PARKINSON'S DISEASE AND MOVEMENT DISORDERS CENTER

On The Move >>>

Northwestern University Feinberg School of Medicine

Fall 2021 Vol. 32

Tele-Medicine During and After the COVID-19 Pandemic

by Danielle Larson, MD

As the COVID-19 pandemic changed the way the world operated in 2020, medical care had to adapt to ensure patient safety and the delivery of quality care.

Northwestern Parkinson's Disease and Movement Disorders Center responded similarly to the medical system by rapidly expanding our telemedicine capabilities to maintain patient care. Telemedicine, or the use of real-time video conferencing between healthcare providers and patients, has been shown in research studies to be feasible and a reliable way of assessing movement disorders. Prior to the COVID-19 pandemic, Northwestern Parkinson's Disease and Movement Disorders Center (NU PDMC) was already offering telemedicine visits to patients to reduce geographic and disability-related barriers to our specialized care, but this was on a smaller scale. In response to the pandemic, the number of televisits we conducted monthly increased from 100 in March 2020 to 300 in April and 294 in May. Televisits were offered to patients across the movement disorders spectrum, from Parkinson's disease (PD) to Huntington's disease.

The need for telemedicine during the COVID-19 pandemic proved that telemedicine can improve access to care in a patient-centered way by decreasing

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the burden of travel and patient/care-partner strain associated with an in-person visit. Televisits are well-received by persons with PD with high satisfaction rates of 94-97% and appreciation of the convenience and comfort, as they are associated with patient time and travel savings. Patient interest is correspondingly high; a survey of over 700 persons with PD showed that 77% indicated interest in video-based visits with a PD specialist.

In light of patient and providers' positive response to telemedicine, televisit utilization is expected to remain higher than pre-COVID levels even after the pandemic. In a survey of 1,800 adults, 83% said they would likely continue to use telemedicine after the pandemic. In the United States, the relaxation of licensure requirements, adoption of reimbursement parity and investment in telemedicine infrastructure enabled telemedicine use during the pandemic, and healthcare providers and systems are advocating for continuation of these policy changes. Beyond direct clinical care, the growth of web-based resources, including webinars, virtual exercise classes and support groups, demonstrates patient and community familiarity and comfort with video-based technology.

While the COVID-19 pandemic forced the rapid and widespread adoption of telemedicine out of necessity, in doing so, it also proved to the medical and patient community that televisits uniquely provide the "four C pillars" for patient care: "care, convenience, comfort, and confidentiality". In keeping with Northwestern's Parkinson's Disease and Movement Disorder Center commitment to provide patient-centered specialized care, we will continue to utilize telemedicine to ensure patient access, satisfaction and quality care.

Parkinson's Foundation and Northwestern Medicine Parkinson's Disease and Movement Disorders Center present:

Parkinson's Disease Patient and Family Symposium

Saturday
October 9, 2021
10 a.m. – 1 p.m.

Topics include:

- **The Future of Care in Parkinson's**
- **Therapeutic Pipeline and Genetics in Early and Advanced PD**
- **Developing Healthy Habits Using Technology**

Following all presentations. there will be a live MD and Clinician Q & A Panel where you can ask your questions!

Cost is free, but registration is required.

Please visit: parkinson.org/northwestern to register or to find more information.

Parkinson's Foundation Expert Briefing Webinars

Join us for our educational webinars, designed for people living with Parkinson's disease (PD), care partners and health professionals.

To sign up and to find more information, please go to:
parkinson.org/Living-with-Parkinsons/Resources-and-Support/PD-ExpertBriefings-Webinars

"Kin-ship"

by Ellen B. Pritsker

When I was diagnosed with Parkinson's disease (PD) two years ago, I was not shy about texting or emailing the jarring news to my immediate family, extended family, and social network. They were concerned and comforting.

Since diagnosed, I inhabit two parallel worlds. One is the Parkinson's universe, whose inhabitants regularly twitch, freeze or stumble. It is no big deal. The other is 'the regular world,' where my symptoms feel disconcerting. For example, when my throat froze up recently while I was chatting at a friend's birthday party, I had to stop in mid-sentence and swallow hard several times in order to 'catch my voice.' Embarrassed, I told my dining partner, "my throat sometimes freezes up." She responded, "we know."

Do I interpret her response as proof that my lapses and falters are increasingly obvious and subject to derision? Or are my friends lovingly sharing concern about me? Diligent about exercise, medications, meal timing and avoiding stress when possible, I still can't prevent symptoms from percolating through my body. These can range from drooling when I talk for more than a few minutes, to lurching right or left when I rise from a seated position. Socializing brings me joy and is healthy for me. How can I continue interacting with others without feeling 'less-than?'

As my disease progresses, I am increasingly thankful to participate in PD group speech, behavior, and movement sessions. My confidence is restored when I inhabit the nurturing, accepting PD universe. I can guess that most of us experience some anxiety when navigating the 'regular' world. We didn't choose PD—it chose us. Parkinson's marks us as special—and we are special—especially to one another. Together, we can continue to benefit from the "kinship" in Par**kin**son's!

New Clinical Trial Addressing Essential Tremor

by Neil Shetty, MD

There is a new clinical trial called "Jazz ET" which is actively enrolling individuals at Northwestern. In this trial, patients with essential tremor (ET) can receive a new medication intended to treat their tremor. This exciting trial will be the first to test a medication that is specifically designed for ET. This is a surprising fact, considering how common this condition is, and welcome news for those with bothersome symptoms from ET.

Essential Tremor (ET) is sometimes referred to by less specific terms like "benign tremor" or "familial tremor." It is a neurologic condition that primarily causes tremor (shaking) of the hands.

ET is sometimes referred to by less specific terms like "benign tremor" or "familial tremor." It is a neurologic condition that primarily causes tremor (shaking) of the hands. People with ET may also experience head tremor, voice shakiness, or less commonly, leg tremor. The hand tremor tends to be seen when actively using the hands for actions or when maintaining a posture. It is therefore characterized as an action and postural tremor. The tremor tends to be fairly symmetric in most but not all cases. This can be contrasted with tremor due to another common condition, Parkinson's disease. Parkinson's tremor typically appears as an asymmetric tremor that is most prominent when the hand or other part of the body is resting (thus called a rest tremor). There are additionally other types of tremor which can be due to medications, stress and anxiety, functional neurologic disorders, dystonia, and other medical and neurologic conditions. These may be distinguished from ET based on an evaluation performed by a movement disorders specialist.

A commonly reported estimate of the number of people in the U.S. with ET is 7 million. However, this is likely an underestimation because many patients with ET do not seek medical care for their tremor. Thus, some large scale international studies actually estimate that about 5% of people worldwide have ET. That puts ET anywhere from 7 to 20 times more common than Parkinson's disease, depending on which estimates are used. About half of patients with ET have a family history of tremor and the other half does not. It is increasingly common with age, but can be noted as early as childhood. Two common age ranges for symptoms to emerge are the teens and 50s. ET is a very slowly progressive condition that tends to plateau or level off at a certain severity, though we unfortunately cannot predict what severity this will be for a given patient.

ET is sometimes referred to as a benign tremor because, aside from some minor balance issues that some patients develop, it is otherwise not associated with the development of other neurologic problems. And for the majority of people with ET, the tremor may be mild enough that it does not significantly impact their day-to-day life. However, for patients who require very steady hands for their work or hobbies, a small amount of tremor may be enough to negatively impact these activities. Additionally, there is a portion of patients who unfortunately have more severe tremor that makes even basic activities like writing, cooking, eating or drinking from a glass quite difficult.

The established medical treatments for ET are drugs that were originally designed for other conditions, but that have been found to be helpful for tremor. Two of the most commonly used and most effective of these drugs are a blood pressure medication called Propranolol and an anti-seizure medication called Primidone. Beyond these two, there are a few other second and third-line drugs that may be variably helpful. For many, these options can be sufficient to achieve reasonable control

of tremor. However, for many others, they are either insufficiently effective or not tolerated due to side effects.

Until now, the only options beyond these few medications were surgical treatments for tremor. Among these, the most commonly performed surgery is deep brain stimulation (DBS). DBS is the surgical implantation of an electrode into a very specific target in the brain. This electrode is then turned on and adjusted remotely after the surgery to modify electrical communication in this part of the brain in order to decrease tremor. DBS can be a very effective treatment for the right patient, and we commonly perform this procedure as well as the subsequent programming of stimulators at Northwestern. However, while these are powerful treatments, they are invasive, which for many patients, is a barrier to pursuing them.

For patients with suboptimal tremor control, who are either not interested in or are not good candidates for surgical treatments, the Jazz ET study provides an alternative option. The exact cause of ET is not known, but there is evidence to suggest that the tremor may be due to abnormal electrical communication between a few specific areas of the brain, which comprise a "tremor network." A particular type of brain cell protein called a T-type calcium channel may be involved in regulating this tremor network. The Jazz study is testing a drug specifically designed to act on these channels. Because of its specificity, we are hopeful about its potential benefit and benign side effect profile. The current medicines to treat ET are repurposed from other conditions and have not changed in a number of years. So, if this new drug proves effective, it will be the first available medication specifically designed for ET, which will be a major step forward for ET patients who continue to suffer from bothersome tremor.

Caregiving...

by Donna Spencer

"Life's challenges are not supposed to paralyze you; they're supposed to help you discover who you are." **~ Bernice Johnson Reagon**

I am, by nature, a problem solver. When my mom was diagnosed with **Huntington's Disease (HD)**, I knew my siblings and I would become caregivers. I was not prepared for how overwhelming the job can be. When I think about caregiving, I cannot lie, I often feel paralyzed. So much so that one time in the heat of the moment I actually said to my mother, "You're sucking the life out of me." I quickly followed it up with "...and what that means is that I am not being a good mother to my own children." I knew she would understand the later emotion. To this day I regret even uttering those words to her.

"This is something caregivers have to understand: you have to ask for help. You have to realize that you deserve to ask for help. Because you need to keep working on your own life." **~ Gail Sheehy**

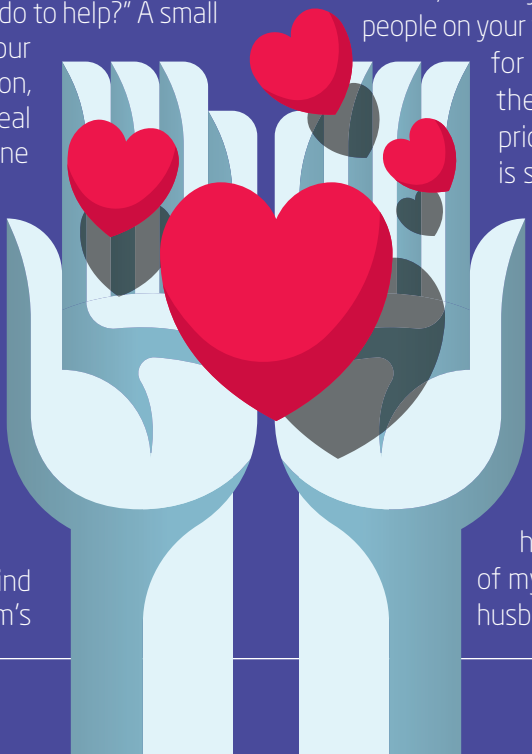
I've always been taught, "If you don't ask, you won't receive!" I'm not just talking about asking for help from family members, I'm talking about accepting help from anyone and everyone. Within our immediate family, we have come to accept our limitations. It's the best thing we could've done for the safety of both my mom and dad. This help keeps our family relationships strong, and it keeps our relationship with extended family, friends and our community strong. Never disregard someone's plea of "what can I do to help?" A small act of someone making a visit, taking your loved one for a walk, having a conversation, watching a favorite show, or having a meal with them, will help engage your loved one with HD, and provide the cognitive and emotional stimulation they need to stay engaged. Don't hesitate to coach the "helper" on how best to interact, it'll make the visit more enjoyable for the "helper" and your loved one.

"Doctors diagnose, nurses heal, and caregivers make sense of it all." **~ Brett H. Lewis**

Not always! Recently, we added a new kind of healthcare professional to my mom's existing healthcare team: palliative care specialists. There is a difference between palliative care and hospice care, and it would be valuable to know and understand the difference between the two. To keep it simple, hospice is for end-of-life care and comfort care. Palliative care is care given to improve the quality of life of patients who have a serious or life-threatening disease and is an approach to care that addresses the person, not just their disease. Palliative specialists can help with the coordination and continuity of care with the various disciplines required to care for the HD patient, such as: specialized and primary care physicians, skilled care, and emotional/behavioral/mental health care. It's about giving your loved one the independence and quality of life for their remaining days. Palliative care has added a tremendous benefit to my mom's care, and more importantly, has been an ally for my mom and her caregiver team. It's never too early to make palliative specialists a part of your HD team. They may also be helpful in identifying government/state/county/local and foundation-based resources that can help financially and with unique needs.

"When you're a caregiver, you need to realize that you've got to take care of yourself, because, not only are you going to have to rise to the occasion and help someone else, but you have to model for the next generation." **~ Naomi Judd**

How true when it comes to HD. As we know this is a family disease, a family journey. You can never have too many people on your team. A caregiver should never feel guilty for protecting their "me" time and making their own physical and mental health a priority so they can rise to the occasion. It is so easy to step into a caregiver role and want to do everything for your loved one to make life easier for them. This can be a trap, as it can make the HD patient become too dependent on the caregiver; making it a 24 hour and 7-day a week job. This then can take be extremely exhausting, physically, emotionally and mentally. For my family, we make a conscious effort to hold our entire health care team accountable for much of my mom's care so that my dad can be her husband, and my siblings and I can be her kids.



What is **Atypical Parkinsonism?**

by Jennifer Adrissi, MD

Atypical parkinsonism, sometimes known as "Parkinson's Plus" syndromes, are conditions that resemble Parkinson's disease (PD) but have atypical features that set them apart.

We sometimes refer to them as "cousins" or "siblings" of PD. "Parkinsonism" is the umbrella term that we use to describe the common symptoms in PD and atypical parkinsonism syndromes. These symptoms include a specific type of slowness that we call "bradykinesia" with the addition of muscle stiffness (rigidity) and/or tremor. The "resting" tremor of parkinsonism worsens when the hand or foot is not being used.

The most common cause of parkinsonism is PD. However, there are also rare conditions that we group with the term "Atypical Parkinsonism." These conditions have additional symptoms compared to PD and the symptoms can progress faster and be less responsive to PD medications. The specific atypical symptoms vary depending on the condition. There are four main conditions that make up the group of atypical parkinsonism disorders: (1) Dementia with Lewy Bodies, (2) Multiple System Atrophy, (3) Paroxysmal Supranuclear Palsy and (4) Corticobasal Syndrome.

Dementia with Lewy Bodies

Dementia with Lewy Bodies (DLB), sometimes called "Lewy Body Dementia," is a condition that has the movement problems of parkinsonism and significant thinking and memory difficulties. DLB is different from PD with dementia because cognitive difficulties start early in the disease – before or within the first year of the motor symptoms. It is a common neurodegenerative cause of dementia, only second to Alzheimer's disease.

Features of DLB may include:

- Fluctuations in cognition/thinking, including episodes of confusion
- Visual hallucinations (seeing things that are not there)
- Changes in behavior like aggression and agitation
- Worsening cognition with increased doses of PD medications

Multiple System Atrophy

Multiple System Atrophy (MSA) is a condition that has the motor symptoms of parkinsonism and additionally has impaired function of the autonomic nervous system. The autonomic nervous system helps to regulate involuntary body functions such as blood pressure, sweating, urination, and digestion.

Features of MSA may include:

- Lightheadedness and dizziness due to abnormal drops in blood pressure with standing or moving around (orthostatic hypotension)
- Early urinary symptoms including incontinence
- Inability to tolerate PD medications due to drops in blood pressure
- Clumsiness and loss of coordination

Progressive Supranuclear Palsy

Progressive Supranuclear Palsy (PSP) is a condition that has the symptoms of parkinsonism and also has significant early difficulties with eye movements, coordination, balance and walking.

Features of PSP may include:

- Early falls (often falling backwards)
- Early freezing when walking
- Slurred speech
- Swallowing difficulties
- Blurred or double vision

Corticobasal Syndrome

Corticobasal syndrome (CBS) is a condition which includes parkinsonism with significant atypical features in one or more limbs. These atypical symptoms are usually asymmetric and can include

dystonia, which is an abnormal, prolonged muscle activation causing abnormal positioning of limbs. For the affected limb(s), people with CBS may have difficulty completing movements or tasks even though they have adequate desire and strength. For example, they may not be able to brush their hair or hammer a nail into the wall with an affected hand. This difficulty is called "apraxia." People with CBS can have other symptoms such as difficulty with language (aphasia), quick jerking movements (myoclonus) and cognitive/thinking difficulties (dementia).

How do we recognize Atypical Parkinsonism?

Atypical parkinsonism, like PD, is a clinical diagnosis, often made by a movement disorders neurologist. This means that there is not a single laboratory or imaging test that can lead to the diagnosis. The diagnosis is based on a combination of medical history, physical examination, and tests. There can sometimes be patterns on a brain MRI which suggest a specific atypical syndrome. Atypical parkinsonism is often mistaken for PD because it can look similar, especially early in the disease. There can also be an overlap in symptoms between the different atypical parkinsonism conditions.

Often, it requires multiple visits over time to identify an atypical parkinsonism syndrome. Clues that suggest an atypical syndrome include quicker progression of symptoms compared to PD, symptoms less responsive to PD medications, and early development of the various atypical symptoms described. While people with PD can also develop symptoms like falls, freezing, incontinence, and orthostatic hypotension, it usually develops slowly and later in the disease.

How can we manage Atypical Parkinsonism?

Like PD, there is no current cure for atypical parkinsonism. However, there is ongoing research investigating ways to slow down the progression of symptoms and disease course. PD medications like carbidopa-levodopa (Sinemet) are often tried, although the response is variable.

The treatment plan is based on symptom management and can include the following:

- Medications to treat motor and non-motor symptoms
- Procedures such as botulinum toxin injections for dystonia
- Physical and occupational therapy
- Speech and swallow therapy
- Palliative care services
- Diet
- Exercise

Social workers are very helpful in providing information about support resources such as home care services, equipment and assisted living information, if needed. They help to coordinate support groups which serve as great resources for patients and their families. There are also national organizations such as CurePSP who provide additional education and resources. Palliative care services are also a valuable resource. While many people associate palliative care with end-of-life services such as hospice, they provide many more services throughout the course of the disease, which focus on maintaining comfort. The neurology team and palliative care team often work together to provide an optimal management plan.

The goal of the care team is to provide the knowledge, medications, therapies and resources to maximize quality of life and provide a support infrastructure for people with atypical parkinsonism and their families.

Henry B. Betts LIFE Center at Shirley Ryan AbilityLab

by Lisa Rosen, M.S.
Manager, LIFE Center

After facing a new diagnosis or being discharged after a hospital stay, patients and their families may face a new life chapter—a new livelihood, lifestyle and sense of self. These changes can require a sudden need to understand a broad array of information in a short period of time.

For example, when an individual is facing a new diagnosis of Parkinson's Disease or another movement disorder, the individual and their family will likely have many questions. They may range from learning about their condition, to identifying new needs such as support services, equipment or learning a new skill. When individuals have access to key information and resources, it aids in the decision-making process and supports quality of life.

Experiencing a life-changing event can be challenging—finding information should not be one of those challenges.

The LIFE Center at the Shirley Ryan AbilityLab provides information, resource assistance and support for people with various levels of physical functioning and conditions across America and around the globe. It's a multimedia education center and web portal that offers opportunities for Learning, Innovation, Family, and Empowerment.

Resources like the LIFE Center play a key role in helping address a range of emotional, interpersonal, physical and financial requirements, and enable individuals to have a successful transition after a new diagnosis, leaving the hospital and/or experiencing a life changing event.

The LIFE Center offers curated resources and knowledgeable educators who assist people in finding information about community services, support groups, government programs and products especially designed for each individual's specific needs.

The LIFE Center provides support to help navigate the complexities of healthcare, community living and lifelong learning through our service model:

• **INFORM** with online and in-person resource assistance.


Henry B. Betts LIFE Center


LIFE Center Staff (left to right):
Cris Mix, Lisa Rosen, Lori Snyder, Jamee Heelan, Elizabeth Wojciechowski

LIFE Center staff provides support in accessing standardized, peer-reviewed patient education and consumer health information that upholds best practices and specific to physical medicine and rehabilitation. Experienced educators work in partnership with the patient and family to identify key resources and information based on learning needs and preferences to support quality of life and transition back to the community.

• **CONNECT** with trusted resources and individuals. Knowledge is power, when individuals can access it, understand it, and apply it. You are not alone!

• **INSPIRE** by showcasing the vast possibilities of ability and disseminating information and discoveries of research and innovative clinical care.

The LIFE Center is also available online at www.sralab.org/lifecenter. The virtual LIFE Center provides access to thousands of resources on the following topics:

- Medical Information & Care
- Caregiving & Equipment
- Housing & Transportation
- Education & Employment
- Support & Wellness
- Recreation & Leisure
- Finance & Law
- Inspiration & Hope

To contact the LIFE Center for more information and support, call 312.238.5433 (LIFE) or visit our website. Educators are available by phone or email seven days a week from 9am-5pm.

Learn more about the LIFE Center: https://www.sralab.org/lifecenter/about

Access Curated Master Listing Index: https://www.sralab.org/lifecenter/resources/master-listing-index

The LIFE Center services are not covered by insurance. Thanks to contributions from individuals, foundations, and corporations, Shirley Ryan AbilityLab provides this unique component of care to help patients and families manage their healthcare journeys.

Shirley Ryan Abilitylab®

Meet the Team

Ala Elyaman, DO

Ala Elyaman, DO is a physiatrist who joined the Parkinson's Disease and Movement Disorders (PDMD) team at Shirley Ryan AbilityLab in July 2021 as their first ever one-year fellow. This innovative program, with support from the Davis Phinney Foundation for Parkinson's, paves the way for training physiatrists (rehabilitation physicians, also known as Physical Medicine and Rehabilitation) in neurorehabilitation specifically for Parkinson's disease and movement disorders. Dr. Elyaman completed her Physical Medicine and Rehabilitation residency at Larkin Community Hospital in Miami, FL. She attended medical school at Lake Erie College of Osteopathic Medicine in Erie, PA, and received her Bachelor of Science in biomedical science at the University of South Florida in Tampa, FL. During her physiatry residency, Dr. Elyaman developed a keen interest in movement disorders diagnosis and treatment and spasticity. Her past research includes acting as a research assistant with the Miami Pain and Diagnostics Center (MPDC) on a study of knee osteoarthritis treatments. She also served as part of a quality improvement initiative project at MPDC, for which, she created and taught an interactive nursing course on bowel regimens in spinal cord injury patients.

Meet the Team *continues on page 11* >>>

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Meet the Team

Paulina Gonzalez-Latapi, MD, MSc

Paulina Gonzalez-Latapi, MD, MSc is a Board-Certified Neurologist who joined the Movement Disorder faculty in July 2021 after completing her Fellowship in Toronto. Originally from Mexico City, she attended medical school at Panamerican University School of Medicine, the top ranked medical school in Mexico. She then completed a Master of Science in Epidemiology at the Harvard T.H.Chan School of Public Health before moving to Chicago to complete her neurology residency at Northwestern. In her clinical practice, Dr. Gonzalez-Latapi sees patients with Parkinson's disease, Dystonia, Atypical Parkinsonism, and other movement disorders. Her main areas of interest include gene-environment interaction in Parkinson's disease and other movement disorders, as well as community outreach and inclusion of underrepresented populations in Parkinson's disease research efforts. Dr. Gonzalez-Latapi will lead the efforts in creating a Spanish speaking Movement Disorders Clinic at Northwestern.

Neil Shetty, MD

Neil Shetty, MD is a board-certified neurologist and a movement disorders specialist who recently joined Northwestern's Movement Disorders faculty in July 2021. After attending medical school at University of Illinois, he completed both his neurology residency and movement disorders fellowship at Northwestern. During his clinical fellowship, Dr. Shetty underwent an additional year of specialized training in deep brain stimulation (DBS) and other advanced therapeutics. In his clinical practice at both Northwestern's Chicago campus and Glenview Outpatient Center, Dr. Shetty evaluates and treats the spectrum of movement disorders and has an additional focus in DBS and advanced treatments for Parkinson's disease, Essential Tremor, Dystonia, and other conditions. He has joined Avram Fraint, MD (movement disorders specialist), Joshua Rosenow, MD (neurosurgeon), and Carolyn Taylor, APN as part of Northwestern's DBS program. He is also currently serving as site investigator on a new drug trial for Essential Tremor.

Niccolo Mencacci, MD, PhD

Niccolo Mencacci, MD, PhD, received his medical degree (2006) and subsequently completed his residency in Neurology (2012) at the University of Milan, Italy. He then joined the Department of Molecular Neuroscience at University College London in the United Kingdom where he was awarded a doctorate in Neurogenetics in July 2016. Shortly afterward, he joined Northwestern University in Chicago, where he is conducting his research—and where he completed a clinical fellowship in Movement Disorders in June 2021, supported by the Parkinson's Foundation. As faculty, Dr. Mencacci will have an outpatient clinic presence in downtown Chicago, where he will run the movement disorder genetics clinic as well as see general movement disorders patients. Dr. Mencacci will also continue to advance his research interests, primarily focused on studying patients with familial or suspected genetic movement disorders, with the goal of identifying novel genes causing Parkinson's disease, dystonia or other movement disorders. In 2017, Dr. Mencacci was awarded the prestigious David Marsden Award for his work in the field of genetics of dystonias and Parkinson's disease. In June 2021, he was also awarded the PD GENEration Fellowship Award from the Parkinson's Foundation. Dr. Mencacci serves as a member of the Medical and Scientific Advisory Committee for the Dystonia Medical Research Foundation. He is also a member of the editorial board of the journal Parkinsonism and Related Disorders. Since January 2020, he is one of the leads for the Global Parkinson's Genetics Program (GP2), a five-year program aimed at dissecting the genetic architecture of Parkinson's disease around the world.

PD Support Groups and Programs

Central Region: Northwestern Memorial Hospital

General Parkinson's Disease Support Group

Date: First Wednesday of the month

Time: 2–3 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 Erin Cecchi, LCSW at erin.cecchi@nm.org

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Parkinson's Disease Care Partner Support Group

Date: Second Tuesday of the month

Time: 2:30–3:30 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 or e-mail Erin Cecchi, LCSW at erin.cecchi@nm.org

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Young Onset Parkinson's Disease Group

Date: Fourth Wednesday of the month

Time: 6–7 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 Erin Cecchi, LCSW at erin.cecchi@nm.org

Parkinson's Disease and Women Online Support Group

Date: Second Tuesday of the month

Time: 11:30 am–12:30 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 Erin Cecchi, LCSW at erin.cecchi@nm.org

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Chair Yoga for Parkinson's

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

Time: 2–3 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 Erin Cecchi, LCSW at erin.cecchi@nm.org

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Art Therapy

Date: Third Monday of the month

Time: 10–11 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 Erin Cecchi, LCSW at 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 or e-mail Erin Cecchi, LCSW at erin.cecchi@nm.org

Resilient Rhythms Music Therapy

Date: Fourth Tuesday of the month

Time: 2:30–3:30 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 or e-mail Erin Cecchi, LCSW at erin.cecchi@nm.org

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Therapy Tuesdays Exercise Group

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 Erin Cecchi, LCSW at erin.cecchi@nm.org

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Functional Neurological Disorder (FND) Support and Education Group

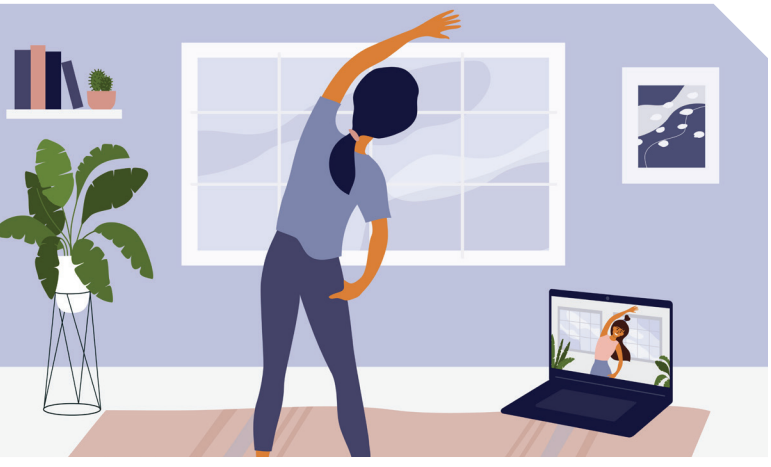
Date: Second Wednesday of the month

Time: 6–7:30pm (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-mai Erin Cecchi, LCSW at erin.cecchi@nm.org



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: 3–4 pm CST (4pm EST, 2pm MST, 1pm PST).

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@sralab.org or 312.238.6825

Lewy Body Dementia (LBD) Education & Support Series

Date: Fourth Thursday of the month. Anticipated launch June 24, 2021. Note: Some changes due to holidays.

Time: 1–2 pm

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

Cost: Free

Contact/Sign-up: http://bit.ly/SRALAB_LBD

North Region: NM Lake Forest Hospital

NM Lake Forest Health & Fitness Center

Exercise Classes:
Strength and Balance
Pedal for Parkinson's
Stride and Strength
Rock Steady Boxing
Yoga for Parkinson's

Support Groups: PD Care Partner and Women and PD group

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

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

West Region: Central DuPage Hospital

Parkinson's Support Group

Date: Third Thursday of the month

Time: 10:30–11:30 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: 10–11 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: October 9, 2021 **Time:** 10 - 11:30 am (CT)
Conversation Topic: Caregiving

Date: November 13, 2021 **Time:** 9:30 - 11:00 am (CT)
Conversation Topic: HD Research and Panel Discussion (Speakers: Dr. Danny Bega and research participants)

Register in advance for this meeting:
https://northwestern.zoom.us/meeting/register/tJUoc-uuqDMrG9Xu-1NhX_f-HRPHcGorhUfR

Date: December 11, 2021 **Time:** 10 - 11:30 am (CT)
Conversation Topic: Thinking About Testing

Contact: For meeting invite, email emily.zivin@northwestern.edu.

HD Caregiver Support Group

Dates: 10/6 and 12/1

Time: 7–8:30 pm (CT)

Contact: Emily Zivin, 630.443.9876 or ezivin@hdsa.org

The Geneva/Rockford/Bloomington Groups

Date: Fourth Sunday of the every month

Time: 2–3:30 pm (CT)

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

Bloomington: Larry Haigh, larryhaigh@gmail.com

Geneva: Joe Wiedemann, joseph.wiedemann@gmail.com

Rockford: Charlotte Rybarczyk, charlotte82963@gmail.com

Lake County Group

Date: Second Monday of every month

Time: 7–8:30 pm (CT)

Contact: Barry or Marilyn Kahn, 847.975.2403
email: marilynkahn1@gmail.com

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

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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.

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 clinical trials of therapies to reduce progression of PD disability. This study will require annual visits with brain imaging, lumbar puncture, and blood samples.

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, and online surveys.

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.

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.

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.

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.

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.

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.

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 2 dose levels of PR001A administered via suboccipital injection into the cisterna magna.

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.

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 (BWLT) improves sleep in Parkinson's disease (PD) and, if so, to select the superior dose frequency. This is a 16week trial in participants with PD and sleep disruption.

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: Danielle Larson, 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 2-minute walk test in the presence of cognitive loading.

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

Clinical Trial Investigator: Rizwan Akhtar, MD

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.

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.

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.

Research Study Title: **Psychometric Validation Study for the Huntington's Disease Everyday Functioning (Hi-DEF) Scale**

Clinical Trial Investigator: Danny Bega, MD

Clinical Trial Description: This is a non-interventional, cross-sectional study (1 visit) of participants identified with early HD. Participants will be asked to complete a battery of online cognitive assessments and three patient reported outcome measures. Clinical history, including details of HD diagnosis and any other relevant medical problems will be collected by the study site staff.

Research Study Title: **TeleHD: Feasibility, Validity and Value of Telemedicine for Motor and Non-motor Assessments in Patients with Huntington's Disease (HD)**

Clinical Trial Investigator: Danielle Larson, MD

Clinical Trial Description: To establish the feasibility, validity, and value of utilizing telemedicine to conduct remote clinical visits and complete the Composite Unified Huntington's Disease Rating Scale (cUHDRS). Feasibility of televisits for HD patients will be determined by completion of study visits, including 2 in-person clinic visits and 2 telemedicine visits.

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.

Research Study Title: **Clinical Study of UX701 AAV-Mediated Gene Transfer for the Treatment of Wilson Disease**

Clinical Trial Investigator: Danny Bega, MD

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

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.

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

Huntington's Disease Society of America Centers of Excellence

Credentialed Huntington Study Group Research Site

Parkinson's Foundation Center of Excellence

NAF National Ataxia Foundation