PARKINSON'S DISEASE AND MOVEMENT DISORDERS CENTER

On The Move >>>

Northwestern University Feinberg School of Medicine

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BIOMARKERS

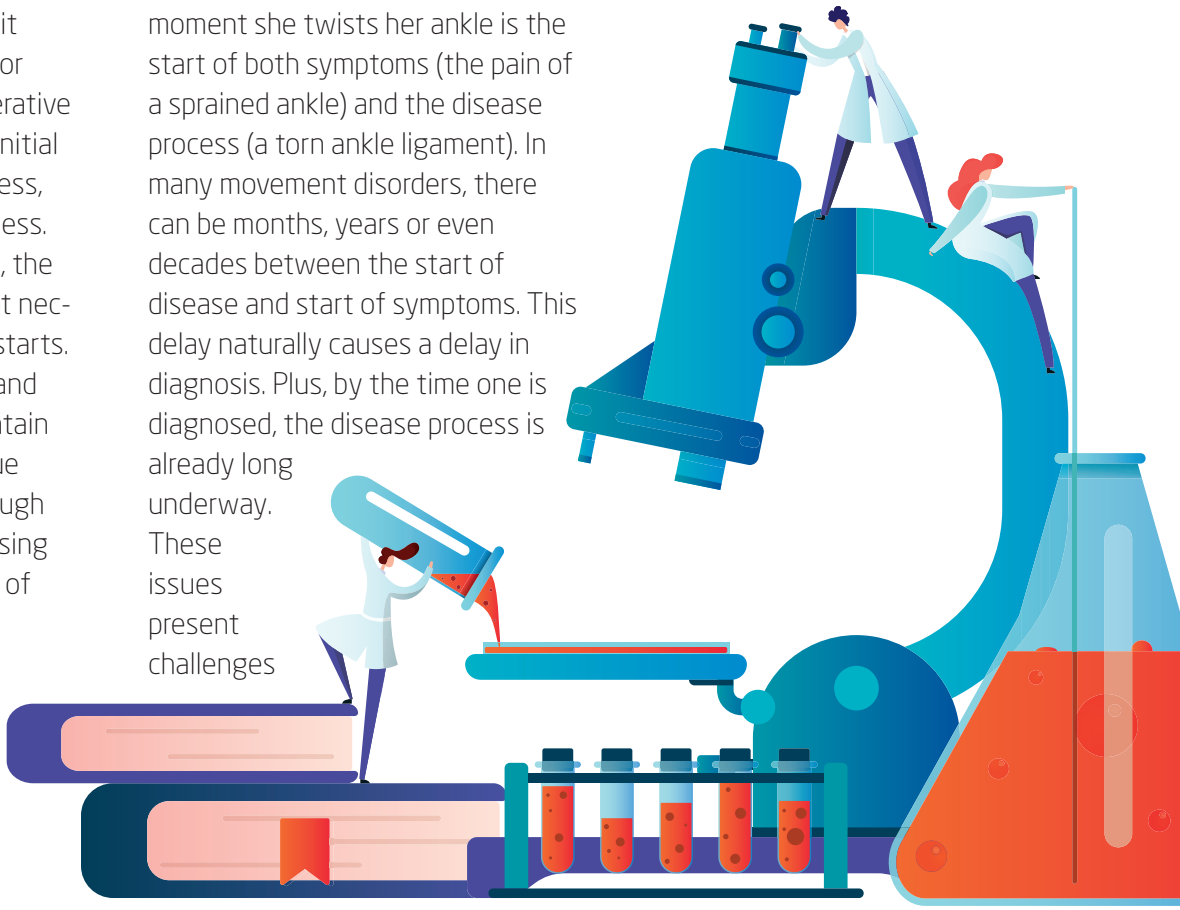
by Rizwan Akhtar, MD, PhD

Patients, their caregivers and family members often have a sense of when their neurological symptoms first started.

For Parkinson's disease, it's the first appearance of a subtle tremor, starting to walk more slowly, or a slight stiffness in an arm or leg. For Huntington's disease, it may be fidgeting movements or irritability. Other neurodegenerative disorders start with different initial symptoms, such as forgetfulness, personality changes or weakness. However, in all these diseases, the time the symptoms start is not necessarily the time the disease starts. Instead, the brain, spinal cord and peripheral nerves usually maintain some reserve, and can continue to function normally even though there is a disease process causing loss of cells and accumulation of toxic proteins.

This disconnect between the start of a disease process and the start of symptoms, is not often seen in other areas of medicine. Consider a basketball player awkwardly landing after grabbing a rebound; the moment she twists her ankle is the start of both symptoms (the pain of a sprained ankle) and the disease process (a torn ankle ligament). In many movement disorders, there can be months, years or even decades between the start of disease and start of symptoms. This delay naturally causes a delay in diagnosis. Plus, by the time one is diagnosed, the disease process is already long underway. These issues present challenges to researchers who are looking for ways to cure the disease.

Biomarkers are one potential solution to this limitation. Broadly defined, the term "biomarker" refers to any measurable substance or characteristic that can indicate the state of an underlying disease process that otherwise is not directly observable. Biomarkers are already very common in medical practice. For example, the amount of total cholesterol in blood can



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serve as a biomarker for risk of vascular diseases like stroke or heart attack. It can also reveal how well therapies to reduce that risk are working: by exercising or eating more healthy foods, risk of these problems is lower—and often, so is the blood cholesterol level. There are intense research efforts to develop biomarkers for the detection of neurodegenerative diseases before the onset of symptoms and to determine which therapies are working to correct those diseases. Each movement disorder can have different biomarker targets, which reflects the different causes of each disease. For example, biomarkers in Parkinson's disease and multiple systems atrophy might focus on proteins like α-synuclein, whereas progressive supranuclear palsy might focus on tau and Huntington's disease on the huntington protein. All of these diseases might benefit from biomarkers that look at brain structure by MRI.

There are currently no biomarkers that are approved to help track progression or make therapeutic decision in patients with neurodegenerative movement disorders. Many biomarkers are actively being developed by research labs throughout the world to address these questions. Researchers are looking at patient biological samples, like blood, cerebrospinal fluid, saliva and urine. Blood-based biomarkers might be useful in the outpatient clinic, where blood draws are already commonplace, and so could act as screening tools. Conversely, cerebrospinal fluid biomarkers might best be used in specialized centers and academic institutions where researchers want to follow what is happening in the brains of patients as the disease progresses and patients receive investigational therapies. The goal is to tailor the ease, accuracy and cost of the biomarker test with the question that biomarker seeks to address. So, patients with an uncertain diagnosis might first experience a blood-based biomarker in a general neurologist's office, while patients with more established diagnoses might experience cerebrospinal fluid-based biomarkers if they are enrolled in clinical trials.

Most neurodegenerative diseases occur because of problems with certain proteins in the brain or spinal cord. These proteins can be excellent targets for biomarkers. For example, in Alzheimer's disease, the proteins amyloid-β and tau can become tangled and clumped. Both proteins can be measured in cerebrospinal fluid from patients. Research suggests these tests might also be abnormal in Parkinson's disease even though they are more widely used in Alzheimer's disease. In Parkinson's disease, the protein α-synuclein is as important as amyloid-β and tau, and research is ongoing to develop both blood and cerebrospinal fluid biomarkers for α-synuclein. One hypothesis is that α-synuclein might become abnormal very early in the disease process, perhaps before symptoms start. On that basis, new clinical trials are examining medications that reduce toxic α-synuclein, and biomarkers are helping investigators know if the medications are working. In Huntington's disease, the huntington gene itself is the target for biomarker development, and there are interventions in the pipeline that directly address the gene expansion.

One major challenge with all biomarker development for diagnostic purposes is the degree of sensitivity and specificity of the test. "Sensitivity" refers to the ability of a biomarker to detect a disease state when the disease is present. A biomarker test with poor sensitivity might miss the diagnosis when the person is actually sick. This scenario is a false negative result. "Specificity" refers to the ability of a biomarker to detect the absence of a disease state when the disease is truly absent. A test with poor specificity might be positive when a person is actually healthy, causing a false positive result. All biomarker tests have different degrees of sensitivity and specificity. Clinicians and scientists work together to try to create diagnostic biomarkers with high sensitivity and specificity.

A good example of these issues is the dopamine transporter scan,

Broadly defined, the term "biomarker" refers to any measurable substance or characteristic that can indicate the state of an underlying disease process that otherwise is not directly observable.

which is an imaging biomarker sometimes used in research studies for Parkinson's disease. This scan can detect levels of dopamine transporters in a specific region of the brain using a special imaging tracer. Patients with Parkinson's disease usually have abnormally low levels of these transporters. This particular biomarker test has good sensitivity, meaning that if a person is already suspected to have Parkinson's disease on the basis of their history and examination, the scan will probably be abnormal. However, it is not as strong in its specificity—which means that even if the scan is abnormal, the person still might not have Parkinson's disease if the typical signs and symptoms are absent. These limitations are one of the reasons dopamine transporter scans are not a part of the clinical diagnostic criteria for Parkinson's disease.

In comparison, the specificity of the genetic biomarker for Huntington's disease is excellent. If a person carries a mutation in the DNA of the huntington gene, they can be diagnosed with the disease. The cell type where the mutation is detected does not matter, since a person's DNA is virtually the same in all cells of the body. So, in Huntington's disease, the focus has shifted from diagnostic biomarkers to creating biomarkers that can track response to interventions, such as medications designed to lower the expression of mutant huntington RNA (RNA is made in all cells from the information stored in DNA). A biomarker that is valid for expression of huntington RNA in blood cells would be minimally invasive and provide information as to whether or not the medication could be working in the brain.

The last few years has seen tremendous advances in biomarkers for many movement disorders, and there are no signs that this momentum is slowing down. There are several large-scale and multi-center efforts working on Parkinson's disease biomarkers, like the Parkinson's Progression Markers Initiative (PPMI) study sponsored by the Fox Foundation for Parkinson's Research, or the Parkinson's Disease Biomarkers Program (PDBP) Consortium administered by the National Institutes of Health. At Northwestern, we conduct the Parkinson's Disease and Movement Disorders Center Biorepository to help enable biomarker research both here and at our collaborating institutions. Many neurologists and movement disorders specialists are hopeful that biomarkers will improve clinical care by helping to make a diagnosis of Parkinson's disease and revealing more about how the disease is affecting the brain.

GENETIC TESTING FOR DISEASE: WHO, WHEN AND HOW?

by Niccolo Mencacci, MD, PhD

Is the cause of my Parkinson's disease in my genes? Can my genes inform me about what to expect from my disease? Are my children at risk of developing Parkinson's disease as well? Can my genetic makeup help me decide what is the best treatment for my disease?

These are only some of the questions that many patients may have when thinking about genetics and Parkinson's disease (PD). These are very exciting times for those interested in the genetics of Parkinson's. Thanks to the exponential increase in understanding of how genetics contribute to this condition, we have recently begun to have answers to some of these very important questions.

For much of the 20th century, Parkinson's disease was considered a neurodegenerative disorder with little or no genetic cause, in contrast to people with other rare movement disorders such as Huntington's disease or spinocerebellar ataxias. This knowledge has dramatically changed over the last 20 years. An increasing number of genes responsible for Parkinson's has been identified thanks to the recent, incredible advances in genetic technologies that we have available. Today, we estimate that roughly 5-10% of people with Parkinson's disease will have a true genetic cause for their disease. Importantly, while genetic forms of Parkinson's were initially thought to be prevalent only in people with young-onset of symptoms (i.e. below age 40) or with a positive family history (i.e. where multiple individuals in the same family have the same diagnosis), we now recognize that genetics actually play a role in a substantially larger number of individuals with Parkinson's disease. One example is the LRRK2 gene, which is commonly present in people of Ashkenazi Jewish and other Mediterranean descents. One other example is GBA, a gene which was previously known to be the most common cause of a rare childhood disorder called Gaucher's disease. More recently this has been discovered to be the most frequently occurring risk factor for Parkinson disease. Indeed, genetic changes in GBA can be found in up to 20% of all Parkinson's disease cases and are particularly frequent in people of Ashkenazi Jewish descent. >

Knowing the gene responsible for your condition bears some important consequences. For instance, we know that certain genetic forms of Parkinson's may have different progressions and risks for certain complications (for example, risk of cognitive decline or risk of developing levodopa-induced dyskinesias). Furthermore, we are learning that different genetic forms of Parkinson's may respond differently to deep-brain stimulation. Consequently, genetic testing may soon become part of the work-up for evaluating the best candidates for this procedure. Finally, and most excitingly, the first clinical trials for patients with specific genetic mutations (i.e. LRRK2 and GBA) are currently ongoing and some are still actively recruiting. Thus, knowing about genetics may soon have direct therapeutic implications, should these trials be successful!

One important issue is that currently, genetic testing for Parkinson's disease is often not affordable and is not covered by health insurance. Moreover, many genetic tests do not offer genetic counseling, which can help interpret test results. This is incredibly important, as genetic results may be very hard to interpret, even for people with expertise the field. For instance, not all genetic changes in a gene are pathogenic (i.e. contributing to disease) but many could merely represent random benign changes with no relevance whatsoever to Parkinson's disease. Furthermore, not all people with a specific mutation known to cause Parkinson's will go on to develop the condition. We refer to this phenomenon as "reduced penetrance," a concept that is very important to explain with clarity when returning a result and providing genetic counseling to patients and their families.

The Northwestern's Parkinson's disease and movement disorders center has launched a dedicated genetics clinic and a biorepository. In addition to providing extensive neurological assessment and genetic counseling before and after the testing, the clinic and the biorepository aim to obtain samples of genetic material from patients (i.e., blood, skin cells, and in some cases, spinal fluid) to better understand the mechanisms behind Parkinson's and other movement disorders. This information may be highly valuable, particularly when matched with clinical data as patients are followed over time. Some samples might be used to develop patient-derived stem cell models of Parkinson's that might provide insights into the disease's pathobiology.

Another important opportunity for genetics of Parkinson at Northwestern is the PD GENEration study (www.parkinson.org/PDGENEration), a clinical trial sponsored by the Parkinson's Foundation. This is a national initiative that offers genetic testing for clinically relevant Parkinson's-related genes and genetic counseling at no cost for those with a confirmed diagnosis of Parkinson's disease.

The Global Parkinson's Genetics Program, or GP2, (www.parkinsonsroadmap.org/gp2/) is another recently launched and very exciting global initiative, and Northwestern is an active member. This is a five-year program, supported by the Aligning Science Across Parkinson's Foundation (ASAP), to further understand the genetic architecture of Parkinson's disease. ASAP uses cutting-edge techniques to analyze data and samples from hundreds of thousands of people with Parkinson's across Africa, Asia, Europe and the American continents. The hope is that such a large and global effort will transform our understanding of the genetic basis of Parkinson's across diverse populations, including those currently under-served in research, thereby addressing a large gap in our knowledge of PD. Furthermore, GP2 will also study rare familial forms of PD with detailed gene discovery efforts toward identification of novel disease-causing genes and mutations. Patients in Chicago will be able to participate in this exciting study if recruited in the biorepository at Northwestern.

This is an exciting time for the genetics of Parkinson's. Genetic testing is helping us uncover biological pathways that cause Parkinson's and this understanding will lead to improved treatments and care for all people with Parkinson's. Understanding genetic differences across people with Parkinson's can help identify clues about how and why one person's experience with the disease differs from another's. Finally, the identification of the specific genetic mutations causing Parkinson's disease is the first step in the development of personalized treatments. Through our extended involvement in translational research programs and our established experience in clinical trials, precision medicine has finally become a reality at Northwestern Medicine.

THE JOURNEY OF
A Hero with Huntington's

by Carlos Briceño

I have a hero. **Her name is Jill.** She's my wife.

She's my hero because she's courageous. She has a giant fist aimed in her direction; it's slowly moving toward her. The fist's name is Huntington's disease. It's a rare neurodegenerative illness that has been described as the equivalent to Parkinson's, Alzheimer's and ALS, also known as Lou Gehrig's disease.

It runs in my wife's family. Her dad died from it, as have multiple family members on his side of the family. Upon completing predictive genetic testing, our 23-year-old daughter received a positive result as well.

A month after Jill was diagnosed with Huntington's, she said to me, "I accept it." I was confused for a moment. That's not a normal thing to say when you have a giant fist aimed at you, and you know it's going to be punching you one day – repeatedly.

So, I asked her, "What do you mean?" I thought I knew what she meant. That she actually accepted having such a rare disease. But I wanted to make sure.

She said, "I accept that I have this."

I looked at her and melted. Melted with love. Melted with appreciation for her courage in the face of such awful knowledge.

The original meaning of courage means "to tell the story of who you are with your whole heart."

Jill's story is that she knows what's in store with her. She took care of her father for years as his health declined from Huntington's. She wheeled him around in a wheelchair when he couldn't walk because of how much his body twitched, affecting his balance.

She mashed and made huge pots of sweet potatoes when he had trouble swallowing. She fed him via his G-tube when that was the only way he could eat. She put his clothes in the dryer over and over – even though the clothes were dry – because his illness made his brain believe that the clothes were still wet. So, she patiently did what he asked.

So, she knows what the giant fist does to a person's brain and body. It smashes each in ways that make the person a shell of themselves. Her dad never complained about having his illness, either.

I imagine that is where Jill's courage comes from. Her story is his story. Their story is told with their whole hearts. And their hearts shout the following: "Huntington's may decrease the effectiveness of how my muscles work; it may distort the way my mind thinks; but it doesn't take away my dignity. It doesn't rob me of my heart. It allows me to tell my story my way."

And Jill's way, like her father's way, is to say: "I accept you. But I will not give up, and you will never defeat me."

Now you know why Jill is my hero.

"Huntington's may decrease the effectiveness of how my muscles work; it may distort the way my mind thinks; but it doesn't take away my dignity. It doesn't rob me of my heart. It allows me to tell my story my way."

The Chicago Movement Coalition:

Closing the Gap and Improving Access in Parkinson's Disease

by Jennifer A. Adrissi, MD and Danielle Larson, MD

Parkinson's disease affects individuals from all races, backgrounds and socioeconomic status.

However, underserved minorities are more likely to have missed or delayed diagnoses compared to non-Hispanic Caucasians. When they are diagnosed, they are less likely to receive specialized care, medication or physical therapy for Parkinson's. Underserved minorities are also significantly underrepresented in clinical trials. As we expand therapeutic and support options for Parkinson's, we must ensure that all communities have access to these resources. Otherwise, we risk widening the divide.

The Chicago Movement Coalition (CMC) was established in 2019 with the goal of increasing Parkinson's disease education efforts and access to specialized care and research opportunities in underserved communities in Chicago. The CMC is an alliance between academic partners and community members. The CMC is led by community leaders, people with Parkinson's and their care partners, as well as movement disorders specialists. Together, we advocate for Parkinson's disease awareness and equitable care, using input from those who know the communities the best. With funding from the Michael J. Fox Foundation and the Parkinson's Foundation, we partner with community programs, religious centers and local organizations to plan culturally relevant educational workshops and distribute resources within the communities. Though initially focused on diverse communities in North and Southeast Chicago and partnering with Movement Disorders specialists from Northwestern and the University of Illinois at Chicago, the CMC is now expanding to include more Chicago communities and academic centers.

Through the CMC, we plan to form sustainable and trusting partnerships within multiple diverse Chicagoland communities, especially those that are underserved. With the joint voices of people with Parkinson's and their care partners, healthcare providers and local community leaders, we continue to learn from one another and pursue our common goal of improving Parkinson's disease awareness and increasing access to care and research opportunities for all Chicagoans.

The executive planning committee of the CMC is housed at Northwestern. The committee includes two Movement Disorders neurologists, Jennifer Adrissi, MD and Danielle Larson, MD; social worker, Emily Zivin MSW, LCSW; and clinical research manager, Karen Williams.

Learn more about the CMC and upcoming events by visiting our website, chicagomovementcoalition.com.

At Home Alone with Parkinson's

by Rebekah Younger

Getting a diagnosis of Parkinson's disease (PD) is devastating at any time. Living alone with numerous unknowns, like "how fast will I decline?" "what will I lose control of?" and "how will I be cared for when I can no longer do it myself?" is enough to make anyone depressed and anxious. Yet here I am, a person with PD, writing this article in the midst of a pandemic, with social and economic upheaval in the daily news—still feeling gratitude and a sense of well-being. I thought I would share my journey from diagnosis, especially the last few months, to show how I got here.

My diagnosis came shortly after my divorce at age 60. My plan was to rebuild my single life and my business near friends in the San Francisco Bay area, after 17 years of marriage in Maine. I drove across the country, full of hope and eager to see old friends. But those dreams floundered in the wake of the diagnosis. I had always been self-employed, so I was just setting up my new business when I received the bad news. Over the next two years, I had to face the reality that building one more business from scratch was more than I could handle.

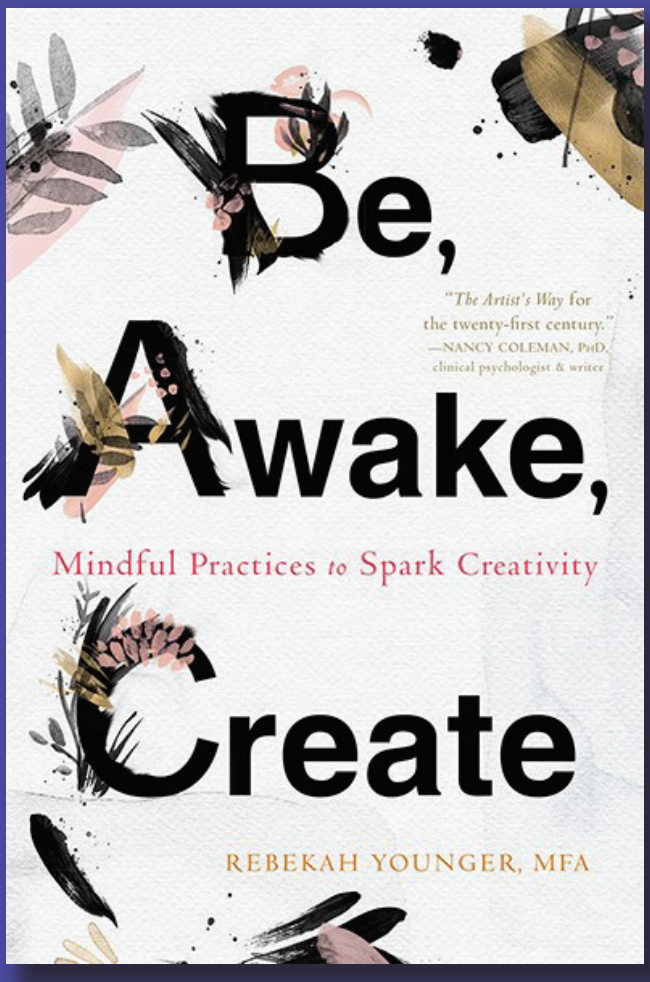
During that time, I was offered a book deal with a small advance, which, along with some part-time work, kept me afloat for a while. Working on the book was a labor of love and gave my life meaning, but not much cash. The cost of living in California was too high for me to be self-sufficient, and my divorce settlement funds were dwindling. I made the tough decision to leave my strong network of friends, especially the new ones I met in the PD community, and move back to Chicago. By returning to my old neighborhood, I would be near family, one close friend, the lake, good medical care and public transit. I found a lovely studio apartment that is within walking distance from my sister, where I live with my cat. But my community of support is small after all these transitions and decades away from Chicago.

When I was first researching Parkinson's disease after my diagnosis, it bothered me that very little was written for those who need help caring for themselves without a caregiver. At this stage of life, many people have spouses or children, or they can afford to pay someone to on whom they can depend. However, many of us are forced to work things out on our own. I appreciate my family's support, but getting connected to fellow PD patients and their caregivers is essential for me to make this new setting work.

In California, I found a wealth of peer support. There was an independent group that included many people with PD living alone or with caregivers, called PD Active, as well as sponsored programs, such as Dance for PD. These people quickly became my most treasured friends as I came to terms with the illness. Their open-hearted acceptance of me made those first years of fear tolerable. Not only was there shared understanding of the trauma of our experience, but also humor, creativity and companionship.

When I got to Chicago, I immediately sought out similar programs. I was grateful for Northwestern's support groups, Improv at Second City and Hubbard Street Dance. Most of the activities took place downtown or on the Northside, so I was thrilled when an exercise program for PD was started within walking distance of the Hyde Park JCC.

When I first moved back to Chicago,



a mutual friend introduced me to another woman with Parkinson's who lived nearby. Betty, a spritely, generous and intelligent person, reached out to me and soon we were sharing our stories over coffee. Betty, who had been diagnosed in 2012, was a retired nurse. Though she was further along in her illness and required canes to walk, she was still in private practice as a licensed clinical social worker. We began taking walks together and exchanging check-in calls. Betty and her husband, Joe, joined the exercise classes and the support group, where we talked about our fears, successes and coping skills. Between sessions, our friendship deepened with shared holiday meals and conversations.

After reading my book (which was finally published in 2019), Betty asked me to coach her on mindfulness and meditation to assist her in coping with the progression of her disease. My book, *Be, Awake, Create: Mindful Practices to Spark Creativity* is based on my study and use of art, meditation and Buddhist philosophy in my own healing journey over the last 30 years. Betty told me that she was inspired by my viewpoint and gentle approach, as she found herself being impatient and self-critical much of the time, which only added to her suffering.

What ensued was a rich dialogue for both of us about life, our histories, the blessings and the curses of this illness. We talked about setting limits with family, self-care when traveling, the joy of her first grandchild and how to stay present and be with pain and panic. Her self-deprecating refrain of, "poor me, poor me" was replaced by "this too shall pass" and "just do the next right thing." We carried each other through some dark times. Her humility, courage and self-awareness were a gift for me.

Often, I too needed to hear the words I would say to her. Most of all, we were gentle and attentive listeners to each other.

Due to COVID-19 spreading through Chicago coupled with my numerous health issues, I made the difficult decision to stop attending the exercise classes and support groups I had grown so fond of. Not only do I have Parkinson's, but my spleen was removed for staging Hodgkins' disease (a form of lymph cancer) when I was 30. The cancer radiation treatments later led to a damaged heart, requiring stents and single bypass surgery by age 50. Thankfully, I had Betty and Joe, who made sure to include me in the support group sessions by speakerphone. Betty and I also continued our one-on-one coaching sessions by phone as well. Her illness was getting more debilitating, with greater anxiety, fatigue, nausea and balance issues.

Approximately two months into the quarantine order, Betty fell, injuring both sides of her brain.

I got the phone call from Joe early the next morning that she had died. This was devastating, as the three of us had come to depend on each other so much over the last year. I am forever grateful for their love. Her sudden death leaves a big gap in my life, for she gave to me at least as much as I gave to her in counsel, wisdom and love. So, treasure your fellow travelers on the path of PD. We need that support, even from a distance, to keep our spirits up and to be reminded that we are facing challenges that others face too. Just to have the ear of someone who understands can be enough sometimes.

The end of May and June were rough. I was just subsisting in my isolation; feeling grief at the loss of my friend, along with an aunt who died of COVID. My cat had surgery and needed special attention. Some days were lost in scrolling on my phone, video games or reading, not even getting out of bed.

I spoke with the psychiatrist about upping my medication. I began counselling with the social worker in Neurology. My dose of Carbidopa/Levadopa was doubled, and eventually Amantadine was added.

Now it is the beginning of July and who knows where I will be by the time this is published. I am coming to terms with life alone and even finding some joy in it. I am beginning to accept that this isolation may not last months, but years. Without a cure or a vaccine for COVID-19, the risks outweigh the advantages of social contact.

So for now, my cat and I are staying close to home. I am grateful for family and for a neighbor who shops for me, though we don't hang out together anymore. I talk frequently with friends and family by phone. I lead online creating classes for readers who want to do the exercises in my book with others. Occasionally, I go for solitary walks, exercise regularly at home and meditate daily. The past few months have deepened my appreciation for some skills I have developed over the years. My current self-knowledge, compassion and equanimity are by-products of a regular meditation practice. I know how to be gentle and listen to myself and others, to recognize my limitations and ask for help. I still struggle with obsessive patterns and will give myself a break when life and PD feels too overwhelming.

I try not to look too far down the road. By staying in the moment, I can face down my fears. After all, we really don't know what comes next, ever. As my dear friend said, "this too shall pass" and all we can do is "the next right thing." In this way, each moment can be treasured as precious. It is an opportunity for me to wake up and be of benefit to others who suffer and want to be happy just like me. After more than 30 years of dealing with major illnesses, I am assertive in advocating for my health care. I am not afraid to ask for help, medically and psychologically, when needed. Finally, I am so grateful for the staff at Northwestern. They are some of the best I have encountered.

Rebekah Younger's book, *Be, Awake, Create: Mindful Practices to Spark Creativity* is available from New Harbinger Publications. If you are interested in her creating or meditation programs, you can contact her at contact@rebekahyounger.com. See her art and learn more about her book and coaching at **rebekahyounger.com**.

Movement Disorders Program at Shirley Ryan AbilityLab

SPECIALTY HIGHLIGHT – PHYSIATRY AND THE ROLE OF THE PHYSIATRIST IN PARKINSON'S DISEASE AND MOVEMENT DISORDERS

Article Contributors: Santiago Toledo, MD; Jennifer G. Goldman, MD, MS; Shari Marchbanks, PT, DPT, NCS

At Shirley Ryan AbilityLab, many of our physician team members are physical medicine and rehabilitation doctors, also known as "physiatrists." We are often asked, "what exactly does a physiatrist do and how can they help me in my Parkinson's and movement disorders care?"

Physical medicine and rehabilitation, or physiatry, is a relatively new field of medicine in the U.S. and worldwide, with its start in the 1920's. The fundamental goal of physiatry is to enhance *functional performance* and *quality of life*. Someone once said that "life is not merely to be alive, but to be well." To put it differently, "medicine adds years to people's life, and physiatry adds quality to those years." The philosophy of physiatry involves treating the whole person, as we do here at Shirley Ryan AbilityLab. A major goal is taking care of the whole person with individualized treatment programs to improve abilities, function, and quality of life.

Physiatrists play a role in the care of individuals who have neurological conditions, including Parkinson's disease and movement disorders, as well as those who have had strokes, brain injuries and spinal cord injuries. In addition, physiatrists help people who have musculoskeletal and orthopedic issues, sports injuries, cerebral palsy, amputations, pain, medical deconditioning and many other medically complex needs. Physiatry training involves a 3-year residency in Physical Medicine and Rehabilitation after a medical internship and medical school. Some physiatrists continue their education to complete specialty fellowships in brain injury, sports medicine—or now, a new fellowship program at Shirley Ryan AbilityLab (the first-of-its-kind in the U.S.) on Parkinson's disease and Movement Disorders Neurorehabilitation!

Physiatrists are crucial members of the care team for a person with a movement disorder and their care partner as they assess the patient as a whole person and focus

Physiatrists in the Parkinson's Disease and Movement Disorder Program at Shirley Ryan AbilityLab

Dr. Christina Marciniak

Dr. Benjamin Friedman

Dr. Santiago Toledo

Dr. Priya Mhatre

Dr. Marciniak retired in August 2020. The PDMD team at Shirley Ryan AbilityLab thanks Dr. Marciniak for all her dedication to patients, their families and the program.

on function. The job of a physiatrist is to determine and direct the treatments and care that are essential for patients to maintain health, prevent complications and optimize wellness. Physiatrists also work closely with other physicians—including primary care physicians, neurologists, orthopedic surgeons and many others to optimize patient care.

Our widespread, community-based model aims to improve access to comprehensive care for patients with Parkinson's and movement disorders.

Evidence for the importance of rehabilitative care in the management of movement disorders is growing. Physiatrists can help guide physicians and patients in the rehabilitation process and in making decisions about the most appropriate timing and settings for rehabilitation therapies (physical therapy, occupational therapy, and speech language pathology), identifying goals of care, and tracking progress to develop new goals from year to year. Currently, the American Academy of Neurology and other organizations recommend evaluations by physical therapy, occupational therapy and speech language pathology across the stages of Parkinson's.

However, many people with Parkinson's and other movement disorders do not see these rehabilitation specialties. Fullard and colleagues published a study in 2017 of Medicare beneficiaries with Parkinson's in the U.S. (almost 175,000 adults). They found that only about 14-15% of people received physical therapy, occupational therapy or speech over a 3-year period. That means that the majority of people with Parkinson's did not have their rehabilitation needs addressed! This also differs dramatically from the high frequency of rehabilitation care including physiatry for Parkinson's in some European countries and the United Kingdom. This is alarming—especially since we know that people with Parkinson's and movement disorders can benefit!

At Shirley Ryan AbilityLab, our team includes several physiatrists who specialize in Parkinson's disease and movement disorders rehabilitation. Our physiatrists can work directly with your neurologist or movement disorders specialist in your care as well as with the rehabilitation therapists. Physiatrists at the Shirley Ryan AbilityLab Parkinson's Disease and Movement Disorders program work in several different environments. They see patients for new evaluations and follow-up in our outpatient Parkinson's disease and movement disorders (PDMD) interdisciplinary care clinic, working alongside other team members: neurology, physical therapy, occupational therapy, speech language pathology, nurses, neuropsychology, social work and more. Physiatrists also provide patient care at our inpatient rehabilitation hospital, 5-day rehab programs in Chicagoland areas, 3 outpatient therapy centers and pain management center. Our widespread, community-based model aims to improve access to comprehensive care for patients with Parkinson's and movement disorders.

The interdisciplinary rehabilitation team model is broad, and at Shirley Ryan AbilityLab, it includes clinical care, research and education programs. Rehabilitation research brings together neuroscientists, bioengineers, computer scientists, biologists, exercise physiologists and more to the forefront of ground-breaking discoveries. We are all focused to help people with Parkinson's and movement disorders live their lives to their fullest abilities and potential and to make new discoveries to help our patients and families.

Let this brief text add to your knowledge of physiatry, a relatively new and important field of medicine. Together with our academic partner Northwestern University, we declare a vision for the person living with Parkinson's and movement disorders: to *achieve functional independence, optimize quality of life and reach new goals*. Our collaboration developed as a response to our patients' quest: your own goal to be better in moving, speaking, thinking and more. We are all here for you.

For more information about our physiatrists and the PDMD program at Shirley Ryan AbilityLab, please call 312-238-PDMD (7363).

Shirley Ryan Abilitylab®

Parkinson's Foundation

I·D·E·A·S for Mental Health in Parkinson's Disease

Interactive Demonstrations, Education, Activities, and Support for Mental Health in Parkinson's Disease

A VIRTUAL PATIENT & CARE PARTNER EDUCATION AND SUPPORT SERIES

This program, directed by Dr. Jennifer G. Goldman and supported by a Parkinson's Foundation 2020 Community Grant, will focus on ways for you to increase your knowledge about mental health issues in Parkinson's disease (PD) and to develop proactive strategies to enhance your mental well-being.

Join us as we explore several topics related to mental health and share tools, tips and resources in an interactive and engaging format.

NUTRITION • EXERCISE

MUSIC AND SPEECH THERAPY • MINDFULNESS

Sessions will include separate tracks for people with PD who are newly diagnosed and those who have had PD for longer durations – and for both tracks, care partners are welcome too!

ALL VIRTUAL SESSIONS • STARTING IN THE FALL 2020

Stay tuned for the dates/times and details of the schedule

> email smarchbank@sralab.org to receive further information <

Meet the Team

Rizwan Akhtar, MD, PhD

Rizwan Akhtar, MD, PhD recently joined Northwestern Medicine as a physician-scientist in the Movement Disorders Program. He was recruited to the Department of Neurology at Northwestern University from the University of Pennsylvania in June 2020. He graduated from the University of Alabama School of Medicine in 2007 before completing his neurology residency and movement disorders fellowship training at the University of Pennsylvania. He also completed a post-doctoral fellowship in neurodegeneration. His research interests are in biomarkers for Parkinson's disease and the atypical parkinsonisms, with a focus on the protein α-synuclein. Dr. Akhtar's vision is to provide comprehensive, patient-focused, and scientifically driven clinical care. Originally from the south, Dr. Akhtar is proud to call Chicago (and its winters!) home.

Danielle Larson, MD

Danielle Larson, MD is a Board-Certified Neurologist joining the Movement Disorder faculty after completing her Fellowship at Northwestern. After attending medical school at Tufts University in Boston, she completed her neurology residency at Northwestern. In her clinical practice, Dr. Larson sees patients with Parkinson's disease, Atypical Parkinsonism, Huntington's disease, Dystonia, Tic Disorders and other movement disorders. Her main areas of interest and research include exercise in Parkinson's disease and community outreach and education for Parkinson's disease. Dr. Larson will be a part of Northwestern's HDSA COE Huntington's Disease Clinic and will lead a study of telemedicine for Huntington's disease at Northwestern.

Jennifer A. Adrissi, MD

Originally from Prince George's County, Maryland, Jennifer Adrissi, MD initially moved to Chicago to attend Northwestern University Feinberg School of Medicine. She stayed at Northwestern to complete her neurology residency where she was also in the McGaw Global Health Scholars Program and completed a global neurology rotation at the University Teaching Hospital in Lusaka, Zambia. During residency, Dr. Adrissi found her passion for patient care in movement disorders and global neurology. She is excited to be starting a two-year clinical and research fellowship in movement disorders at Northwestern. Her research interests include identifying and creating interventions to address health disparities in Parkinson's disease.

Maggie Sullivan BSN, RN

Maggie Sullivan BSN, RN joined Northwestern's Movement Disorder team in March 2020. Maggie earned her Bachelor of Science in Nursing degree from Eastern Michigan University and Bachelor of Arts degree from Loyola University Chicago. She has worked with patients who have a variety of neurological disorders over the past 5 years. She is a member of the American Association for Neuroscience Nurses.

Meet the Team

Lotte Wimmel, BSN, RN

Charlotte Wimmel, MSN, RN received her Bachelor of Science in Nursing from the University of Iowa. After moving back to Chicago, she began working at Northwestern Medicine on the Neurology/Stroke inpatient unit. Her preceptor encouraged her not to wait—so after one month of being a nurse, she decided to apply to Rush University's Psych-Mental Health Nurse Practitioner Program. She is now happily a student in the program and will graduate in 2022. She is looking forward to being able to address the psychiatric needs of neurology patients. In the meantime, she enjoys learning from such a great team and great patients.

Erin Cecchi, MSW, LCSW

Erin Cecchi, MSW, LCSW is a licensed clinical social worker with more than seven years of experience in healthcare and has a deep passion for working with individuals with neurological conditions. She received her Bachelor's of Social Work from Michigan State University (Go Green!) in 2012 and received her Master's of Social Work from The University of Michigan the following year. She joined Northwestern in April 2020 as the Senior Program Coordinator for the Parkinson's Disease and Movement Disorders Center. In this role, Erin facilitates several support groups and coordinates the center's educational offerings. She previously worked at Rush University Medical Center for six years, where she gained experience in transitional care and ambulatory clinical care management, with a specialized focus on the neurology population since 2017. She is also a Senior Health Insurance Program (SHIP) counselor, where she provides options counseling to Medicare beneficiaries and their families.

Ashley Bozeman, LPN

Ashley Bozeman, LPN joined the Movement Disorder team at Northwestern Medicine in April 2020 as our LPN clinic coordinator. Ashley has a wide range of experience from working within different specialties in the outpatient clinic setting as a float nurse for Froedtert and the Medical College of Wisconsin for 4 years. Before joining the Movement Disorders team, Ashley also worked as an LPN within our neurology department on the Neuromuscular Disorder team. This is where her passion for caring for patients with neurological conditions really grew. She strives to make navigating the health care system easier for our patients and to smoothly coordinate their care.

Michael Reyes, BSN, RN

Michael Reyes, BSN, RN joined Northwestern's Movement Disorder Team in July 2020. Originally from Los Angeles, California, Michael earned his Bachelor of Science in Nursing at Loyola University Chicago in 2017. He has experience in both inpatient rehab and medical/surgical - neuro/spine. He brings a passion for working with the older adult population and looks forward to learning alongside an amazing team.

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

Parkinson's Disease Patient and Family Symposium

Saturday
October 10, 2020
10 a.m. – 12:30 p.m.

Cost is free, but registration is required.

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

This program is open to people with Parkinson's, their family, friends, care partners and the community.

Parkinson's Foundation Expert Briefing Webinars

Join us for our new season of educational webinars, designed for people living with Parkinson's disease (PD), as well as their care partners and health professionals. This season, Parkinson's Foundation webinars will highlight two critical themes of interest to our community: Young Onset Parkinson's disease (YOPD) taking place Fall 2020, and Symptoms Management taking place Winter/Spring 2021.

All webinars will be held on a Tuesday @ 1pm ET

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

Parkinson's Moving Day Chicago Virtual Walk

Saturday, October 24, 2020

Activities Begin at 10:30am

www.parkinson.org/GreaterIllinois

Visit the Northwestern's Team Page to join our team and donate:
www3.parkinson.org/goto/Northwestern2020

A recording from Soldier Field will air on the Greater Illinois Chapter's Facebook page on October 24 at 10:30 am, featuring Parkinson's stories and exercise demos.

*Please gather and **walk safely in your community** after the online event!*

CurePSP Caregiver Conference

Fri., November 13, 2020
11:00 AM – 2:30 PM EST

The CurePSP Virtual Caregiver Conference is a day of learning simple and effective techniques for self-care while living with stress. We will show you techniques to cope with burnout and become empowered and inspired to live a healthier and happier life.

The conference will allow caregivers to feel supported and know that they are not alone and there is hope for a brighter future while looking after a loved one with a neurodegenerative disease. Viewers will learn to shift the burnout and burdens so they may lead with momentum.

To register, please visit: curepspcaregiver.eventbrite.com

CurePSP Family Conference

Sat., November 14, 2020
10:30 AM – 3:00 PM EST

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

To register, please visit: curepspvirtualfamily.eventbrite.com

Monthly Support Groups

Call 312.926.8048 for More Information • Chicago – Northwestern Medicine (251 E. Huron, Chicago)

General Parkinson's Disease Support Group

Date: First Wednesday of the Month

Time: 2 pm to 3 pm

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 e-mail Erin Cecchi, LCSW at erin.cecchi@nm.org

Parkinson's Disease Care Partner Support Group

Date: Second Tuesday of the Month

Time: 2:30 pm to 3:30 pm

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 e-mail Erin Cecchi, LCSW at erin.cecchi@nm.org

Young Onset Parkinson's Disease Group

Date: Fourth Wednesday of the Month

Time: 6 pm to 7 pm

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 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 to 12:30 pm

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 e-mail Erin Cecchi, LCSW at erin.cecchi@nm.org

Chair Yoga for Parkinson's

Date: 2nd, 3rd, 4th and 5th Tuesday of the Month

Time: 2 pm to 3 pm

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 e-mail Erin Cecchi, LCSW at erin.cecchi@nm.org

Parkinson's Disease 101

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

Date: Varies

Time: Varies

Location: Virtual for 2020; classes rotate amongst NM Downtown, Central DuPage Hospital, and NM Lake Forest

Cost: Free

Contact: For more information about the December 2 class, please e-mail Erin Cecchi, LCSW at erin.cecchi@nm.org

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

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

Contact: Call the fitness center at 847.535.7060 for more information about class times, or visit lakeforesthfc.com/services/medical-fitness/parkinsons

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

Northwestern/Rush/Cellini Foundation Group

Date: Saturday, September 19, October 17, November 21 and December 19th

Time: 10 am to 12 pm

Cost: Free

Contact: Please contact Sam Lunde, Samantha_R_Lunde@rush.edu or Emily Zivin, emily.zivin@northwestern.edu

Geneva/Rockford/Bloomington Group

Date: 4th Sunday of every month

Time: 2:00 pm to 3:30 pm

Cost: Free

Contact: 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 Support Group

Date: 2nd Monday of every month

Time: 7 pm to 8:30 pm

Contact: Marilyn Kahn, Marilynkahn1@gmail.com

HD Caregiver Support Group

Date: October 21 and December 21

Time: 7 pm

Contact: Emily Zivin, ezivin@hdsa.org

Huntington's Disease Virtual Symposium 2020 - Recording Available!

For those who were unable to join the webinar, please view the talks by going online to: https://www.nm.org/conditions-and-care-areas/neurosciences/movement-disorders/patient-support-and-information/classes-and-events/classes-and-events-on-demand

Donor Spotlight: Jim and Susan Todd

by Reneeta C. Renganathan,
Philanthropy Manager (Contractor), Northwestern Memorial Foundation

A multi-year pledge was graciously given by Jim and Susan Todd to support Northwestern Medicine's Parkinson's research efforts and the Parkinson's Junior Investigator Awards Program. Two current Parkinson's Junior Investigators, Willayat Yousuf Wani, PhD, and Thorsten Kahnt, PhD, are engaged in studies aimed at unlocking some of the remaining mysteries of Parkinson's, with the ultimate goal of improving the scientific and medical communities' understanding, early-stage diagnosis and treatment of the disease.

Susan Todd explains, "I was diagnosed with PD at Northwestern in 2008, and from that point forward, I felt blessed to be cared for by the staff in Chicago. The professionalism of the doctors and other caregivers; their knowledge and experience; their commitment to patient care and support; their follow-up and commitment to finding a cure, all have caused my husband and me to support their research efforts with a multi-year pledge. With Dr. Tanya Simuni as division head and director of the Parkinson's Disease and Movement Disorders Center at Northwestern Medicine, we remain confident that a cure can be and will be found."

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: http://www.parkinsons.northwestern.edu/clinical_trials.html

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

Clinical Trial Investigator: Tanya Simuni, MD

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

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

Clinical Trial Investigator: Tanya Simuni, MD

Clinical Trial Description: The purpose of this study is to evaluate how offering certified genetic testing for PD genes to patients with Parkinson's impacts clinical care and potential enrollment in clinical trials. There will be an initial screening visit, followed by a genetic counseling session to discuss the results, plus online surveys.

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: **A Multi-center, Prospective, Longitudinal, Digital Assessment Study of Disease Progression in Subjects with Early, Untreated Parkinson Disease (PD) (WATCH-PD)**

Clinical Trial Investigator: Cynthia Poon, PhD

Clinical Trial Description: This study will be a longitudinal, multi-center study to evaluate disease progression in persons with early Parkinson disease. Standard clinical assessments will be performed alongside a series of assessments completed using digital tools that include wearable sensors and mobile devices. The primary focus will be on using wearable sensors to obtain objective data during the clinical motor exam performed periodically in a clinic setting.

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 Phase 2 Study In Early Parkinson's Disease Patients Evaluating The Safety And Efficacy Of Abl Tyrosine Kinase Inhibition Using K0706 (PROSEEK)**

Clinical Trial Investigator: Tanya Simuni, MD

Clinical Trial Description: The primary objective of this study is to determine if K0706 (daily oral powder sachets) reduces the rate of progression of early-stage Parkinson's disease (PD) versus placebo over 40 weeks, as defined by subjective clinical examinations.

Research Study Title: **A Randomized Controlled Study to Compare the Safety and Efficacy of IPX203 with Immediate-Release Carbidopa-Levodopa in PD with Motor Fluctuations**

Clinical Trial Investigator Name: Tanya Simuni, MD >

Clinical Trial Description: The primary objective is to compare the efficacy, safety and tolerability of IPX203 with IR CD-LD following multiple doses over 13 weeks. The study drug is an extended-release product that hopes to attain therapeutic levels rapidly and maintain constant effectiveness for a longer duration than currently approved products for PD with motor fluctuations.

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

Clinical Trial Investigator: Avram Fraint, MD

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

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: 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 16-week trial in participants with PD and sleep disruption.

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: 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 impact.

Research Study Title: A Phase III, Long-Term, Randomized, Double-blind, Placebo-controlled Trial of BHV-4157 in Adult Subjects with Spinocerebellar Ataxia

Clinical Trial Investigator: Puneet Opal, MD, PhD

Clinical Trial Description: The purpose of this study is to compare the efficacy of BHV-4157 (200mg once daily) versus placebo after 48 weeks of treatment in subjects with spinocerebellar ataxia (SCA).

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 Spring newsletter FAQ section—please email jessenia.erickson@nm.org.

Partnerships

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

WDA Wilson Disease Association

Credentialed Huntington Study Group Research Site

PSG Parkinson Study Group

Parkinson's Foundation Center of Excellence

Huntington's Disease Society of America Centers of Excellence

NAF National Ataxia Foundation