

# On The Move >>>

Northwestern University Feinberg School of Medicine

Spring 2021 Vol. 31

## ACCESSING YOUR MEDICAL RECORDS NEW RULES BENEFIT PATIENTS IN 2021

by Allan D. Wu, MD

Patients who want to see their medical records will hopefully find it easier to do so later this year.

While patients have always had the ability to request their medical records, a new "information blocking" rule will require that medical practices promptly share medical information with patients. As a result, many medical notes and test results will often be released to patients electronically and automatically. And even if patients are not savvy with computers, the rules will likely increase the priority of and responsiveness to patient requests for medical information. Studies show that patients with access to read

their medical notes have improved understanding of their health and medical conditions, recall their care plan more accurately, are better prepared for visits, more likely to take medications as prescribed, and feel more engaged with their physicians.

### Don't patients have access to medical records now?

Since medical records are stored in physician offices and within medical centers, patients have not always had easy access to see the contents of their medical record.

Since electronic medical records (EMR) are now widespread, access to medical information for patients has been improved. Nevertheless, access still tends to require manual effort. Patients usually have to submit a formal request through the Medical Records department (now often called the Health Information Management System (HIMS) office). It is not always straightforward to do this. There may be fee charged and oftentimes, there is a delay in obtaining the records.

### Opportunities to improve:

While many offices and medical centers routinely provide records to patients, there has been little



guidance on how quickly a patient request is acted upon, in what format the information is provided, what information can be requested, and the degree of administrative effort that patients may have to undergo. As such, the experience and ease of obtaining medical records can vary significantly from place to place.

### **So then what happened?**

In 2016, Congress passed the 21st Century Cures Act with bipartisan support to accelerate bringing medical innovation to patient care. One part stated that “information blockers” would be subject to penalties. Information blocking was defined as any practice that is likely “to interfere with access, exchange, or use of electronic health records.”

In May 2020, an official “information blocking” rule was finalized. The rule focused on providing patients direct access and control over their electronic health information. In general, most medical information such as notes and laboratory results (i.e., bloodwork) would be immediately and automatically released without charge in electronic format for patients. Delaying or holding back information from immediate release to patients would only be allowed only under a narrow list of defined exceptions – or the office/health system could be considered being an “information blocker.” Penalties were described for groups that engaged in information blocking. The rule was originally going to start in November 2020; this date has since been postponed to April 2021.

### **What does the information blocking rule say?**

The information blocking rule specifies that no barriers should

be in place to limit sharing medical information in an electronic format upon request. Practically, this means that patients who sign up for an electronic portal to access medical communications will also be able to obtain immediate and automatic access to medical information. Starting in April 2021, a defined set of clinical note types, lab results and other common parts of the medical record (medications, allergies, vital signs, problem lists and more) must be immediately released or available to patients electronically. By 2023, most of the medical record is anticipated to be available for such release.

### **Are there exceptions to immediate sharing of information?**

There are exceptions where medical notes or labs can be delayed or withheld from automatic release. Psychotherapy notes are not subject to release. Releases of information are also subject to local state laws which alter these requirements. For example, Illinois state law specifies that positive HIV results must be delivered “by personal contact whenever possible.” In this case, automatic and immediate electronic release of HIV positive results is unlikely to occur in Illinois and delays in release would not be “information blocking.”

Additional limited exceptions are described in the information blocking rule. For example, the “Preventing Harm” exception allows a clinician to NOT share a note/lab result with a patient if they assess that individual facts and circumstances indicate an anticipated risk to a person’s life or physical harm.

### **What do physicians think?**

Most physicians are supportive of greater transparency in sharing information with patients. Some physicians share concerns that providing easier access to notes and lab results will cause confusion, misunderstandings and embarrassment (for example, an abbreviation used by physicians SOB actually means “shortness of breath”). Other concerns are that patients will contact the office more often with questions or requests for correction of trivial errors. While there are always situations that can illustrate each of these points, repeated studies across many medical centers suggest that sharing notes automatically and openly with patients does not support these concerns. In fact, recognizing that any patient has always been able to request their entire medical record at any time via the Medical Records department mitigates many of these concerns. Further, increases in between-visit contact with the office because of released notes seem likely counterbalanced by reduced contact from patients who no longer need to call to ask for clarifications about their medications or care plan because they can read review relevant notes themselves.

### **Bottom line for patients:**

Overall, the new rule is a win for patients who would like to be more engaged with their healthcare. Here are a few take-home points to keep in mind:

- 1.** Patients have always had access to their medical information; this rule is making much of it immediate, automatic and electronically available.

- 2.** If you have not yet signed up for your healthcare providers' electronic portal (when available), this is a good year to learn how to do so.
- 3.** If you are not comfortable or do not have access or ability to access an electronic portal, be aware that requests for medical information should be more prioritized than usual.
- 4.** If a situation exists where automatically shared medical information is at risk because others may have access to your electronic portal (parent, guardian, spouse), please contact your health care provider and ask about appropriate limitations in access.
- 5.** Be aware that you may be seeing test results or consultation notes before your healthcare team has had time to review or act. Be a partner with your care team and understand that some notes/results may require a scheduled clinical appointment to discuss to interpret and explain certain results/notes.
- 6.** Consider reviewing notes from your previous clinic visit before the next visit so you are up to speed with your doctor and you have more prepared clinic visit.

## Useful links:

To sign up for the  
Northwestern Patient Portal:

[www.mynm.org](http://www.mynm.org)

Northwestern Medicine  
Medical Records website:

[www.nm.org/patients-and-visitors/  
mynm-mychart-and-medical-records](http://www.nm.org/patients-and-visitors/mynm-mychart-and-medical-records)





# MY JOURNEY WITH *Wilson's Disease*

by Ginta Ginaityte, RN

**I first became aware of Wilson's Disease when I was in nursing school. I vividly recall my professor telling our class that this condition is extremely rare, and that we will probably never encounter a patient who has it.**

During the nursing program, at the age of 22, I started to realize that something was very wrong with my body. My entire life, I had suffered from migraines and was very uncoordinated—my friends would laugh about me being a klutz as I would trip and fall constantly.

While in nursing school, I started to experience new and worsening symptoms and struggled to keep pace with life as my symptoms rapidly progressed. I experienced migraines several times a week, vomiting, weight loss, imbalance, frequent falls, difficulty swallowing, slurred speech, dystonia (involuntary muscle contractions), severe pain in my feet, muscle rigidity, chronic fatigue and a variety of other neurological symptoms. I started to notice when taking notes that my previously neat handwriting had become illegible. No matter how hard I tried to write neatly, it seemed impossible. I remember the 8-hour clinicals when I could hardly stand on my feet due to the nerve pain I was experiencing. I had been blaming my symptoms on stress and never saw a doctor—but deep down I knew it was not stress-related. I was petrified to know the truth.

Miraculously, I graduated nursing school at the age of 24, but the months after graduation were brutal for me. I couldn't get out of bed most days and I was rapidly getting worse as the days went on. I decided to visit an optometrist to have my vision checked, thinking that's what could be causing my migraines. That is when I met Dr. Khan. Almost immediately upon examination, Dr. Khan asked me if I had Wilson's Disease because he saw Kayser-Fleischer rings in both of my eyes. The very next day I visited my primary care doctor and,

after multiple tests and a brain MRI, received my diagnosis a week later.

My world was flipped upside-down. The medical facility I went to told me they had never seen anyone with this condition and did not have any experience treating it. I thought my nursing career was over, and I was on a mission to find someone that knew how to treat this condition. I felt so alone. I did research for days trying to find the right doctors. I finally came across a handful of clinics in the United States that knew how to treat Wilson's Disease, and Northwestern Medicine happened to be one of them! I was ecstatic to find a clinic that could help, and I scheduled an appointment right away. I met with neurologist Dr. Danny Bega and hepatologist Dr. Richard Green at Northwestern Medicine. They gave me hope that I would get better.

I began treatment right away and started improving quickly. I was still relying on my family for everything at that point. My mom was my 24/7 caretaker. I felt like a burden to my family and hated relying on others to help take care of me. At the same time, I was not going to let this disease define my life, and I did everything I possibly could to try to heal. I was in physical therapy three times a week to help with balance, walking and the rigidity I had all over my body. After several months of treatment and medication adjustments, I was finally able to start working part-time as a phone triage nurse! It was satisfying not to have to rely on my family financially. However, it was not easy working because there were still symptoms that I dealt with on a daily basis. I felt endlessly exhausted, but I pushed myself every day and reminded



myself that I can do anything I put my mind to. Eventually I switched to a full-time position and moved out of my family's home. For going on 3 years now, I have lived with my boyfriend and our two shih-tzu's.

Something that always bothered me was the lack of awareness about this rare condition. I wanted to do something about this and do more to help others. So, along the way of my journey with this condition, I held a walk called the BIG WOW to raise money for Wilson's Disease research. I am an advocate for Wilson's Disease patients through Bausch Health, and have created several videos and educational guides, in addition to advising others living with Wilson's.

My ultimate goal was to be a nurse at Northwestern Medicine, the hospital that saved my life. I went back to school for my Bachelor of Science in Nursing at UIC while continuing to work full time. I am currently two classes away from graduating, and I accomplished my ultimate goal when I started working at Northwestern Medicine Internal Medicine four months ago!

Being diagnosed with Wilson's Disease changed my life completely. I appreciate each and every day that I am given, and I appreciate the little things in life more than ever before. My medical journey with Wilson's Disease taught me to be a better nurse and made me more empathetic, compassionate and committed to advocating for others.

# Sleep Problems in Movement Disorders

## AND GETTING A BETTER NIGHT'S SLEEP

by Roneil Malkani, MD

**S**leep problems are common in people with movement disorders, including Parkinson's disease (PD), dementia with Lewy bodies, multiple system atrophy and Huntington's disease. Various sleep problems can be seen, including difficulty falling asleep, difficulty staying asleep, daytime sleepiness, sleep apnea, restless legs syndrome and acting out dreams during sleep. One can also have multiple sleep problems. Addressing sleep disorders is critical because sleep problems can significantly impact function, including motor and cognitive functions, and quality of life for individuals and for caregivers.

Sleep problems have been studied extensively in PD and can occur due to a variety of reasons. For example, it can be from the motor symptoms of PD, including slowness at night making it difficult to turn in the bed, or non-motor

symptoms such as nighttime urination or depression. Disruption in brain regions that control sleep and wake states and changes in the circadian rhythm—the internal clock—can also be implicated. Even medications used in PD contribute, causing either insomnia or daytime sleepiness. Sometimes, other sleep disorders such as sleep apnea or restless legs syndrome cause sleep disruption and night and daytime sleepiness.

Many different sleep problems are seen in these disorders. One of the most common issues is sleep fragmentation. Sleep can be disrupted due to insomnia (as a primary issue), nocturnal motor symptoms, medications, depressed or anxious mood, sleep apnea, and restless legs syndrome. Nocturia, or nighttime urination, is particularly common in PD and multiple system atrophy. Daytime sleepiness is a frequent complaint and can manifest with frequent dozing or needing multiple or long naps. Fatigue is a lack of physical or mental energy. Fatigue and daytime sleepiness often occur together, and it can be difficult to distinguish them. Insomnia and daytime sleepiness worsen motor and cognitive function in PD.

Sleep apnea is a condition when one snores and has difficulty breathing while asleep, typically due to obstruction in the airway. The disruptions in breathing and resulting arousals can cause poor quality sleep, daytime sleepiness, fatigue, increase in nighttime urinations, worsening in mood and difficulty concentrating. Sleep apnea can be identified on a sleep study, which can be done at home or in the sleep laboratory. There are many treatments for sleep apnea, such as CPAP and dental devices. CPAP is a device that blows air pressure through a mask that one wears at night; the air pressure keeps the airway open, thereby reducing the airway obstruction and improving breathing. There are many mask options, some of which are small and



do not even cover the mouth. Dental devices for sleep apnea are worn in the mouth and pull the jaw forward to improve the space in the airway and improve breathing.

Restless legs syndrome, also known as Willis Ekblom Disease, involves uncomfortable sensations in the legs with an urge to move. This sensation improves with movement and worsens at rest (e.g., in the bed or sitting for a long time) and occurs primarily at night. This can be associated with PD but is often independent of PD and can be caused by iron deficiency. This can be diagnosed based on a combination of the above symptoms, and there are many medical treatment options, some of which overlap with PD treatments.

Another sleep disorder commonly seen in people with PD, dementia with Lewy bodies, and multiple system atrophy is REM sleep behavior disorder. In REM sleep, during which one typically dreams, the body is typically paralyzed; this is a safety mechanism to prevent acting out the dreams during sleep. This paralysis can be lost in PD, leading to acting out of dreams. The behaviors can include talking, screaming, punching or even jumping out of bed, resulting in injuries to oneself or a bed partner. Nearly half of patients with PD have this, and it is even more common in people with dementia with Lewy bodies and multiple system atrophy. There are medications that are useful to reduce these behaviors and improve sleep quality.

There are many strategies that can improve sleep, particularly difficulty falling and staying asleep. It is important to have a good environment for sleep, including a cool, dark and quiet room. White noise can be used to mask sounds that would otherwise disrupt your sleep. Keeping a regular sleep and wake schedule improves stability of the

daily rhythm and can help the body prepare for sleep at a regular time each day. While having a short nap up to 30 minutes per day will not usually disrupt sleep, longer or frequent naps, or naps in the late afternoon can interfere with sleep at night and should be avoided. Regular exercise improves

sleep quality improves motor and cognitive functions. Caffeine in the late afternoon may make it more difficult to fall asleep. Alcohol close to bedtime—though it may induce sleepiness—can cause more nighttime awakenings and worsen sleep apnea. Light-emitting screens, such as smartphones, tablets and computers, can also disrupt sleep. Light is activating to the brain and interferes with the circadian rhythm. While using them is tempting if one is unable to fall asleep, the light from the screens is blue-enriched (blue light is particularly disruptive) and devices are generally held close to the face. It is less disruptive to turn on a lamp and read a book, do some puzzles, or listen to music, audiobooks or a podcast.

When the above strategies do not work, or when the main sleep issues are daytime sleepiness, sleep apnea, restless legs syndrome or REM sleep behavior disorder, you should discuss the issues with your doctor or even a sleep specialist. Evaluation may entail a sleep study (either at home or in the sleep lab), blood tests or sleep diaries. Treatments may include behavioral strategies, medications or sleep apnea treatments.

While medications can be helpful for a variety of sleep disorders in people with Parkinson's disease, there is a great need to find new treatments—particularly ones that do not involve medications. One emerging treatment is light therapy using a light box. One recent small study found benefits in daytime sleepiness in people with PD. A large clinical trial sponsored by the National Institutes of Health is underway to determine the best type and dose of light therapy. Northwestern University is one of the clinical sites, and we are actively recruiting patients for the study. The contact information for the study is at the end of the newsletter.

In summary, sleep disorders are common in people with Parkinson's disease, and there are treatments that can improve sleep, daytime function and quality of life. At Northwestern Medicine, we have a specialized clinical program for sleep disorders in neurodegenerative disease, including PD, other movement disorders and dementias. If you would like to be seen, please discuss with your doctor for a referral.



# Meet the Team

## Northwestern's Neuro Palliative Clinic

by **Carolyn Taylor, RN, MSN, AGPCNP-BC, Josh Hauser, MD, Edward Penate, DMin, BCC, and Charlinda Brashear, MSW, LCSW, ACM-SWS**



**Carolyn Taylor**



**Dr. Josh Hauser**



**Edward Penate**



**Charlinda Brashear**

Neurological movement disorders, such as Parkinson's Disease and related disorders, are associated with a variety of both motor and nonmotor symptoms.

Early on, these symptoms are usually well managed with medications, exercise and lifestyle adjustments. But as movement disorders progress, symptoms may become more bothersome to patients and less responsive to traditional medications, such as levodopa. Disease progression can also be associated with pain, increased cognitive challenges, caregiver burden and fears about the future.

In order to support patients facing these challenges, Northwestern Medicine formed a multi-disciplinary Neuro Palliative Care Clinic in 2017. Palliative care is care that focuses on quality of life, relief of suffering and symptom control for patients with advanced illness of any type. In the past, this type of care focused on hospice care which

is comfort-focused care often near the end of life and historically centered on patients with cancer. But over the last two decades, palliative care has broadened its focus to be delivered alongside more traditional disease-modifying care and to include many more medical illnesses in addition to cancer. Palliative care has been shown to improve quality of life for patients and their families with heart disease, lung disease and neurological illnesses.

In treating neurological movement disorders, the role of palliative care is to provide interdisciplinary care to support quality of life and decision-making for patients with advanced illness and their families. As an interdisciplinary team that includes a physician, nurse practitioner, social worker and chaplain,

our goal is to address what Dame Cicely Saunders, one of the founders of palliative care, called "total pain": the physical, psychological, social and spiritual sources of suffering that a patient and family might be going through.

Our Palliative care physician, Dr. Josh Hauser, writes: "my focus [in the palliative clinic] may be a little more on medical approaches to pain and other symptoms and decision-making around current and future medical interventions, but I also hope to be able to explore with my interdisciplinary colleagues the ways that Parkinson's is affecting a patient in the psychological, social and spiritual realms as well."

Social workers are another important component of the Palliative Care team. Our social worker, Charlinda Brashear, LCSW acts as an additional support for patients and their families, and brings depth of knowledge about available resources, especially in the home setting. Often, patients




and their families are not aware of all the community resources available to them. These resources, such as private duty caregivers—or if the patient meets certain financial criteria, homemakers—can be critical to allowing patients to remain as independent as possible, while still receiving needed support. Speaking with a social worker during the difficult process of end-of-life planning is a great way to help guide patients and families in both navigating challenges and identifying opportunities for enhanced patient-centered care. For example, social workers can help guide discussions and answer questions for considerations like advanced directives. Social workers can also provide emotional support to patients and families during this challenging and sometimes confusing time.

A palliative care chaplain is a clinically trained member that can help navigate the healthcare experience and is trained to support belief systems across faiths and cultures, including supporting patients and families emotionally. Our chaplain, Edward Penate, feels that “Palliative Care stands at the forefront within health care, providing a unique response that involves better symptom control, creates more discernment of and honors choices about quality of life, decreases anxiety and depression, supports less caregiver distress, including acknowledging and responding to the spiritual dimension of health.”

The final member of our Neuro Palliative Care team is our nurse practitioner, Carolyn Taylor. As a movement disorders nurse practitioner, Carolyn plays an active role in identifying patients and families who may benefit from a palliative care consultation. She works alongside the palliative physician, social worker and chaplain, to develop a care plan for patients which takes into consideration their unique movement disorder, including medication safety concerns. Says Carolyn, “I was drawn to a career in nursing because of the profession’s focus on holistic care. Similarly, working in the Neuro Palliative Clinic has allowed me to focus on care of the ‘whole person’ – including neurological, psychological, social and spiritual manifestations of chronic neurologic illnesses.”


**If you have questions about palliative care, you can call 312-695-7950, or talk to your neurologist about a referral to the Neuro Palliative Clinic at Northwestern.**




# Parkinson's Disease

## SIGNS AND SYMPTOMS


Four major symptoms of Parkinson's disease




TREMORS



STIFFNESS




POSTURAL INSTABILITY



SLOWED MOVEMENT

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

**WHAT YOU CAN SEE**



Tremors

**WHAT YOU HAVE TO LOOK CLOSELY TO NOTICE**

Change in balance

Weakness in voice

Postural instability: posture may become stooped and shoulders may become rounded

Bradykinesia: slowed movement

Mask-like expression

Micrographia: small, cramped handwriting

Difficulty with fine motor movement: picking up change, buttoning a shirt

Gait changes: shuffling or taking smaller steps

**WHAT YOU CAN'T SEE**

Stiffness and muscle rigidity

Constipation due to the slowing of involuntary muscular movement

Change in sleep patterns

Pain due to muscle rigidity

Loss of smell

Depression

Anxiety

Bladder problems

Memory loss

Changes in vision: blurred or double vision, trouble reading, decreased sensitivity to color and brightness, hallucinations


Dizziness

**Sources:**

<https://www.parkinson.org/understanding-parkinsons/non-motor-symptoms>

<https://parkinsonsnewstoday.com/2017/04/13/eleven-facts-about-parkinsons-disease/>

<https://www.parkinson.org/Understanding-Parkinsons/Treatment/Exercise/Neuroprotective-Benefits-of-Exercise>



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# SHIRLEY RYAN ABILITYLAB:

## A SPOTLIGHT ON SEVERAL UNIQUE SPECIALTY SERVICES

by Members of the Shirley Ryan AbilityLab Specialty Services Teams

Edited by Jennifer G. Goldman, MD, MS and Shari Marchbanks, PT, DPT, NCS

Along with recommending various rehabilitation therapies like physical therapy, occupational therapy and speech language pathology, our physiatrists may recommend some of the specialty services here at Shirley Ryan AbilityLab. Three specialty services are highlighted below and are commonly used for our patients with a variety of movement disorders.

### Technology Center:

The Shirley Ryan AbilityLab Technology Center, also known as the Tech Center, is comprised of Occupational and Speech Therapists who specialize in all things technology. For people with movement disorders, the Tech Center can help with items such as navigating and accessing your phone, computer and environment. We help identify the best solutions for you based on your strengths, difficulties, activities and preferences. For example, for people with tremors, there are a number of options. We can help identify voice activated solutions; these can include use of your phone, dictation with your voice on your computer, or even using your voice to change the channel on the TV. Another popular solution is a software that makes your computer mouse use smooth and steady. Some other solutions include quick, easy and free adjustments that you can make on your computer and phone, including changing the size of icons, auto-expansion of text and filtering out keystrokes, or presses of the screen that were accidental.

The Technology Center has Speech-Language Pathologists who will help guide you with options to increase your intelligibility to communicate verbally or through the use of

Alternative Augmentative Communication. We can help you by using the technology you already own, trial equipment prior to purchasing and facilitate the funding process through insurance. Our goal is to focus on your strengths and empower you to communicate however is easiest and most effective. In an evaluation, we can discuss what types of challenges you may have with communication and see what technology or even paper-based options we can offer to increase your independence.

**For a Tech Center speech or occupational therapy evaluation, fax your doctor's order for Speech evaluation or Occupational therapy evaluation to 312-238-1516; our administrative coordinator will contact you to schedule an appointment. You can also call us at 312-238-2988.**

### Vocational Rehabilitation:

For over 50 years, the Vocational Rehabilitation Program at the Shirley Ryan AbilityLab has been helping people with disabilities find and retain gainful employment. The



Vocational Rehabilitation program is one of only a few of its kind in the United States, and the only hospital-based program in the Chicagoland area.

People with a neurological condition may have questions about what their work and workplace might look like after being diagnosed, or if there are changes in symptoms over time. They may wonder about their ability to perform essential job functions or have questions about how to talk to their employer about their condition. The purpose of the Vocational Rehabilitation Program is to help individuals apply specific job retention strategies in the workplace and navigate any changes or accommodations for their work. Program services may include comprehensive vocational evaluations, individuals job retention or return to work plans, assistance with long-and short-term disability paperwork, and recommendations for navigating disclosure and accommodations conversations with employers.

**For more information on the Vocational Rehabilitation Program at the Shirley Ryan AbilityLab, you can contact the vocational rehabilitation manager at 312-238-6819**

## Wheelchair Seating & Positioning Center:

The Shirley Ryan AbilityLab Wheelchair Seating and Positioning Center evaluates the complex wheelchair needs of individuals with many different types of diagnoses, including a variety of movement disorders.

When making recommendations, the Wheelchair Seating and Positioning Center team factors in the patient's specific impairments, environment, goals and insurance requirements. The Wheelchair Seating and Positioning Center

works to provide clients with manual or power wheelchairs that they need in order to perform their mobility related activities of daily living. The Wheelchair Seating and Positioning Center therapists collaborate with a team of individuals, which include suppliers, primary physical or occupational therapists, the medical team, and most importantly, the clients and their families. The therapists then provide medical justification for the recommended wheelchair and associated seating/positioning equipment. Once the medical justification is reviewed by the physician, the documentation for the device is sent to insurance for approval of the device. Upon insurance approval, the supplier builds and provides the wheelchair. At this point, the client returns to the Wheelchair Seating and Positioning Center for a fitting appointment to ensure that the chair is appropriately sized and is configured for the client in a way that optimizes their abilities.

The Wheelchair Seating and Positioning Center sees many individuals with a diagnosis of Parkinson's and other movement disorders each year. We know that the presentation of each individual is unique, and therefore our recommendations are also specific in nature to that person. No matter what level of function the patient may have, we do our best to meet the needs of the client. At the Shirley Ryan AbilityLab Wheelchair Seating and Positioning Center, we aim to use our considerable resources and ideas to promote ability for all individuals that come into our clinic.

All three of these services work closely with our physician and therapy teams, and are in collaboration with the Parkinson's and Movement Disorders team members.

**If you have any questions or would like further information about any of our programs, please call Shari at 312-238-PDMD (7363).**



# Parkinson's Foundation Expert Briefing 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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## Mental Well-being and Memory

### Event Date:

**Tuesday, April 20, 2021**

**Time: 10am PT / 11am MT /  
12pm CT / 1pm ET**

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To sign up and to find more information:

[parkinson.org/Living-with-Parkinsons/Resources-and-Support/PD-ExpertBriefings-Webinars](https://parkinson.org/Living-with-Parkinsons/Resources-and-Support/PD-ExpertBriefings-Webinars)

# Meet the Team

## Allan D. Wu, MD

Allan D. Wu, MD was recruited to Northwestern Medicine in the Movement Disorders program in October 2020. Dr. Wu completed Movement Disorders fellowship training at the University of Southern California in 2001 and was faculty at UCLA from 2005 to 2020.



For the last decade, Dr. Wu has worked as a physician informaticist on electronic health record (EHR) projects

to improve patient engagement, reduce physician burnout, enhance efficiency and raise awareness of informatics as a specialty. Dr. Wu is active in the California Parkinson's Disease Registry and the American Academy of Neurology.

At Northwestern, Dr. Wu is the Director of Applied Clinical Informatics at the Stanley Manne Children's Research Institute and will work to develop a vision of learning healthcare systems for patients with neurologic disorders where the patient care generates real-time information that can guide shared decision making, as well as drive improvements in the delivery of care.





# April is **Parkinson's Awareness** Month

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

- 60,000 people are diagnosed with PD each year.
- 1 in 100 people over age 60 have PD.
- Men are 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](http://www.nm.org/parkinsons) or from our partner, the Parkinson's Foundation, at [www.parkinson.org](http://www.parkinson.org).
- Sharing what you've learned with your family, friends and community.
- Making an impact. Donations are gratefully accepted online at [foundation.nm.org](http://foundation.nm.org) or over the phone at (312) 926-2033. Our representative 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.

Founded in 1957 and located in Miami, PF is a premier international organization that funds



**CENTER OF EXCELLENCE**

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](http://www.parkinson.org/GreaterIllinois)**

## **Do you have questions about working with PD?**



The Shirley Ryan AbilityLab offers a free Virtual Vocational Rehabilitation Counseling service supported by a Parkinson's Foundation Community Grant. A vocational rehabilitation counselor can help you work through the decision about disclosing your diagnosis, requesting accommodations or interviewing for new jobs.

Anyone in the United States with Parkinson's disease in need of employment support is eligible. Free counseling is delivered over confidential web-based videoconference platform or telephone in English or Spanish. If you are interested in more information, please click here or contact Sydney Achler at [sachler@srnlab.org](mailto:sachler@srnlab.org) or (312) 238-6825.

# 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 email 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 Tuesday of the month

**Time:** 2:30 pm - 3:30 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 email 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 email Erin Cecchi, LCSW at [erin.cecchi@nm.org](mailto:erin.cecchi@nm.org)

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### Parkinson's Disease and Women Online Support Group

**Date:** Second Tuesday of the month

**Time:** 11:30 am - 12:30 pm (CT) >>>>>

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### Parkinson's Disease and Women Online Support Group (continued)

**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 email Erin Cecchi, LCSW at [erin.cecchi@nm.org](mailto:erin.cecchi@nm.org)

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### Chair Yoga for Parkinson's

**Date:** 2nd, 3rd, 4th and 5th 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 email Erin Cecchi, LCSW at [erin.cecchi@nm.org](mailto:erin.cecchi@nm.org)

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### Parkinson's Disease 101

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

**Date:** Wednesday, May 19

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

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

**Cost:** Free

**Contact:** For more information and to register, visit [nm.org/parkinsons-support](http://nm.org/parkinsons-support) or email Erin Cecchi, LCSW at [erin.cecchi@nm.org](mailto:erin.cecchi@nm.org)

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### Art Therapy for PD

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

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## Improv for PD

**Date:** Offered at various times throughout the year

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

**Cost:** \$80 for 8-week series (\$10/class)

**Contact:** For more information and to register, visit [nm.org/parkinsons-support](http://nm.org/parkinsons-support) or email Erin Cecchi, LCSW at [erin.cecchi@nm.org](mailto:erin.cecchi@nm.org)

## Wilson's Disease Virtual Support Group

**Date:** 1st Tuesday of April, July and 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 and to register, email [emily.zivin@northwestern.edu](mailto:emily.zivin@northwestern.edu)

## Central Region: Shirley Ryan Ability Lab

### Virtual Peer Support Group for People with Parkinson's disease who are Working

**Date:** 2nd and 4th Friday of the month

**Time:** 3 pm - 4 pm (CT)

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

**Cost:** Free

**Contact:** For more information, please contact Sydney Achler at [sachler@srilab.org](mailto:sachler@srilab.org) or (312) 238-6825

## 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

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## NM Lake Forest Health & Fitness Center (continued)

**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. You may also visit [lakeforesthfc.com/services/medical-fitness/parkinsons](http://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

## Huntington's Disease Society of America (HDSA) Support Groups

### Northwestern Medicine HD Support Group:

We will be alternating between general support groups and topic-driven discussions.

**Date:** Second Saturday of every month

**Time:** 10 am - 11:30 am (CT) unless otherwise noted

**Contact:** For a meeting invite, email [emily.zivin@northwestern.edu](mailto:emily.zivin@northwestern.edu)



## Northwestern Medicine HD Support Group (continued):

**April:** Gene negative or non-HD in an HD family

**May:** General support group

**June:** Gene positive

**July:** Managing Difficult Behaviors  
Speaker: Dr. Eric Gausche, psychiatrist  
1 pm - 3 pm (CT)

Register in advance for this meeting:  
<https://northwestern.zoom.us/join/join?secret=1234567890>

**August:** Planning for the future

**September:** General support group

**October:** Caregiving

**November:** HD Research and Panel Discussion  
Speakers: Dr. Danny Bega, Leora Fox and research participants  
9:30 am - 11 am (CT)

Register in advance for this meeting:  
<https://northwestern.zoom.us/join/join?secret=1234567890>

**December:** Thinking about testing

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## HD Caregiver Support Group

**Dates:** 4/7, 6/2, 8/4, 10/6 and 12/1

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

**Contact:** Emily Zivin, 630-443-9876 or [ezivin@hdsa.org](mailto:ezivin@hdsa.org)

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## The Geneva/Rockford/Bloomington groups

**Date:** Fourth Sunday of every month

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

For more information, please reach out to one of the following support group leaders:

**Bloomington:** Larry Haigh, [larryhaigh@gmail.com](mailto:larryhaigh@gmail.com)

**Geneva:** Joe Wiedemann, [joseph.wiedemann@gmail.com](mailto:joseph.wiedemann@gmail.com)

**Rockford:** Charlotte Rybarczyk, [charlotte82963@gmail.com](mailto:charlotte82963@gmail.com)

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## Lake County Group

**Date:** Second Monday of every month

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

**Contact:** Barry or Marilyn Kahn, 847-975-2403 or [marilynkahn1@gmail.com](mailto:marilynkahn1@gmail.com)

# CurePSP Virtual Spring Family Conference

**WHEN:** May 21, 2021 at 11:00 am through May 22, 2021 at 2:00 pm

**WHERE:** Virtual Event

CurePSP organizes family conferences across the country, providing people with the opportunity to learn more about PSP, CBD, and MSA and to develop a sense of community. We recognize that these diseases present daily challenges for patients and families. The conferences include various speakers with in-the-field expertise, movement disorder specialists, and allied health care providers who work directly with patients and their families. These experts address issues related to day-to-day life including the best ways to manage symptoms, the impact of the diseases on the family, and how to cultivate a perspective of meaning and joy despite the struggles of the disease. In addition to the educational facts learned during the session, patients, caregivers and families learn that they are not alone.

The CurePSP Virtual Spring Family Conference is a two-day conference dedicated to learning management techniques for patients, caregivers and families living with the neurodegenerative diseases PSP, CBD and MSA. CurePSP encourages and organizes activities that foster communication, exchange of ideas and information, and interaction for people on this journey.

## Topics:

- Brain donations and research
- Neuro-ophthalmology
- Occupational therapy
- Emotional support and self-care
- Daily practical tips
- A tour of CurePSP available resources and support groups
- And much more!

**For more information:** [www.psp.org/event/springfamilyconference/?instance\\_id=260](http://www.psp.org/event/springfamilyconference/?instance_id=260)

# 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: [www.parkinsons.northwestern.edu/clinical\\_trials.html](http://www.parkinsons.northwestern.edu/clinical_trials.html)**

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**Research Study Title: Northwestern Movement Disorders Center Biorepository**

**Clinical Trial Investigator:** Tanya Simuni, MD

**Clinical Trial Description:** The Movement Disorders Center (MDC) Biorepository is a registry aimed to collect biologic and clinical information, such as blood and tissue samples, and family and medical histories from patients diagnosed with a movement disorder. The purpose of studying materials from the registry is to identify factors that either cause these neurologic conditions or increase one's risk for developing them. Samples collected for this biorepository include a blood sample (or a saliva sample) and a skin biopsy. Participants may choose to donate one or both samples.

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

**Clinical Trial Investigator:** Tanya Simuni, MD

**Clinical Trial Description:** This will be the largest PD observational study conducted by MJFF. The overall goal of PPMI 2.0 is to identify markers of disease progression for use in the clinical trials of therapies to reduce progression of PD disability. This study will require annual visits with brain imaging, lumbar puncture and blood samples.

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

**Clinical Trial Investigator:** Tanya Simuni, MD

**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. There will be an initial screening visit followed by a genetic counseling session to discuss the results, plus online surveys.

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**Research Study Title: The Fox Bionet ECV 004 Study**

**Clinical Trial Investigator:** Tanya Simuni, MD

**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.

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

**Clinical Trial Investigator:** Cynthia Poon, PhD

**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.

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**Research Study Title: Multicenter, Randomized, Double-blind, Placebo-controlled Study to Evaluate the Efficacy, Safety and Tolerability of 36 Weeks of Treatment with NLY01 (GLP-1R agonists) in Early Stage PD**

**Clinical Trial Investigator:** Tanya Simuni, MD

**Clinical Trial Description:** The primary objective of this study is to determine the efficacy of 36 weeks of treatment with 2 dosages of NLY01 (weekly subcutaneous injections) relative to placebo, based on the change from baseline, as defined by subjective clinical examinations.

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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 Investigator:** Rizwan Akhtar, MD

**Clinical Trial Description:** The primary objective of the study is to demonstrate the superiority of UCB0599 over placebo with regard 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.

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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 Investigator:** Tanya Simuni, MD

**Clinical Trial Description:** The primary efficacy objective for this study is to evaluate the efficacy of prasinezumab compared with placebo on the basis of time to meaningful progression on motor signs of the disease, as assessed by change from baseline.

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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 Investigator:** Tanya Simuni, MD

**Clinical Trial Description:** The primary objective of the study is to evaluate the safety and tolerability of single and multiple doses of BIIB094 administered via intrathecal injection to participants with PD.

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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 Investigator:** Tanya Simuni, MD

**Clinical Trial Description:** The primary objective of this study is to evaluate the safety, tolerability and immunogenicity of two-dose levels of PR001A administered via suboccipital injection into the cisterna magna.

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**Research Study Title:** A Randomized, Placebo Surgery Controlled, Double-blinded, Multi-center, Phase 2 Clinical Trial, Evaluating the Efficacy and Safety of VY-AADC02 in Advanced Parkinson's Disease with Motor Fluctuations (RESTORE-ADAPT)

**Clinical Trial Investigator:** Avram Frait, MD

**Clinical Trial Description:** The purpose of this study is to assess the delivery and resulting enzyme activity of VY-AADC02 administered to the brain (bilateral putamen) using enhanced delivery with MRI guidance and the efficacy and safety of VY-AADC02 gene therapy.

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**Research Study Title:** Resistant Maltodextrin for Gut Microbiome in Parkinson's Disease: Safety and Tolerability Study

**Clinical Trial Investigator:** Roneil G Malkani, MD

**Clinical Trial Description:** This study will evaluate the safety and tolerability of a dietary fiber-resistant maltodextrin in people with Parkinson's disease. It will also evaluate the fiber's effect on the gut microbiome and potential effects on motor function and non-motor functions. Half of the participants will receive resistant maltodextrin and the other half will receive a control substance, maltodextrin.

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

**Clinical Trial Investigator:** Roneil G Malkani, MD

**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.

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**Research Study Title:** A Randomized, Double-blind, Placebo-Controlled, 2-Period Crossover, Phase 2 Study to Evaluate the Efficacy, Safety, Tolerability, Pharmacokinetics, and Pharmacodynamics of Oral TAK-071 in PD Patients with Cognitive Impairment and an Elevated Risk of Falls

**Clinical Trial Investigator:** Kathrin LaFaver, MD

**Clinical Trial Description:** The primary objectives are to evaluate the safety and tolerability of TAK-071 in subjects with PD, and to evaluate the efficacy of TAK-071 versus placebo on gait dysfunction, as measured by gait variability during a two-minute walk test in the presence of cognitive loading.

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**Research Study Title:** A Study to Evaluate NYX-458 in Subjects with Mild Cognitive Impairment or Mild Dementia Associated with Parkinson's Disease, or Prodromal or Manifest Lewy Body Dementia

**Clinical Trial Investigator** Name: Kathrin LaFaver, MD

**Clinical Trial Description:** The objective of the study is to evaluate the safety, tolerability and effect (including cognitive testing) of NYX-458 in subjects with cognition-related functional impairment associated with mild cognitive impairment or mild dementia with idiopathic Parkinson's disease or dementia with Lewy bodies.

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**Research Study Title:** A Validation Study to Assess the Validity, Measurement Responsiveness, & Reliability of the Parkinson's Disease Functional Impacts Digital Instrument (PD-FIDI) in Patients with PD with or without GBA Mutations (PD-FIDI)

**Clinical Trial Investigator:** Tanya Simuni, MD

**Clinical Trial Description:** The primary objective is to determine the PD-FIDI's content validity, reliability, construct validity and measurement responsiveness in PD patients' home environments, to determine if it is fit for purpose as a PD measurement instrument.

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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 Investigator:** Danny Bega, MD

**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.

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**Research Study Title:** Phase 3, Randomized, Double-Blind, Placebo-Controlled, Parallel Arm, Multicenter Study Evaluating the Efficacy and Safety of Pridopidine in Patients with Early Stage of Huntington Disease (PROOF-HD)

**Clinical Trial Investigator:** Danny Bega, MD

**Clinical Trial Description:** The purpose of this study is to further evaluate the effect of pridopidine on functional capacity, as well as motor and behavioral features of HD in early-stage participants.

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**Research Study Title:** Clinical Evaluation and Assessment of Instruments and Biomarkers in Subjects with Wilson Disease

**Clinical Trial Investigator:** Danny Bega, MD

**Clinical Trial Description:** The primary objective of this study is to determine the relevance and appropriateness of outcome assessments, including biomarkers, within the Wilson disease population to inform study design and endpoint selection for future clinical studies.

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

**Clinical Trial Investigator:** Puneet Opal, MD, PhD

**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.

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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.

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

