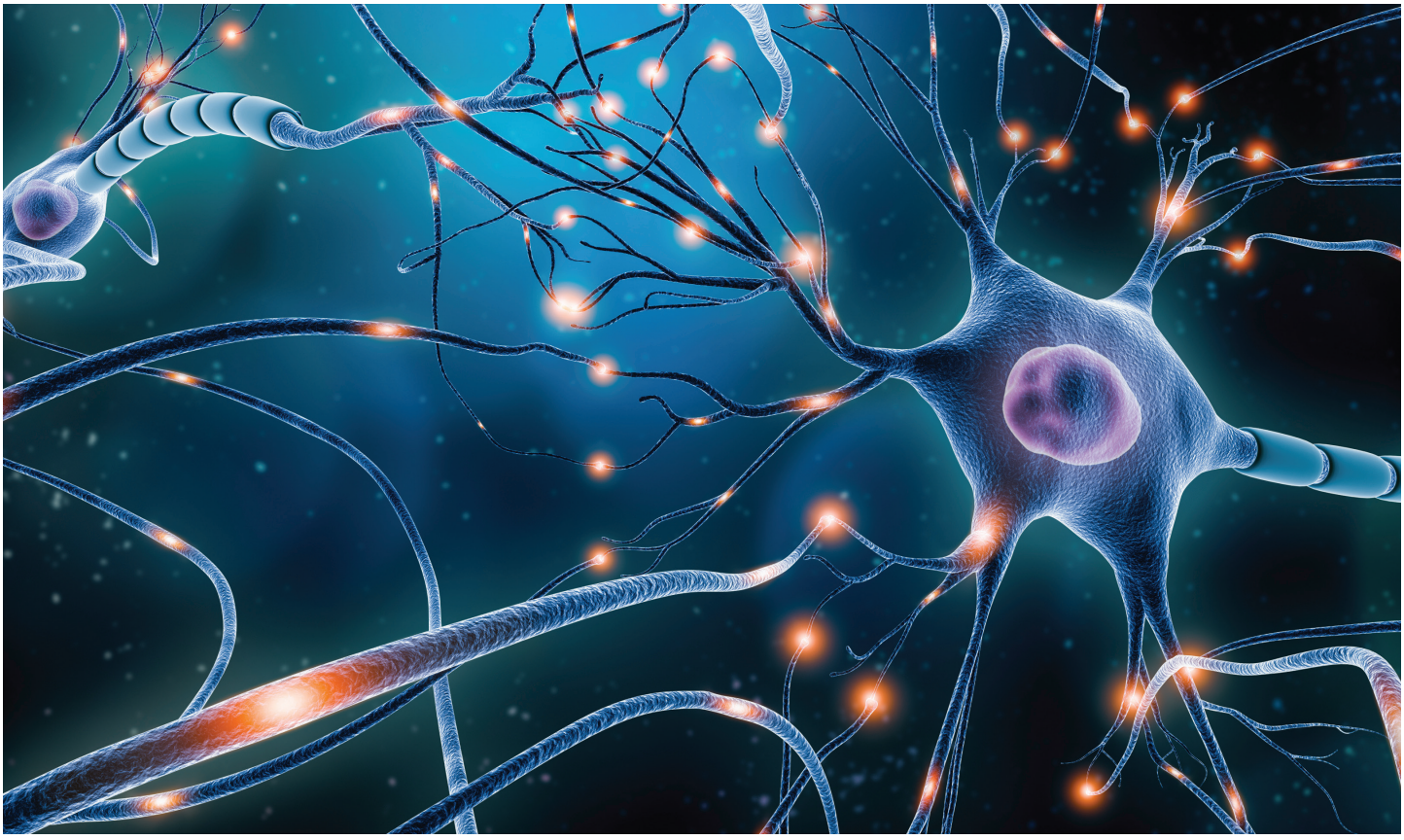
Parkinson's Foundation

Helpline: 800.473.4636/Parkinson.org

Chemistry and Electricity: Two Complementary Ways to Fuel the Networks in Your Brain

by Leo Verhagen Metman, MD, PhD
Professor of Neurology, Division of Parkinson's disease and Movement Disorders Center
Co-Director of the DBS and Advanced Therapeutics Program, Northwestern University Feinberg School of Medicine

Movement disorders like Parkinson's disease (PD), essential tremor (ET) and dystonia may look very different but share characteristics. I'll focus on one common factor: that they are all network disorders. What does that mean? The brain contains, among other elements, close to 100 billion nerve cells (neurons) that make over 1,000 trillion connections (synapses) with other neurons. Electrical signaling passes information from one cell to the next, releasing chemical messengers (neurotransmitters). Fortunately, this jamboree has some order because neurons and synapses are organized in areas, pathways or networks that are structurally or functionally connected. This allows us to have thoughts, execute movements, have emotions and so on, all by activating separate, albeit overlapping, networks. This is great, but the flip side is what I call the "European blow-dryer concept." When a guest from overseas uses their blow-dryer in your 110V outlet, you know a fuse will blow and knock out the power in an entire section of your house. The same holds true for the circuit board that is our brain. One small, localized misfiring area in the brain will affect all the connected neurons, i.e.,



the entire network of nerve cells, resulting in that particular network no longer (net)working smoothly and a loss of function.

To get to the point (finally, you might say!), I'll use (PD) as an example because we know more about that disease than the other two mentioned. In PD, the main problem is the loss of dopamine-producing cells in a relatively small area of the brain called the substantia nigra. This area is part of many networks, the most obvious being the network involved in movement (motor network). As mentioned earlier, communication within the network is a result of an intricate working relationship between electrical signals and chemical messengers, or, in short, electricity and chemistry. Dopamine, representing the 'chemistry' component, is the neurotransmitter of choice in this network. In PD, the lack of that neurotransmitter causes abnormalities in the electrical signaling and the electricity of the entire network. We see the appearance of tremor, slowness and stiffness, which are the hallmarks of PD. We do not know if there is an equivalent of dopamine in ET or dystonia, but we do know that electrical signaling is also altered in those disorders.

It will finally become clear why we needed (or did we?) this long introduction as we explore possible treatments, again taking PD as an example. When there is a dopamine deficit in the brain, a logical thought is to replace that dopamine with a medication that acts the same way. That is the chemical approach. And that is exactly what we have been doing since 1967, when levodopa was first used. This medication is metabolized into dopamine once it enters the brain. It is truly one of the most rational therapies in all of neurology. There are other medications, but they usually cannot compete with levodopa. But, some people cannot tolerate levodopa, and there are people whose tremor does not respond well to levodopa. Some develop 'fluctuations' in their response to levodopa, with each dose giving only a couple of hours of relief before symptoms return, and others develop involuntary movements called dyskinesia. Fluctuations and dyskinesias, called motor response complications, develop with the progression of the disease and are present in 90% of PD patients after ten years of levodopa therapy.

So, if and when chemistry does not provide satisfactory results for any of the reasons mentioned above, is there a different strategy we can use? Yes, and, you may have guessed, that strategy is electricity! Just like one new fuse in your switchboard at home will make the lights come back on in your entire house (of course, first, toss that European blow dryer!), inserting electricity into a specific area of the brain can improve the functionality of the entire network by regulating the abnormal electrical signals known to be present in the network of all three disorders.

This strategy has been successfully applied in PD, ET and dystonia for 35 years and is known as DBS, which stands for deep brain stimulation. This therapy has matured over the past three decades and, owing to improved imaging, operative techniques and innovative hardware, has become a tested and proven standard of care treatment option when medications fail to provide sufficient benefit. Because in DBS, the electrical stimulation is delivered into the brain via a thin electrode in a surgical procedure, DBS may not be appropriate for everyone. Your neurologist will guide you and, if desired, have you evaluated by one of our DBS clinicians. The DBS team at Northwestern distinguishes itself by the extensive experience of team members, their dedication to a collaborative, multidisciplinary approach and their desire to do what is in the best interest of each patient. Therefore, an evaluation by the DBS team does not always end in the operating room; the true goal of such a visit is to be informative and educational and provide you with additional, personalized treatment options to keep your network buzzing!

April is **Parkinson's Awareness** Month

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

- 60,000 people are diagnosed with PD each year.
- 1 in 100 people over age 60 have PD.
- Men are 1½ times more likely than women to have PD.
- Exercise is vital in managing PD.
- The causes of PD are unknown.

Join us in our efforts by:

- Getting the latest information about Parkinson's from our center at www.nm.org/parkinsons or from our partner, the Parkinson's Foundation, at www.parkinson.org
- Sharing what you've learned with your family, friends and community
- Making an impact. Donations are gratefully accepted online at www.nm.org/foundation or by contacting Leslie Post-Weissinger at either 312.926.0450 or lpostwei@nm.org. She will ensure your gift is designated for the Parkinson's Disease and Movement Disorders Center.

Partnering with Parkinson's Foundation

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

Parkinson's Foundation
CENTER OF EXCELLENCE

Founded in 1957 and located in Miami, PF is a premier international organization that funds research and provides support services, educational outreach and advocacy for people with PD and their loved ones. Its Centers of Excellence must provide the highest quality in patient care, implement best practices, provide leadership in developing targeted research to extend knowledge of PD and create innovative models of education, services and outreach. Northwestern and PF work together to deliver high-quality patient care, form a united front against Parkinson's and make a difference.

To receive education and support and find events in your area, visit Parkinson's Foundation Greater Illinois Chapter Website at: www.parkinson.org/GreaterIllinois

Parkinson's Foundation Expert Briefings Webinars

Whether you are an individual touched by Parkinson's disease (PD) or a healthcare professional, the Parkinson's Foundation's online Expert Briefings offer a course for you. These webinars provide first-hand access to the latest PD research and updates from experts in the field. Designed with the Parkinson's community in mind, each hour-long webinar offers an opportunity to learn more about managing PD symptoms, progression, treatments and more.

To sign up and to find more information:
www.parkinson.org/resources-support/online-education/expert-briefings-webinars

Botulinum Toxin *in the* Movement Disorders Clinic

by Allan D. Wu, MD
Professor of Neurology, Division of Parkinson's Disease and Movement Disorders Center

Botulinum toxin has become an important tool in treating some movement disorders. Botox is the most well-known brand, but several other brands are available (Xeomin, Dysport, Myobloc). What is botulinum toxin used for in our Movement Disorders clinics? Is it the same as cosmetic Botox? How does it work, and what should you know about it? Read on to learn more about this treatment option.

What is it?

Botulinum toxin, produced by a bacteria called Clostridium botulinum, survives only when there is no oxygen, so it is not present during our daily routines.

The toxin blocks the connection between the nerves that control muscles and the muscle itself. This is called nerve-muscle (neuro-muscular) blockade. For those exposed to botulinum toxin at higher doses, paralysis of muscles can result.

Fortunately, at medical dilutions and doses, the toxin can be safely injected directly into muscles and cause selective, mild weakness for conditions causing uncontrolled or constant muscle movements.

What botulinum toxin brands are there?

Four different botulinum toxins are available in the US market: Botox, Dysport, Xeomin and Myobloc. Each has a different set of additional FDA-approved indications. However, since they all share the mechanism of action, each can be considered for treating the same conditions.

It is important to note that the dosing units of each toxin are not directly comparable to any other toxins. Though all toxins have the same effects (and side effects), each person may respond differently to different toxins.

What is it used for?

Botulinum toxin is used for an ever-increasing number of conditions. The most common uses in the Movement Disorders neurology clinics are to treat focal dystonia or hemifacial spasm. Sometimes Parkinson's disease (PD) is associated with dystonia and drooling, and botulinum toxin injections are recommended. Neurology clinics may also offer use for spasticity and migraine.

Dystonia, a neurologic condition, causes involuntary muscle contraction that pulls body parts into sustained postures or patterns. Dystonia is not the only cause of muscle contraction problems, and the proper diagnosis depends on an experienced neurologist. Dystonia can be a symptom, or it can occur on its own. The latter is more typical for most patients who are receiving botulinum toxin. It's important to note that not all dystonia is the same. An experienced neurologist should evaluate whether this is a stand-alone condition or due to another condition requiring treatment.

The most commonly treated dystonia is focal dystonia which occurs in a specific body part. The most common focal dystonias are blepharospasm (affecting eyelids), cervical dystonia (affecting the neck), oromandibular dystonia (affecting the jaw or tongue) or spasmodic dysphonia (affecting vocal cords). There are also hand, upper extremity, foot and

lower extremity forms of focal dystonia. Occasionally, dystonia only occurs during specific actions, such as writing or playing a musical instrument; this qualifies as focal dystonia. Meige syndrome is a combination of neck and face dystonia, also known as cranial-cervical dystonia.

For focal dystonia, an injection into the muscles causing involuntary muscle contraction can provide significant functional relief for several months. The dosage and muscles selected for injection must be re-evaluated at each repeat injection to maximize benefit and minimize side effects.

A hemifacial spasm is an involuntary contraction of muscles on one side of the face due to facial nerve irritation, which can affect vision, speech or appearance. Sometimes this occurs after an injury to the facial nerve, such as Bell's palsy; other times, it appears on its own. Botulinum toxin is often helpful, but the possible side effect of drooping of one side of the face must be considered.

Drooling, also called sialorrhea, may occur with conditions seen in the Movement Disorders clinic, such as PD. All botulinum toxins can contribute to dry eye and dry mouth, but the type B toxin (Myobloc) tends to have more dry mouth than the type A toxins. When injected into salivary glands, the toxins can maximize the side effect of dry mouth if drooling remains a problem after more conservative approaches are not beneficial.

Many other conditions are treatable with botulinum toxin. Two are frequent in neurology clinics: spasticity and migraine. Spasticity is an involuntary tightness of the muscles that often occurs after a stroke. It is typically associated with some weakness and loss of control of the limb from the underlying stroke or neurologic condition. Treatment with botulinum toxin must be weighed against the risk of further weakness in an already affected limb.

For migraine, only a subset of patients suffering from severe episodic migraine headaches will qualify for botulinum toxin therapy. The treatment aims to reduce the severity and intensity of migraine attacks rather than serve as an acute treatment for stopping them.

Other conditions include cosmetic use to reduce wrinkles, bladder frequency and gastrointestinal conditions involving muscle spasms or tightness. The toxins used for cosmetic purposes are the same as that used for neurologic conditions.

The physicians performing an injection should have experience with that condition. The Movement Disorders clinic will be most experienced in conditions related to movement disorders and PD as described above and can advise on which physician clinics are appropriate for other needs.

How is botulinum toxin used?

Botulinum toxin is diluted into a solution and injected directly into the muscle using a needle. The toxin brand used, the dose given and the muscles injected will often vary from visit to visit. Injections typically take a week to take effect. The weakness effect and clinical benefit gradually increase over time, reaching peak effect in about four to six weeks. Effects of botulinum toxin will typically last about two to four and sometimes up to six months. Usually, the benefits gradually wear off, and if the clinical condition recurs, the typical result is repeated botulinum toxin injections every three to four months. >>>

Generally, booster injections are not offered between the three to four-month procedure visits because of the possibility that the body may become immunized (resistant) to the toxin. This is one reason some patients no longer benefit from repeat injections of the same toxin. The risk of immunization increases when injections occur sooner than every three months. Because initial doses are typically low, to avoid side effects of excess weakness, it can take two to four dosing cycles every three to four months to reach a dose and injection pattern optimal for symptoms.

It is important to know that the botulinum toxin is a symptomatic treatment that relieves symptoms associated with muscle pulling. Although botulinum toxin is frequently the first-line treatment option for focal dystonia, it is only one of several management options, including medications and sensory-motor re-training with physical or occupational therapy.

What are the side effects?

The primary concern of botulinum toxin is weakness of the injected muscles. Injecting the face may cause abnormalities in appearance, particularly with speech or emotions. In the neck, there can be decreased control of head movements. For example, lifting the head while bending over or on all fours may feel heavier than usual. Weakness of the hands is often a limitation of botulinum toxin treatment of hand dystonia. Caution must be given when injecting leg or foot dystonia because of its potential effects on gait or balance. Mild weakness side effects often occur and are well-tolerated because of the greater clinical benefit in treating dystonia (or other conditions).

Although botulinum toxin tends to stay within the muscles where it is injected, the toxin can spread at a very low level to distant areas of the body with no noticeable consequences. On rare occasions, particularly at larger doses or with doses near the face and neck, the spread of the toxin can affect swallowing muscles and contribute to swallowing difficulties, choking or aspiration pneumonia. For this reason, although very rare, all botulinum toxins have an FDA black box warning requiring that all physicians who administer botulinum toxin inform patients of this potential side effect. In practice, this is extremely uncommon, and appropriate lower doses should be used to start before slowly escalating the dose over subsequent procedure visits.

Getting botulinum toxin from more than one physician (including cosmetic).

Some patients may find themselves having a botulinum toxin treatment offered for varying conditions and by different physicians and clinics. Patients should inform each physician offering botulinum toxin about all other physicians that have also recommended or are administering botulinum toxin. Because there is no difference between the botulinum toxins given for cosmetic (wrinkles) treatment and those used for neurologic conditions, ensure that all cosmetic uses of toxins are known to each physician.

Because the effects and side effects of botulinum toxin typically last three months, the following general advice is useful: it is best to stick with one brand of toxin and not mix and match different brands of toxin within the same person simultaneously. If one cosmetic physician is using Dysport, neurologists would ideally use Dysport to treat focal dystonia in the same patient. Also, it is ideal if all botulinum toxin injection is done within a week or two of each other to keep a cycle of total botulinum toxin injections in sync. It can become difficult to identify clinical benefits and troubleshoot side effects if there is an overlap in when the injections are given. It is also essential to track the number of units given to the patient in each cycle. At least one physician should be responsible for monitoring the total dose of toxin given during each cycle. Patients also have access to their medical records and are encouraged to track the doses of toxins each physician gives at each visit over time. Each toxin has a recommended maximum dose, and it is useful for

the care team to keep this in mind when patients receive added botulinum toxin doses from more than one physician.

The bottom line.

Botox tends to be the most well-known botulinum toxin. Be aware that other brands are available and know which one you receive.

Benefits tend to kick in over several days, with peak effect at four to six weeks and clinical benefit lasting two to four months. Repeat injections are typically done at a recommended minimum of 3-month intervals.

Botulinum toxin is part of a broader treatment plan with your care team and with other interventions such as medications or physical/occupational therapy. If you are unaware of a broader treatment plan, ask about it.

There is a very low risk of systemic side effects. There are risks of mild weakness of muscles injected, dry mouth or dry eye. There is an FDA warning on all botulinum toxins requiring patients to be informed of the uncommon risks of weakness, including swallowing problems.

You can request a patient-oriented guide to each toxin brand from your clinic. These are also available online by searching for the "Medication Guide" for each toxin brand.

If you get botulinum toxin from multiple physicians, including for cosmetic purposes, keep track of the date, brand and doses you receive. Share this information with each of your physicians to help ensure the appropriate assessment of botulinum toxin's effects and side effects and that the total dose of toxin received each cycle is within reasonable maximum limits.

Medicare and most insurances cover most movement disorder indications, such as dystonia, hemifacial spasm and sialorrhea. Because each toxin brand has a different set of approved indications, some insurance may recommend approval of certain toxins over others. Some focal dystonia (arm, leg) do not have a specifically named FDA indication and may require more effort but can generally be approved as movement disorder indications.

A savings program for all toxin brands helps cover out-of-pocket expenses for a procedure, deductibles, co-pay or co-insurance for commercial insurance. This typically needs to be renewed and reviewed at the start of each year. Look for these resources where you get botulinum toxin injections.

Find out more.

Brainandlife.org – Botulinum Toxin Article

Link to Botox Savings Program and other savings programs for Xeomin, Dysport, Myobloc:
https://dystonia-foundation.org/living-dystonia/treatment/botulinum-toxin-injections/

Meet the Team

Emily Kuettel, MS, RD, LDN

Emily Kuettel, MS, RD, LDN, is a registered dietitian who joined the Movement Disorders Clinic in October 2022. Emily provides food and nutrition-related care to patients with varying movement disorders, most commonly Parkinson's, Huntington's and Wilson's diseases. Specifically, she offers support for patients experiencing nutrition-related consequences of disease or side effects of medications. In addition to her involvement in the Movement Disorders Clinic, Emily works at Northwestern Memorial Hospital as a clinical dietitian, providing medical nutrition therapy for patients. Emily completed her Master of Science in nutrition and dietetic internship training at Loyola University, Chicago, and received her Bachelor of Science in nutrition at Syracuse University. She is involved in the dietetics profession; she recently served a two-year term on The Accreditation Council for Education in Nutrition and Dietetics and continues to serve the Chicago Academy of Nutrition and Dietetics.

Erica McDonald, BSN, RN

Erica McDonald, BSN, RN, recently joined Northwestern's Movement Disorders Clinic clinical nurse team in August. She is originally from Kansas City (Kansas side), where she received her Bachelor of Science in Nursing in 2019 from a small, private university. Erica moved to Chicago in 2020 for a change of pace. Her main areas of interest have always been neurology and psychiatry/mental health. Since becoming an RN, she has worked in inpatient neurology stepdown and med-surg units before switching to ambulatory care here at Northwestern. She is currently in her first year of graduate school at the University of Illinois at Chicago, working on obtaining her Doctorate of Nursing Practice (DNP) to become a psychiatric/mental health nurse practitioner. Erica is excited to be a part of such a caring and well-educated team of people and hopes to help patients and families navigate their diagnoses.

Katie Fagan, MSW, LCSW, CDP

Katie Fagan, MSW, LCSW, CDP, is a licensed clinical social worker who joined the team as the senior program coordinator for the Parkinson's Disease and Movement Disorder Clinic. Originally from Scottsdale, Arizona, Katie is a graduate of Loyola University Chicago. She graduated in 2010 with a BS in psychology and a BA in religious studies. She returned to Loyola for her MSW with a concentration in clinical social work and graduated in 2013. Katie has worked in senior living communities for the last ten years-specifically King-Bruwaert House in Burr Ridge, The Birches in Clarendon Hills, and Artis Senior Living of Lakeview. As a result, Katie has worked with seniors at varying points in their journey—from folks who are skydiving and traveling to those at the end of life. Katie has focused much of her career on bringing quality of life to seniors affected by dementia and their caregivers. To that end, she is a Certified Dementia Practitioner (CDP). Katie is thrilled to be a part of this incredible team!

PD 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: May 17 and August 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 or e-mail movementdisorders@nm.org

PD Support Groups and Programs Continue on Page 13

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: September 6

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 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

---

Improv for PD

Date: Thursdays, May 4 - June 22 **Time:** 2pm - 3:30 pm (CT)

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

Cost: $100 for the 8-week series

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

---

Dance for PD

Date: Coming this summer

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

Cost: Free

Contact: Registration coming soon. For more information, email movementdisorders@nm.org

---

Caregiver Bootcamp

Date: Coming this summer

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

Cost: Free

Contact: Registration will be coming soon. For more information, email movementdisorders@nm.org

---

General HD Support group:

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

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: Third Thursday of the month, March, June, September and December

Time: 1:30 pm - 2:30 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

---

Wilson's Disease Support Group

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

Time: 7 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

PD Support Groups and Programs Continue on Page 14

Central Region: Shirley Ryan Ability Lab

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 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 and Wednesdays

Time: 9:45 am (CT)

Location: Shirley Ryan AbilityLab Adaptive Sports and Fitness Center 541 N. Fairbanks Ct. (accessible entrance at 303 E. Ohio) Mezzanine Level, Chicago, IL 60611

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

---

Flex-ABILITY

Date: Mondays

Time: 9 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

---

Nordic Poles Agility

Date: Seasonal class offered April-October

Location: 808 N. Lake Shore Park Drive

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

Parkinson's Disease Integrated Class

Date: Tuesdays and Thursdays

Time: 3:30 pm - 4:15 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

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

ProACTIVE PD Exercise Class

Date: Thursdays

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

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

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

Contact: 312.238.5003

PD Support Groups and Programs Continue on Page 15

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
Stride and Strength Levels 1 & 2
Flexibility Fitness for Parkinson's Levels 3 & 4
Rock Steady Boxing For All Levels
Yoga for Parkinson's 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

Powerful Tools for Caregivers

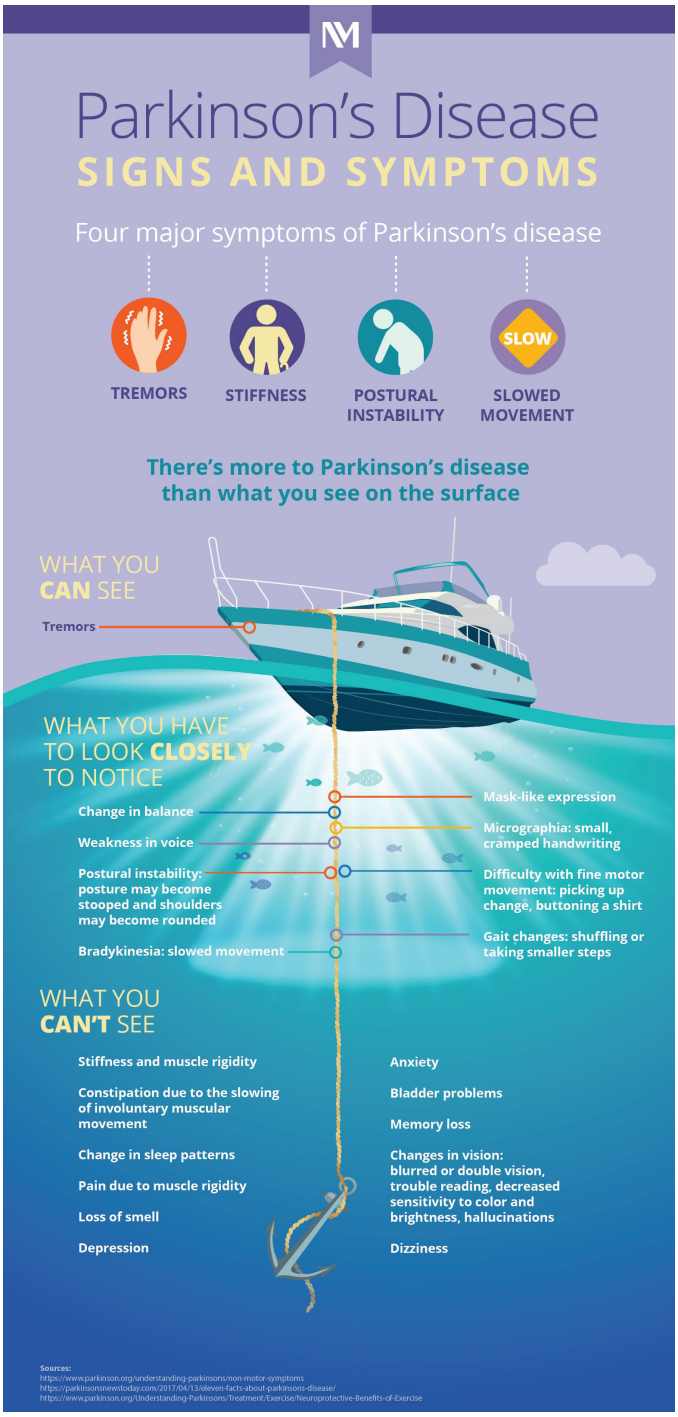
Date: Wednesdays May 3 – June 7
*We will meet on Tuesday, May 23 instead of Wednesday, May 24 due to the Douglas L. Johnson Symposium

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

Location: Central DuPage Hospital

Cost: $15 which includes a copy of The Caregiver Helpbook which follows the curriculum and provides additional tools to address specific caregiving issues.

Contact: You can register online at https://classes.nm.org/wlp2/classes/info/DWP0091F or by calling 630.933.4234.



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: Natasha Maria Cabigon, T 312.503.0510, natasha.cabigon@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 ≤ 2.5)
- On stable medication for at least 30days 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 con 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

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 con 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.

CurePSP | Center of Care

WDA Wilson Disease Association

PSG Parkinson Study Group

Parkinson's Foundation Center of Excellence

Huntington's Disease Society of America Centers of Excellence

NAF National Ataxia Foundation

Credentialed Huntington Study Group Research Site