PARKINSON'S DISEASE AND MOVEMENT DISORDERS CENTER

On The Move >>>

Northwestern University Feinberg School of Medicine

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Comprehensive Behavioral Intervention for Tics (CBIT)

by Charlinda Turner Brashear, LCSW, ACM-SW, CCTP

Comprehensive Behavioral Intervention for Tics, or CBIT for short, is a treatment approach endorsed by The Tourette Association of America for the treatment of Tic Disorders, including Tourette Syndrome.

A "tic" is generally defined as a sudden, rapid, recurrent, rhythmic movement or vocalization. Tics are involuntary, but they can sometimes be suppressed. CBIT blends psychoeducation about tic disorders with multiple components of behavior therapy to help manage tics.

One principle of behavior therapy found in CBIT is habit reversal training (HRT). The core of habit reversal training is increasing awareness of tics and the urge to tic, combined with the use of competing responses (CRs).

A competing response is a behavior a person can engage in when the urge to tic appears, or soon after the tic has started. The goal is for competing responses to either be incompatible with the tic or be less socially noticeable than the tic. Creating appropriate competing responses is a collaborative effort between the person and a trained CBIT provider.

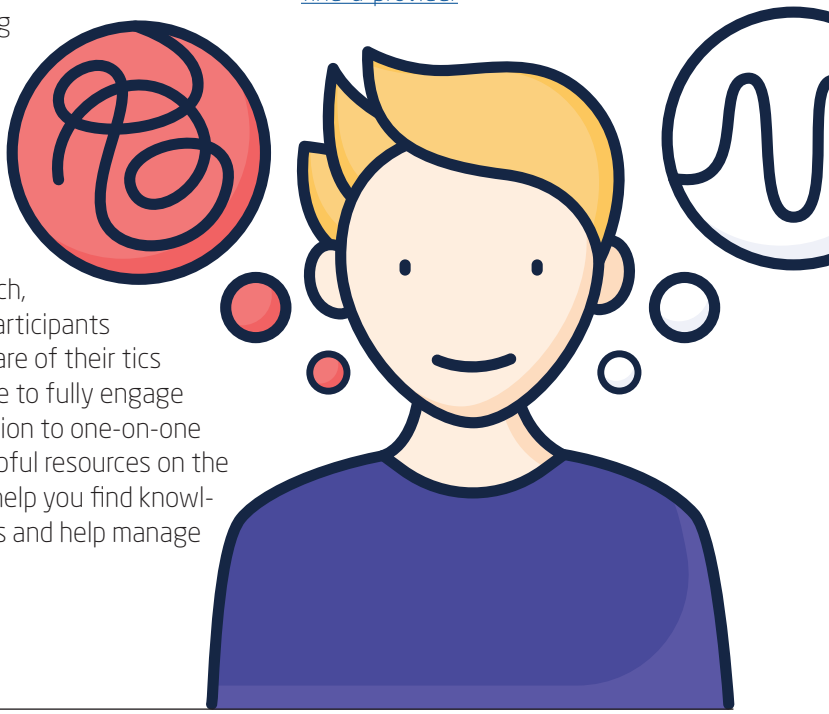
Relaxation training and function-based treatments are also behavioral components used in the CBIT approach. Tics do tend to be worse in times of stress, function-based treatments simply isolate things that make tics worse and modify or change those factors to help reduce the tics. Coping skills such as progressive muscle relaxation and deep breathing are also taught to patients during CBIT.

The research suggests that CBIT can be a successful approach, especially when participants are motivated, aware of their tics and urges, and able to fully engage in therapy. In addition to one-on-one CBIT, there are helpful resources on the Internet that can help you find knowledgeable providers and help manage tics and urges on your own. TicHelper is a web-based interactive self-help program based on the CBIT protocol. The program is recommended for children aged 8 years or older and includes parent skills training. While not suited for everyone, it has shown promise in reducing burdens such as difficulty accessing a professional trained in CBIT.

Though the overall goal of CBIT is to teach people effective tic management skills, rather than to cure the tic disorder, many patients do also see reduction in tics following a course of CBIT.

To schedule a visit at Northwestern's Tic and Tourette Syndrome Program, call 312.695.7950.

You can also find a provider in your area by going to: www.tourette.org/find-a-provider



Northwestern Medicine®

April is **Parkinson's Awareness** Month

Parkinson's disease (PD) 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 or from our partner, the Parkinson's Foundation, at www.parkinson.org
- Sharing what you've learned with your family, friends and community
- Making an impact. Donations are gratefully accepted online at www.nm.org/foundation or over the phone at 833.443.8663. 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.

Parkinson's Foundation
CENTER OF EXCELLENCE

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

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

Parkinson's Foundation Expert Briefings Webinars

Whether you are a person touched by Parkinson's disease 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.

Upcoming Webinar: Expert Briefing: Can We Put the Brakes on PD Progression?
Event Date: Wednesday, April 6, 2022 • **Time:** 10:00 am PT / 11:00 am MT / 12:00 pm CT / 1:00 pm ET

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

Meaning Intervention
for Newly Diagnosed with Huntington's disease (MIND-HD)

by Leonard L. Sokol, MD

Despite the more than 40,000 people in the USA who live with Huntington's disease (HD), limited evidence guides what medications may improve emotional health-related quality of life. We also lack understanding into what non-medicinal treatments could lessen the emotional disability associated with HD. Consequently, a growing and recent interest surrounds identifying and testing potential psychotherapeutic interventions that have worked in other populations and applying them to HD.

One candidate area for intervention is easing the sense of meaninglessness experienced by 18-20% of people at the time of their HD diagnosis and onward. These symptoms often consist of a feeling that life lacks purpose, remains incomprehensible, and does not matter. A multi-million ~~***participant or $$***~~ five-year USA study, called HDQLIFE™, determined HD's essential health-related quality of life priorities. HD stakeholders, including patients, caregivers and clinicians, decided that a sense of meaning and purpose is paramount to emotional health-related quality of life. Overwhelmingly, since HDQLIFE's conclusion, an additional study determined that around 90% of HD clinicians believe that a high sense of meaning and purpose predicts better emotional health outcomes (e.g., depression) in the future.

Using the HDQLIFE cohort, we demonstrated the vital link between a high sense of meaning and purpose with high joy, life satisfaction and happiness—regardless of other physical and cognitive symptoms—across all stages of HD. We also discovered that a high sense of meaning and purpose predicts better emotional and social health outcomes at 12 and 24 months, correlates with less burdensome HD symptoms, and uniquely contributes to overall health-related quality of life beyond the influences of depression and anxiety.

These encouraging findings point to the possibility that a Meaning-centered Intervention for Newly Diagnosed with HD (MIND-HD) could improve quality of life for people with HD. Indeed, over the past twenty years, a large body of work from Memorial Sloan Kettering Cancer Center supports that a meaning-centered intervention, called "Meaning Centered Psychotherapy," improves spiritual well-being and alleviates existential distress, depression and anxiety in the cancer populations.

Based on the works of the late neurologist, Viktor Frankl, MD, PhD, Meaning-Centered Psychotherapy involves connecting and re-connecting to four forms of meaning (attitudinal, experiential, historical, and creative) through educational and experiential activities. Delivery of the intervention occurs within individual or group formats, via in-person or video conference technology, and involves seven to eight one-hour sessions.

With funding from the Huntington disease Society of America and backing from Memorial Sloan Kettering Cancer Center, we plan to adapt Meaning-Centered Psychotherapy to people with HD. Researchers will optimize the intervention to meet the unique emotional, cognitive and language needs of people with HD, based on input from multiple stakeholders.

The initial MIND-HD clinical trial will determine the feasibility and acceptability of the intervention to people in the early symptomatic and initial stages of the disease. Delivery will occur through one-on-one interactions through video conference technology. Based on the necessary adaptations discovered during MIND-HD, future clinical trials will involve recruitment from multiple HD Centers of Excellence to examine its efficacy and the potential to influence several pathways that promise to improve health related quality of life.

Recruitment for the initial MIND-HD clinical trial is currently paused. You can email Dr. Sokol at leonard.sokol@nm.org with any questions or to be notified when clinical trials resume. Visit www.clinicaltrials.gov to find a comprehensive list of active HD studies.

MY EXPERIENCE PARTICIPATING IN RESEARCH

by Robert Bansfield

Participating in medical research can be a way to give back to society, with the hope of reaping personal benefits. Whether or not to participate in research is a personal decision that can be influenced by many factors, and I wanted to share my experiences with a research study to help others.

I was diagnosed with Parkinson's disease (PD) more than three years ago by a movement disorder neurologist at Northwestern Medicine. I went through a period of shock and denial; I wasn't yet 60 years old and was physically active. I had run the Chicago Marathon numerous times over the last 12 years. How could I have PD? Well, a thorough evaluation by my neurologist uncovered that I had mild tremors, some rigidity and movement symptoms. He immediately prescribed medications to address these symptoms.

Not long after my initial visit, my wife and I attended the Northwestern Medicine Parkinson's Disease Patient and Family Symposium. This is where some of my shock originated. I was much younger than most other PD patients attending the symposium and seemingly more physically able. Many of the individuals in attendance needed to use a cane, walker or wheelchair. I could see the fear in my wife's eyes without her needing to say a word, this was our future. A side note, I've attended every symposium since and found each to be very informative and highly educational.

If you haven't attended one, I highly recommend you do so!

Three months later, it was time for my second appointment with my neurologist. Fortunately for me, I had quickly moved beyond the shock and denial of my diagnosis. I accepted that I had PD and began my fight against it. The fight included education. I wanted to learn all I could about PD and what research studies were underway. My neurologist had, and continues to have, an optimistic yet realistic approach to treating PD. The initial goal we set was to stall the progression of my PD for the next six plus years. Over that period, new drugs and other treatments would likely be developed to aid my fight. With each subsequent appointment, we discussed the research studies that were underway and any for which I was eligible. I participated in studies that focused on physical and cognitive ability. I did so in part for future PD patients who might benefit from the various conclusions of these studies, and also so we would have more data for my own PD assessment.

Fast forward to October 2020, my neurologist advised there was a clinical trial underway for a new drug to address movement disorders. We discussed the qualifications and research scope, and I decided to participate. I hoped I could benefit from this new drug, or that my data would at least be helpful to others. Thus began my 14 months for the clinical trial of a new drug.

During this time, I had numerous physical exams, electrocardiograms (EKGs) and blood tests. While this meant I was committing a decent amount of time to complete these activities, it was worth it. A side benefit of the trial was getting a second perspective on my PD. Over those months, the primary investigator and my primary

neurologist collaborated closely to monitor my overall health and reaction to the drug. Here again, I benefited personally by having not one, but two doctors to guide me on my journey fighting PD.

The clinical study was just completed in January 2022. I can tell you my reaction to the trial drug was very favorable. Many others in the study had favorable outcomes as well. The pharmaceutical company is now consolidating the results from participants around the globe and beginning the process to submit the drug for FDA approval. I am hopeful the drug is approved and ultimately available to PD patients like you and me!

Would I participate in the clinical trial again if given the chance? The answer is yes, a resounding yes! Over those 14 months I received medical care from not one but two highly qualified neurologists. And their collaboration was beneficial to the study and to me personally. You need to know for a study like this, it is important to be in tune with your physical state and keep thorough, accurate records of your reactions to the drug. If you get the chance to participate in a future trial, I hope my own experience encourages you to do so! If not for your benefit personally, for the future benefit of others with Parkinson's disease and related movement disorders.

To find a research opportunity at Northwestern, please see a list of options at the end of this newsletter or visit: https://www.neurology.northwestern.edu/divisions/movement-disorders/clinical-trials.html

PD CAREGIVER BOOT CAMP SERIES

NORTHWESTERN UNIVERSITY
DEPARTMENT OF NEUROLOGY

Parkinson's disease (PD) caregivers are invited to participate in a PD Caregiver Boot Camp Series, to be held virtually via Zoom. This is a program (PF-CORE-856793) and research study (IRB Study Number: STU00215633) conducted by Danny Bega, MD, MSCI, and Linda Egan, PT, at Northwestern University and is supported by a Centers of Excellence CORE grant from the Parkinson's Foundation.

Who is Eligible?

- Age 18 or older
- Are taking care of or have taken care of someone with Parkinson's disease

What will you be asked to do?

- Participate in a consecutive weekly series of interactive webinars; each webinar session will be 60-90 minutes
- Complete a survey of perceptions of the program, satisfaction with program, and recommendations for improvement
- Complete pre and post surveys to assess mood, quality of life and burden

The risks of participating in this program are minimal and unlikely. However possible risks include psychological distress, social risks and compromised confidentiality. These effects are usually transient and will be directly addressed by co-investigator, Linda Egan, PT.

The main benefit of being in this study is reduction in caregiver burnout, improvement in mood and improvement in quality of life.

To participate in the group, please e-mail or call to sign up.
linda.egan@nm.org • 847.535.8244

Participants will be compensated $25 for participation in the series. Questions or concerns, please contact Linda Egan at linda.egan@nm.org.

My Journey with FND

by Laurie Sanzana

When my journey with Functional Neurological Disorder (FND) began more than 20 years ago, no one could explain the strange symptoms I was experiencing—migraines that evolved into tremors and shakes and tunnel vision. Every neurologist I visited identified I had a rare condition but had no idea why I had it or how to treat it. FND Hope, an organization promoting awareness and support for individuals affected by FND, defines the disorder as, "a problem with the functioning of the nervous system and how the brain and body send and receive signals." Well, this is how I understand FND in my own words: my body's hardware is fine, but the software goes haywire sometimes.

My first episode happened when I was 16 years old during a shift at my retail job. My head felt like it was going to explode from the migraine I was fighting. I began to experience tunnel vision, body shakes and felt like my whole body was stiff. I did my best to drag myself to the front of the store with the intention to ask for help, but I couldn't get the words out. My manager asked if I was ok, and with my hands trembling, all I could do was write the words "No, NOT ok, HELP," on a piece of paper. The other employees helped me to the break room, my dad picked me up, I slept for about a day, and then was fine. My parents believed it was just a strange reaction to a bad migraine and we never gave it a second thought.

My second year in college I had another episode, again while at work. The manager had me call my doctor who thought it was a bad reaction to the new migraine medication I was given. Shortly afterwards, I had episodes almost every month but now they involved convulsions. The only relief I felt was to literally crawl under my mattress for as much deep pressure as I could handle. I honestly was not sure what to do. I just though the symptoms were part of the migraines.

After I graduated college, I moved to New Mexico. Within a year the episodes got worse, involving left leg weakness and high tone in my right arm. Many times, I wondered if I was having a stroke, but the symptoms always went away after the migraine calmed down. So, I tried not to worry about it.

However, one day, things got much worse. I was 28, married, living back in the Midwest, and working full time as an Occupational Therapist in a K-8th grade school district. I had an episode at the school. I wanted to just go home and rest, but the school nurse was very concerned and insisted on calling 911. I wound up staying in the hospital for 5 days, where I underwent many tests, was taken off all my medicines in case it was an allergic reaction, and eventually sent home with no answers.

Sadly, after that, the episodes became chronic and lasted for days rather than hours. I was unable to work for more than a few hours a day, could barely manage taking a shower and working in the same day. It honestly felt like my whole world was turned upside down, falling into this darkness that had no name and no hope. I would start to notice this unbearable vibration deep in the bones of my legs. Then my ears would begin

to burn, my throat would tighten, I had tunnel vision, sounds felt like they were muffled and miles away, and then my muscles would tighten and spasm throughout my whole body creating a rhythmic tremor in my back causing me to walk worse than Frankenstein's monster. I felt completely out of control and helpless.

After years of invasive testing, seeing at least five different neurologists and two specialty clinical evaluations, I received multiple confusing diagnoses, none of which led to helpful treatment and just made me feel crazy. Each time I was politely told something to the effect of, "Your subconscious is most likely just over-reacting to stress." I felt lost, alone, and devastated; that my life was over.

I finally began to feel better when I stopped searching for a diagnosis and began to study and treat the symptoms with a more holistic and alternative medical approach. I saw a traditional Chinese medicine practitioner for acupuncture and herbal medicine, a Nutritionist for dietary supplements, and yes, a psychologist for Cognitive Behavioral Therapy (CBT). I researched extensively how to use Emotional Freedom Technique (EFT), magnet therapy, Yoga and Qigong, energy medicine techniques, sound therapy and sensory strategies to regulate my nervous system. I feel blessed, because as an OT, I was taught that regardless of what is wrong with someone, adaptations and accommodations can allow them to do whatever they want in life. After many tears, heartbreak, loss and struggles, I decided I HAD to look at myself the same way I was taught to look at my patients and live as best I could.

Now, at 47 years old, I finally feel I understand my diagnosis of FND, but it took almost 20 years to get there. An important part of the process was a referral to Dr. Kathrin LaFaver at Northwestern Medical Center who specializes in FND, truly a rare find. Meeting with Dr. LaFaver was the first time I felt heard and understood. Not only did she diagnose me with FND, but she explained what it was, what was happening in my body and brain that led to the unusual symptoms AND sent me home with resources including a local support group. For the first time, I no longer felt alone. I had real hope.

FND has taught me to recognize what helps my body and what doesn't. I have learned what my triggers are and how to live life around them. I now have episodes only a few times a year. Thankfully, the intensity and frequency have significantly decreased. I had to learn what helps me and what doesn't when having an episode. I have given myself permission to say to others, "I'm ok, but I am having a bad motor day. I am having tremors from a neurological condition and just need a little help," and then go on with my day. Then some days I need to say to myself, "This is too much, and I give myself permission to rest in bed for the day."

FND has not been an easy journey for me, but yes, it has been a blessing in disguise. It forced me to face my fears, to develop a strong internal connection with myself, to become my own detective, and to make changes in my life that can only benefit me as I move forward on this journey. My hope and desire are that I can be that voice that lets others know they are not alone, to help friends and family better understand what their loved one is experiencing as they begin their journey with FND, and to be a light in a world that is still dark-just beginning to be explored by the medical community.

FND is a difficult and challenging diagnosis to receive, but in time, it can help one grow, heal, and see life from a different perspective. For me, FND initially caused me to be disabled, but with the right interventions, I have regained my life and am moving forward with more strength and insight. I have hope that, in time, the medical community will also advance in their ability to diagnose and treat FND in a way that gives others hope from the very beginning of their unexpected journey.

Bridging Care Inequalities in Movement Disorders in the **Hispanic Population**

by Paulina Gonzalez-Latapi, MD, MSc

The Hispanic population includes those individuals who have an ancestral background in a Spanish-speaking country, including most Latin-American countries and Spain. Hispanic is one of the largest ethnic groups in the US, making up 17% of the United States population, a number estimated to grow to 30% by the year 2050. Nonetheless, this population is significantly underrepresented in medical care and research.

A recent study documented substantial racial and ethnic disparities in neurologic health care access and utilization in the United States. Disparities were found across all neurologic subspecialties and illnesses, with Hispanic individuals being nearly 40% less likely to see an outpatient neurologist. The reasons for these differences are multifaceted, including misunderstanding of the health care system; differing cultural beliefs and attitudes about aging; and limited resources to make informed health decisions. Additionally, health systems may not provide meaningful language assistance—impeding clinician's understanding of patient's complaints and patient's understanding of clinician's assessments and recommendations.

This trend also includes the care of people with a movement disorder. Several studies show a greater delay in diagnosis in Hispanic people with Parkinson's disease. Hispanic patients are also more likely to present in advanced disease stages, which may be due to misinterpreting signsof disease as part of aging and the culturally taboo topic of seeking help for mental health and cognitive changes. Reports discussing race or ethnicity in Parkinson's provide evidence of disparities in prescribing medications; referral to advanced treatment options such as deep brain stimulation; decreased recruitment to clinical trials; and availability of resources. These inequalities remain under-studied for other conditions as well, including dystonia, essential tremor and Huntington's disease to name a few.

"Diversity is a fact, but inclusion is a choice we make every day" – Nellie Borrero

Recruitment to research efforts is another area of significant concern. It is deeply important for physicians to provide disease education and referrals to research. Nevertheless, more than half of Hispanic patients receiving their care at a Movement Disorders clinic state that their physician did not discuss or recommend participation in research. While physicians identify lack of healthcare coverage, family responsibilities, legal status and work schedules to be potential barriers to care, patients and families did not personally report these concerns to be barriers when they were interviewed. These factors are not unique to the Hispanic community and should not be specifically assumed to exist only for Hispanic people.

Participation of a diverse population in clinical trials is important to ensure results are applicable to a wide range of people. Nonetheless, Hispanics are under-represented in most clinical research studies, making up only 7.6% of participants according to a National Institute of Health report. Interestingly, one of the most significant barriers was lack of awareness of ongoing research studies. This trend seemed to improve in individuals receiving their care in an academic institution. Hispanic people with Parkinson's and other movement disorders who were seen at an academic institution were more likely to be interested in research. Even more, a recent survey showed that Hispanic patients and their families preferred working with their research and care teams as individuals on those teams spoke Spanish and had a better understanding of the Hispanic culture. In this way, cultural competency plays an important role in providing care for this population.

Despite the advantages that this culturally competent model provides, there are very few health systems across the nation who offer a Hispanic Clinic for Movement Disorders. This is of particular importance in Chicago where the Hispanic population is now the second largest ethnic group (only behind White non-Hispanics).

To address this need of our Spanish-speaking patients, we have started the Hispanic Movement Disorders Clinic. This clinic will provide expertise in the care of Parkinson's disease, tremor, dystonia and ataxia for Spanish-speaking patients and those of Hispanic descent.

For more information or to schedule an appointment, call our Spanish-speaking patient liaison at 312.694.7700.

Tips For Managing the Physical And Mental Symptoms of PD

This National Better Speech And Hearing Month

by Anne Montana, MA, CCC-SLP

Who are speech language pathologists and what do they do?

At Shirley Ryan AbilityLab, speech language pathologists are part of our interdisciplinary care team for Parkinson's disease (PD) and other movement disorders. The role of the speech language pathologist is to evaluate and treat disorders of speech and voice, swallowing, cognition and communication. We work together with you and members of your healthcare team, including your movement disorders neurologist, physical medicine and rehabilitation (physiatrist), physical therapist, occupational therapist, and psychologist or neuropsychologist, among others. At Shirley Ryan AbilityLab, speech language pathologists see patients as part of our Parkinson's Disease and Movement Disorders interdisciplinary clinic, in our Early Intervention PD program, and through our outpatient, DayRehab and inpatient rehabilitation services.

Too often, the non-motor symptoms of movement disorders, such as those affecting cognition, language, communication and mood, do not get as much attention as the motor changes. Cognitive symptoms may not occur in everyone with a movement disorder, yet when they do, they can range from mild changes to more severe symptoms such as dementia. Recognition of these symptoms with baseline and follow-up assessments are key. In addition, there are many strategies to manage cognitive changes that can be used by people with PD and movement disorders or by their care partners. It is also important to speak with your physician or healthcare provider if you have cognitive changes, whether sudden or new onset or more gradually occurring symptoms, so they can perform any needed assessments or investigations.

Recognizing Cognitive Symptoms in PD and Movement Disorders

Common symptoms can include the following:

- Slower processing speed, or taking longer to process information or respond to questions
- Difficulty with paying attention or concentrating
- Trouble with organization, planning, multi-tasking
- Impaired executive skills including planning, reasoning, problem solving and organization
- Difficulty with short term memory
- Trouble finding the "right words"
- Changes in visuospatial skills such as getting lost or difficulty finding one's way from one place to another
- Accompanying mood symptoms (e.g., depression or anxiety), apathy (lack of interest, initiation or motivation), or hallucinations or delusions with disease progression

A speech language pathologist can evaluate cognition and language to identify changes and develop a comprehensive treatment plan to address cognitive symptoms, at any stage of their disease, even soon after initial diagnosis. Speech language pathologists may provide strategies and compensation techniques to help manage and cope with changes in thinking and memory. Speech language pathologists often work together with other specialists like neuropsychologists, who may perform in-depth cognitive assessments, as well as occupational and physical therapists.

Practical Tips for People with Mild Cognitive Impairment:

1. Keep a calendar! Even if you've never needed to use one in the past or don't think it's necessary, now is the time to develop systems that you can continue to use into the future. It is important for all appointments, events and scheduled tasks to be written on a master calendar, which should be reviewed daily.

2. Keep notes and to-do lists. If in doubt, write it down.

Some people prefer to use apps on their phone, while others prefer using pen and paper. Whatever systems work best for you should be done consistently and kept in an easily accessible location.

3. Harness technology. You can use technology to help keep you organized and on top of tasks. A speech language pathologist can help identify appropriate tools, such as alerts, reminders and alarms on your phone or electronic device.

4. Use medication reminders. If you find you often forget to take your medications on time, it's time to implement a pill box system! Medication reminder alarms on your phone can also help you stay one time with meds.

5. Keep your brain active. We know that physical exercise is critical for people with movement disorders, but it is also important to keep our brain engaged and challenged through cognitive and language stimulation. A speech language pathologist can help identify brain-training programs, tasks and games, which can help keep you sharp!

6. Create a practice schedule. Many people with movement disorders have difficulty finding time and remembering to complete their prescribed home exercise programs. It can be helpful to create a practice schedule to keep you accountable and help establish a sustainable home exercise routine.

7. Prioritize your sleep. Sleep deprivation often has a negative impact on memory, attention, higher-level cognitive functions and mood. Work with your medical team to help optimize your sleep routine and attempt to get enough sleep per night.

8. Assess your work place needs. If you are employed, vocational therapists can help you identify and communicate modifications to your employer, where appropriate.

9. Be safe! A driver's evaluation may be necessary if safety while driving is impacted by cognitive or motor planning symptoms.

10. Learn something new. This is one of the best things we can do for an aging and changing brain. Learn a new game, study an interesting topic, or pursue that second language you have always wanted to learn!

Shirley Ryan Abilitylab®

Tips for People with More Advanced Cognitive Impairments or Dementia:

1. Monitor and reassess. A speech language pathologist can help track cognitive change over time through use of screening tools and assessments and can use these to guide new programs for cognitive strategies.

2. Bring a family member or other person to your session. Treatment sessions may incorporate a family member or caregiver into the education process to optimize carryover of recommendations from therapies into the home environment.

3. Try a white board. A dry erase board or white board can serve as a tool to keep track of the date and basic activities or events of the day. A care partner can help write important information down, as needed, and encourage the individual to check the board if they need a reminder of the daily happenings.

4. Keep track of the date and time. A large, bold-faced digital clock with the date may be useful to help with orientation to date, day of the week and time.

5. Look back at old memories. Photo albums can be used as a fun way to reminisce, encourage engagement in conversation and recall information such as names, places and important events in someone's life.

6. Keep it simple. Break tasks down into short, simple steps whenever possible. Repetition of the same steps can help reinforce a safety technique or steps to an exercise such as: Sit to Stand: 1- Scoot to edge of chair, 2- Lean forward - nose over toes, 3- Push up from armrests

7. Get your "zzz's." Once again, don't forget to prioritize a good night's sleep!

8. Stay hydrated. People with movement disorders and swallowing difficulties often run the risk of dehydration, which can have negative effects on memory and cognitive function.

9. Provide supporting cues throughout the day and repetition of information to reduce the cognitive burden. E.g., "Joe is coming over to visit today. Joe is your nephew who lives in Milwaukee."

10. Check in with your doctor. Treatment with a speech language pathologist is not a one-time occurrence and may change with different stages of your disease. These treatments should be an ongoing relationship over the course of your disease. Check in with your doctor to determine if a therapy tune-up may be warranted.

Meet the Team

Franchesca "Frankie" Arguelles, BSN, RN

Franchesca Arguelles, BSN, RN, received her Bachelor of Science in Nursing from The University of Nevada-Reno in 2018. She began her career as an inpatient neuroscience/telemetry RN, caring for patients with a variety of neurological and cardiac concerns. She made the transition to home health, initially as a visit nurse, but then became a case manager with experience in wounds, movement disorders, and cardiovascular diseases. She moved back to the Chicagoland area and joined the Northwestern Movement Disorders team in July 2021. She enjoys working with a variety of movement disorders and is excited to be a part of the team.

Sushma Kola, MD

Sushma Kola, MD, is a first year Movement Disorders Fellow at Northwestern. She completed her medical training at the University of Pittsburgh followed by neurology residency at Mayo Clinic Rochester, where she served as Chief Resident. Dr. Kola has developed clinical and research interests in Movement Disorders rehabilitation and was selected for Northwestern University's Medical Education Clinical Scholars program.

Behzad Elahi, MD

Behzad Elahi, MD, is a Movement Disorders Fellow at Northwestern. He joined the program after finishing medical school in Tehran, Iran and earning his PhD in neuroscience at University of Toronto. After university, Dr. Elahi completed his residency and chief residency at Tufts. He was also a fist fellow at Mayo clinic Rochester in clinical neurophysiology and electromyography (EMG). He is interested in neurophysiology of movement disorders and deep brain stimulation.

Northwestern Medicine®

Advance Care Planning Series

presented by Northwestern Medicine Neurology

Advance care planning can be a gift you give yourself and your family.

It is a way to ensure that your wishes and preferences are consistent with the care you receive now and in the future.

Please join us for our virtual Advance Care Planning Series. Each session will feature experts in the medical and legal fields discussing financial, legal and long-term care questions.

There will be a live Q&A at the end of each session.

Date: 2nd Tuesday of each month, March-May 2022
Time: 6:00 – 7:30 PM (CT)
Where: Zoom (online)
Cost: FREE

~~**March 8**: Planning for Care: Setting the Stage for Ongoing Dialogue~~
April 12: Legal Planning
May 10: Palliative, Hospice, and End-of-Life Decisions: Reframing the Discussion

Register here:
https://northwestern.zoom.us/webinar/register/WN_MeZssupmSqupkOKaJNuCaA

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 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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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 Wednesday of the month

Time: 11 am - 12 pm (CT)

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

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail Erin Cecchi, LCSW at erin.cecchi@nm.org

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Chair Yoga

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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Parkinson's Disease 101

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

Date: Wednesday, May 18, August 17 and November 16

Time: 4 - 5:30 pm (CT)

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

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail Erin Cecchi, LCSW at erin.cecchi@nm.org

Parkinson's Disease 201

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

Date: Wednesday April 6 and September 7

Time: 4 - 5:30 pm (CT)

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

Cost: Free

Contact: For more information and to register, visit nm.org/parkinsons-support or e-mail Erin Cecchi, LCSW at erin.cecchi@nm.org

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Art Therapy

Date: Third Monday of the month

Time: 10 - 11am (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

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Atypical Parkinson's Support Group

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

Date: Third Thursday of March, June, September and December

Time: 1:30 - 2:30 pm (CT)

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

Cost: Free

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

Wilson's Disease Support Group

Date: Last Thursday of the Month for the months of April, July and October

Time: 7 - 8 pm (CT)

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

Cost: Free

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

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Functional Neurological Disease Support Group

Date: Second Wednesday of each 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: Referral and consent form are required to participate. For more information, e-mail Erin at erin.cecchi@nm.org

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Northwestern Medicine HD Support Group

Date: Second Saturday of every month

Time: 10 am (CT)

Location: Zoom

Contact: E-mail Emily at emily.zivin@northwestern.edu

To Register: https://northwestern.zoom.us/meeting/register/tJIqf-2vqT8qE9KddIKdiOkVyTijeHFvyhYL

Odd Months: Caregiver support group

Even Months: General HD support group

For the months that we are hosting education sessions, we will be hosting a support group after the education session

Upcoming Sessions:

Saturday, April 9: Asymptomatic Gene-Positive

Please join Seth Rotberg as he shares his HD journey. This will be an interactive session for individuals who are asymptomatic gene-positive.

Register in advance for the meeting: https://northwestern.zoom.us/meeting/register/tJcsdu2uqDouGdUlJEu5eatDkT-HH455iUoH

*General HD support group to follow education session

Upcoming Sessions continue on the next page >>>

Northwestern Medicine HD Support Group Upcoming Sessions:

Saturday, August 13: Couples Retreat

Please join Emily Zivin as she provides an interactive education session for couples to talk about their HD journey together with other couples in the community.

Register in advance for this meeting: https://northwestern.zoom.us/meeting/register/tJYlc-qsqDkuH9fUN4UUJ4jAHjLI7FHw0g8w

*General HD support group after education session

Saturday November 12:
Clinical Research Update with Dr. Danny Bega

Register in advance for this meeting: https://northwestern.zoom.us/meeting/register/tJUvde6vrz8tHNB-iwdeFGrIQxTkcU6d47wy

Central Region: Shirley Ryan AbilityLab

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

Date: The Group meets twice per month, on the second and fourth Fridays of each month at 4:00 – 5:00 pm ET (3 pm CT, 2 pm MT, 1 pm PT).

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

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 am - 11 am (CT)

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

Cost: Free

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

Research Participation Opportunities at Northwestern Medicine

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

Clinical Trial Eligibility Criteria:
- Disease subjects and family members
- Diagnosis of a movement disorder

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

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

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

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

Clinical Trial Eligibility Criteria:
- Diagnosis of PD 2 years or less -or-
- PD with genetic mutation < 2 years duration -or-
- Prodromal and Healthy Control

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

Coordinator Contact: Heidi Friedeck, T 312.503.1519, heidi.friedeck@northwestern.edu

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

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

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

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

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

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Research Study Title: The Fox Bionet ECV 004 Study

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

Research Study Visits: 1 visit

Coordinator Contact: Heidi Friedeck, T 312.503.1519, heidi.friedeck@northwestern.edu

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

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

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

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

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

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

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

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

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

Coordinator Contact: Justine Houseman, T 312.503.2128, justine.houseman@northwestern.edu

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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 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 (MDS-UPDRS)

Clinical Trial Eligibility Criteria:
- Onset of PD symptoms 5 years or less and 30-80 years of age at screening.
- Not expected to start PD meds at least 9 months from baseline

Research Study Visits: 1-year study with 10 clinic visits and 5 telephone visits (DatScan required)

Coordinator Contact: Dorina Veliceasa, T 312.503.1999, d-veliceasa@northwestern.edu

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

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

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

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

Coordinator Contact: Justine Houseman, T 312.503.2128, justine.houseman@northwestern.edu

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

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

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

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

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

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

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

Clinical Trial Eligibility Criteria:
- Between 40-75 years of age who have a clinical diagnosis of PD (H&Y 3-4)
- On stable medication for at least 8 weeks prior to baseline
- At least 1 GBA mutation

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

Coordinator Contact: Cynthia Poon, T 312.503.8216, cynthia.poon@northwestern.edu

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

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.

Clinical Trial Eligibility Criteria:
At least 60 years of age
Diagnosis of PD
• on stable medication for at least 30 days prior to study

Research Study Visits: 3 visits over 5 weeks with weekly phone calls between visits

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

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

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

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

Research Study Visits: 5 visits over 16 weeks

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

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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 Description: This is 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 Parkinson's disease patients. TAK-071 is an investigational drug that is being studied as a possible treatment for people with Parkinson's disease who have a history of falls.

Clinical Trial Eligibility Criteria:
• Between 40 - 75 years of age who have a clinical diagnosis of PD
• Have study partner supervising and assisting with medication administration
• On stable medication for at least 4 weeks
• At least 1 fall in the last 6 months prior to screening

Research Study Visits: 23 weeks total with 6 weeks screening, 2 six-week treatment period, and 14-day follow-up

Coordinator Contact: Justine Houseman, T 312. 503.2128, justine.houseman@northwestern.edu

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

Clinical Trial Description: The purpose of this study is to test the performance of the wAID-P algorithm in differentiating different types of diseases including Parkinson's disease (PD), multiple system atrophy parkinsonian variant (MSAp), and progressive supranuclear palsy (PSP). Each site will perform imaging, clinical scales and diagnosis. The clinical diagnosis will be blinded to the diagnostic algorithm and the imaging diagnosis will be compared to the movement disorders trained neurologist diagnosis.

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

Research Study Visits: 2 visits

Coordinator Contact: Kyle Tingling, T 312.503.8229, kyle.tingling@northwestern.edu

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

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

Clinical Trial Eligibility Criteria:
• Age 18 - 75 years, inclusive
• Diagnosis of motor manifest HD
• Genetic dx of HD with CAG repeat ≥ 37
• TMC score ≥ 8 and TFC score ≥ 5

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

Coordinator Contact: Zsa Zsa Brown, T 312.503.4121, zsazsa.brown@northwestern.edu

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

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

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

Research Study Visits: Up to 136 days

Coordinator Contact: Zsa Zsa Brown, T 312.503.4121, zsazsa.brown@northwestern.edu

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

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

Clinical Trial Eligibility Criteria:
- Between 18-70 years old
- Diagnosis of HD with MOCA > 21

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

Coordinator Contact: Destiny Gomez, T 312.503.2778, destiny.gomez@northwestern.edu

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

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

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

Research Study Visits: Up to 6 weeks study duration

Coordinator Contact: Destiny Gomez, T 312.503.2778, destiny.gomez@northwestern.edu

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

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

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

Research Study Visits: ???

Coordinator Contact: Zsa Zsa Brown, T 312.503.4121, zsazsa.brown@northwestern.edu

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

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

Clinical Trial Eligibility Criteria:
- 18 - 80 years old with diagnosis of ET
- Moderate to serve disability associated with tremor (per scored assessments)

Research Study Visits: 21 weeks

Coordinator Contact: Dorina Veliceasa, T 312.503.1999, d-veliceasa@northwestern.edu

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

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

Study information continues on the next page >>>

Clinical Trial Eligibility Criteria:
- Age 18 - 75 years of age
- SCA 1-3, SCA 6-8 and SCA 10
- SARA score ≥ 8; score of ≥ 2 on gait subsection

Research Study Visits: Up to 64 weeks

Coordinator Contact: Kyle Tingling, T 312.503.8229, kyle.tingling@northwestern.edu

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

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

Research Study Visits: 1 visit

Coordinator Contact: Kyle Tingling, T 312.503.8229, kyle.tingling@northwestern.edu

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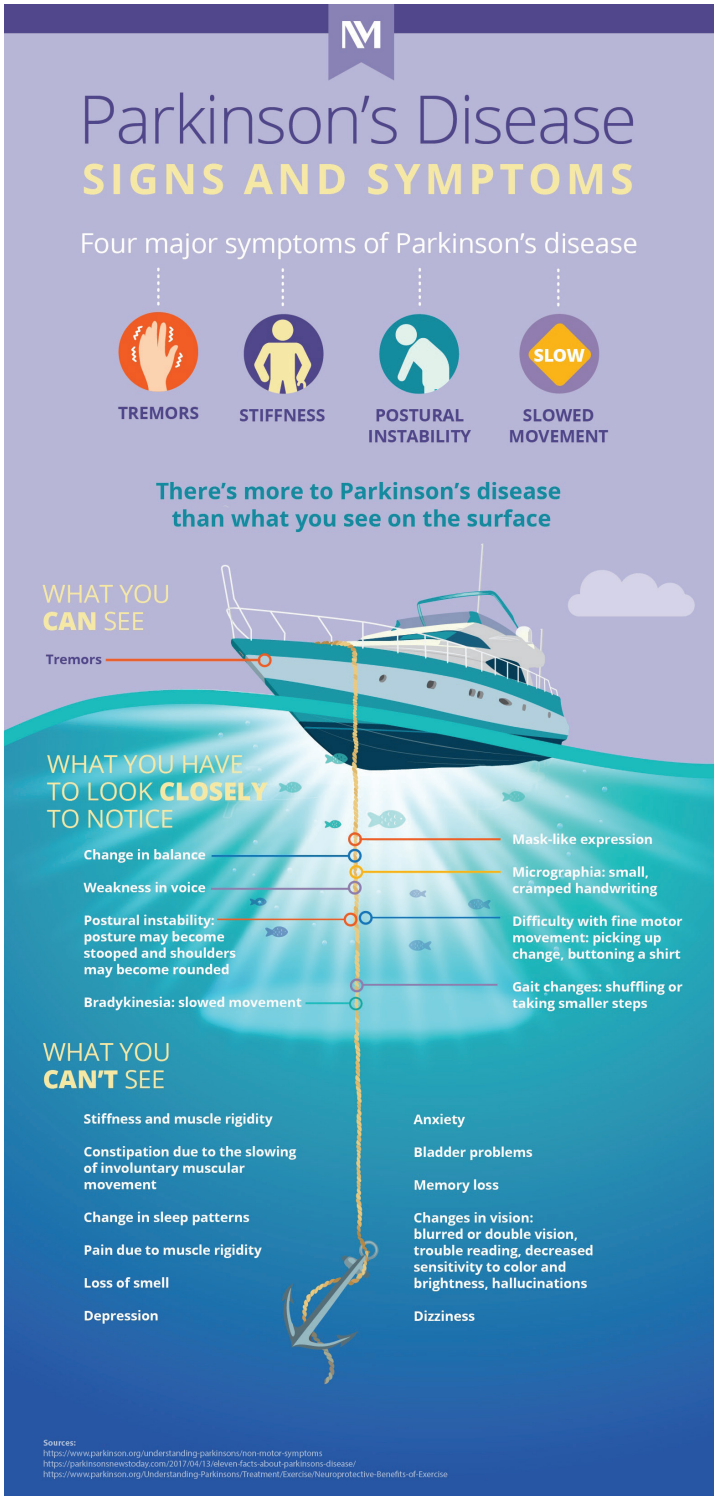
Join the Mailing List / Questions?

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

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 Research Site
Parkinson's Foundation Center of Excellence
NAF National Ataxia Foundation