

On The Move >>>

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The Northwestern Medicine Parkinson's Disease & Movement Disorders Center

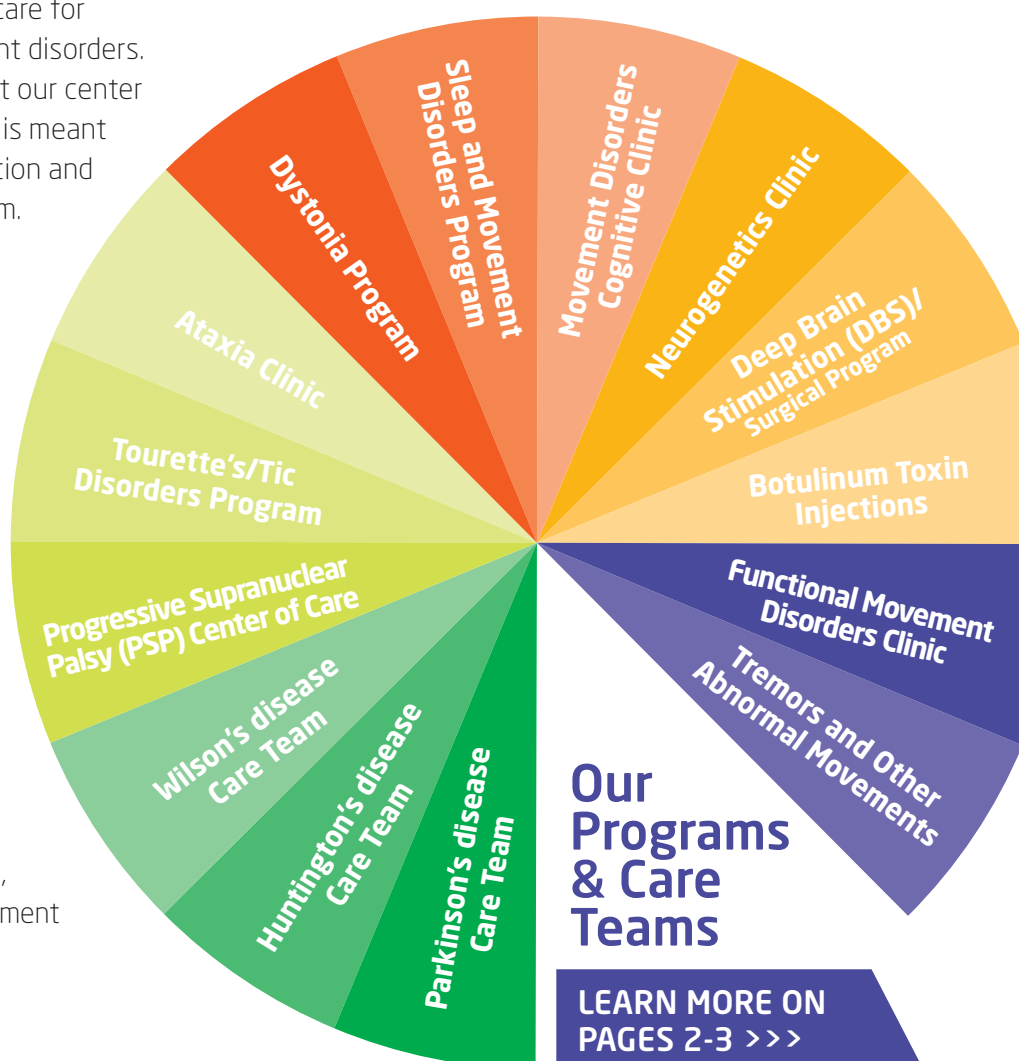
by Danny Bega, MD

Welcome to the new Northwestern Medicine Parkinson's Disease & Movement Disorders Center (PDMDC) newsletter, *On The Move*.

Our mission is to provide multidisciplinary care for patients and families affected by movement disorders. There is a lot of exciting work happening at our center in downtown Chicago, and this newsletter is meant to reflect the breadth of expertise, innovation and opportunities that are provided by our team. Each issue of this newsletter will tackle different aspects of clinical care, research and education related to Parkinson's disease and a variety of other movement disorders that are also managed by our group.

Our team is comprised of neurologists who are fellowship trained in movement disorders, and they work alongside the support of neuropsychiatrists, nurses, medical assistants, social workers, genetic counselors, research coordinators and more. At our downtown location, we have six movement disorders clinicians and ten basic scientists doing research in movement disorders. Our team is led by Dr. Tanya Simuni, Director of the Parkinson's disease and Movement

Disorders Center. We have important collaborations with colleagues at Lake Forest and Central DuPage, as well as the rehabilitation team at the Shirley Ryan AbilityLab. >



Our program is a designated **Center of Excellence for Parkinson's disease (Parkinson Foundation Center of Excellence), Huntington's disease (Huntington's Disease Society of America Center of Excellence), Wilson disease (Wilson Disease Association Center of Excellence) and Progressive Supranuclear Palsy (CurePSP Center of Care)**. Centers of Excellence are **top medical institutions** featuring comprehensive care teams that meet every patient need and provide access to clinical trials and experimental therapies. In addition to these programs, we have expert care in Ataxia, Tic Disorders, Dystonia, Essential Tremor and other movement disorders. A unique aspect of our programs is that clinicians work hand in hand with the researchers to develop a better understanding of the mechanisms of the diseases and novel therapies.

Parkinson's disease Care Team

Our Parkinson's disease care team, led by Dr. Tanya Simuni, includes highly experienced professionals in the fields of neurology, psychiatry, nursing, genetics and social work. They all work together to establish a treatment plan that addresses the full spectrum of physical, mental and emotional challenges. In addition, we are a Parkinson Study Group research site and have numerous trials involving patients at all different stages of disease, as well as scientists working on leading-edge projects that are receiving worldwide recognition.

Huntington's disease Care Team

Our Huntington's disease care team, led by Dr. Danny Bega, includes professionals in neurology, neuropsychiatry, genetic counseling, social work and rehabilitation medicine. Our goal is to help patients and families through the testing process and then manage symptoms and improve quality of life. We are also a Huntington Study Group research site and participate in important HD clinical trials.

Wilson's disease Care Team

Our Wilson's disease team, also led by Dr. Danny Bega, includes professionals in neurology, hepatology, ophthalmology and neuropsychiatry. Once again, we offer management of disease while also participating in trials for novel therapies.

Progressive Supranuclear Palsy (PSP) Center of Care

Our PSP Center of Care offers comprehensive management of atypical parkinsonian syndromes including progressive supranuclear palsy (PSP), multiple system atrophy (MSA) and corticobasal degeneration (CBD). Additionally, for patients with advanced disease, we offer the support of a specialized movement disorders palliative care program to improve quality of life.

Tourette's/Tic Disorders Program

Our Tourette's/Tic Disorders Program involves expert neurologists, psychiatrists, nurses and social workers working collaboratively with patients to plan the best care program to reduce tics. Northwestern Memorial Hospital is one of the few Chicago locations offering Comprehensive Behavioral Intervention for Tics (CBIT). CBIT is recommended as first line therapy for tic disorders by the Tourette's Association America.

Ataxia Clinic

Our Ataxia clinic, directed by Dr. Puneet Opal, involves a tailored approach for each patient to address the full spectrum of challenges, including problems with balance, gait, coordination and slurred speech. Patients are evaluated for both acquired and genetic causes through clinical examination and ancillary laboratory testing and imaging. The clinic is a member of the Clinical Research Consortium for the Study of Cerebellar Ataxias (CRC-SCA), a research consortium funded by the National Ataxia Foundation. Dr. Opal is himself a renowned ataxia researcher.

Dystonia Program

Our program has a strong relationship with the Dystonia Medical Research Foundation, and our experts are trained in the management of all forms of dystonia. We have expertise in botulinum toxin injections as well as deep brain stimulation (DBS) for dystonia. We have experts in genetics to help identify causes of genetic dystonias.

Sleep and Movement Disorders Program

Our Sleep and Movement Disorders program is led by Dr. Roneil Malkani. Dr. Malkani is trained in both movement disorders and sleep medicine and has a specialized

approach to handling the intersection of these problems, as many movement disorders are associated with sleep disturbances.

Movement Disorders Cognitive Clinic

Our Movement Disorders Cognitive Clinic is led by Dr. Jennifer Goldman. This unique clinic involves a neuropsychologist, and is dedicated to the assessment and management of psychiatric and cognitive concerns related to movement disorders including Parkinson's disease, Dementia with Lewy Bodies and others.

Neurogenetics Clinic

Our Neurogenetics clinic, led by our department chairman Dr. Dimitri Krainc, is one of the only neurogenetics clinics in the country serving both adults and children with movement disorders, and the only one in Illinois with a full-time genetic counselor on staff.

Deep Brain Stimulation (DBS) / Surgical Program

Our Deep Brain Stimulation/Surgical Program is led by Dr. Avram Frait and neurosurgeon Dr. Joshua Rosenow. DBS delivers high-frequency electrical stimulation to precise areas of the brain—which minimizes the brain signals that result in tremors, stiffness, slowness and extra movements caused by Parkinson's disease, essential tremor and dystonia. It can offer many benefits, including the ability to take less medication, and therefore experience fewer medication side effects. Northwestern Medicine performs more DBS surgeries than any other health system in Illinois.

Botulinum Toxin Injections

Botulinum Toxin injections are increasingly used to treat a variety of neurological conditions involving abnormal muscle movement. Our neurologists are experts at botulinum toxin injections for a variety of conditions, including dystonia, spasticity, drooling, facial spasms and chronic migraines.

Functional Movement Disorders Clinic

One of our newest programs will be launching in the Fall with the newest member of our team: Kathrin LaFaver, MD, FAAN. In addition to seeing patients with all different movement disorders, Dr. LaFaver, in collaboration with the team at Shirley Ryan Ability Lab, will be starting a Functional Movement Disorders clinic dealing with the management of bothersome neurological symptoms that have their origin in disrupted connections between the mind and the body. The clinic will be multidisciplinary and include assessments by a psychologist and a physical, occupational and speech therapist for treatment planning.

Tremors and Other Abnormal Movements

Tremors and other abnormal movements are also approached with the same level of care and expertise.

Our goal is to help our patients manage their disease and improve their quality of life by working to reduce symptoms, prevent complications and provide support and assistance to patients and their families. We put on numerous educational events and support caregivers, family members, healthcare providers and the community. We strive to provide care for diverse populations. We also conduct pre-clinical and clinical research in order to extend the knowledge and treatment of movement disorders, and to offer leading-edge pharmacological, surgical and clinical trials for patients with movement disorders. A unique aspect of our program is that all of our physicians are involved in research aimed to better understand the mechanisms of the diseases and develop novel therapeutics.

We hope that through this newsletter, you will not only learn about the clinical programs we have to offer—but also how to take advantage of many educational opportunities, support groups, exercise classes, research opportunities and other events tailored to your conditions and needs.

Please enjoy the newsletter!

Partnerships

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



Information Overload!

How to Avoid Making PD Your New Career

by Susan Krueger

You have Parkinson's Disease.

Whether it's a new diagnosis or you've had it many years, you want to know as much about it as possible. You do your best to understand the many facets of the disease itself. You keep up with the latest medication innovations. You peruse complementary therapies and read about how others have had success with them, or not. You try to establish a foundation of knowledge in order to make informed decisions regarding your care and your life with PD. This is a job!

It's good to be informed, but bad to be swept away with an avalanche of articles, links and email. Your time is valuable. Use it wisely. How much is too much? Here are some simple suggestions that may help.

- Register with 3-4 reputable sources to provide you with reliable information. Receive their emails, reference their manuals, participate in their studies. This will be enough to keep you up with the latest, while extracting a manageable amount of your discretionary time.
- Be selective when reading blogs, especially the comments on blogs. Something about responding on public forums releases the inhibitions and common sense of otherwise normal folks. Form your own opinions by reading the post if it interests you, then skip the comments.
- Discern which sources stay positive while considering the gravity of the disease. You'll want to align with organizations who provide all the facts without spin.
- Sometimes Google is not your friend. Develop your online skills to find information from trusted sources, then stop! If you keep digging you will find questionable, negative, scary places. Don't go there.
- You could spend your day at the computer reading articles. Not unlike a kid with a video game, you need to limit yourself. Engage with real life. Leave the chair and get moving!
- Be careful what you Like on social media. You'll start to receive some shady advertisements. A lot of these will sound like your saving grace—when in truth, they are slick advertisements for unproven treatments. Ask your doctor before pursuing anything that sounds too good to be true.
- Beware of anything that wraps PD up neatly in a one-size-fits-all box. Remember that the disease presents itself differently in every single person. Everyone has a different mix of symptoms, to varying degrees. There are some symptoms you will never have. Some will go away and return, and some may never return. Never compare yourself to others.
- Support programs that are supporting you! If you are participating and benefitting from a great support group, exercise program or educational resource, support it. Monetary donations are always gratefully accepted, but treasure is just one way. Time and talent are others.

Participate in the studies, provide needed feedback, share what you know and help others. You'll feel better from the inside out.



New Program

Movement Disorders Cognitive Behavioral Clinic

The Northwestern University Parkinson Disease and Movement Disorders Center is excited to announce the Movement Disorders Cognitive Behavioral Clinic.

This new, specialty program is established and directed by Jennifer G. Goldman, MD, MS, and offers a comprehensive and patient-centered approach to movement disorders patients with cognitive, behavioral and emotional issues, or concerns about these features.

Over the years, we have learned that many movement disorders such as Parkinson's disease, Lewy body dementia, atypical parkinsonian disorders and others can affect much more than movement. Non-motor symptoms can occur across different stages of disease and can affect thinking and memory (cognition), behavior (apathy, impulse control disorders, psychosis) and mood (depression, anxiety). These symptoms may be referred to as neuropsychiatric features.

Not everyone with a movement disorder experiences cognitive, behavioral or emotional symptoms—and even if they do, people may not experience them in the same way. However, we do know that it is important to assess these features in our visits and attend to them, if present. Many symptoms are treatable with medications and non-pharmacological approaches, and others await improved therapies with ongoing research.

Being proactive about one's brain health and wellness is an essential part of one's care—not only for motor, but also neuropsychiatric symptoms. Since cognitive, behavioral and emotional challenges can impact not only the person with a movement disorder but also relationships with family and care partners, our clinic's holistic approach aims to help treat and empower the person with Parkinson's or other movement disorder, as well as provide psychosocial support to their care partners in this process. >

Meet Our Team

Jennifer G. Goldman, MD, MS

Movement Disorders Neurologist, Professor of Physical Medicine and Rehabilitation and Neurology at Northwestern University, Section Chief, Parkinson's Disease and Movement Disorders program at Shirley Ryan AbilityLab



Dr. Goldman is an internationally recognized clinician, researcher and educator on cognitive, behavioral and emotional aspects of Parkinson's and movement disorders, as well as interdisciplinary care for patients and families. She has been practicing for almost 20 years and joined the group in December 2018.

Erica Sieg, PsyD

Neuropsychologist, Assistant Professor of Psychiatry and Behavioral Sciences at Northwestern University



Dr. Sieg completed her postdoctoral fellowship in Neuropsychology at Northwestern University and specializes in cognitive and psychiatric aspects of movement disorders and neurological conditions.

Cathy O'Connell, RN, BSN

Movement Disorders Nurse



Cathy earned her Bachelor of Nursing degree at Loyola University in Chicago. She has worked in Adult Day Care and Internal Medicine and as a Neurology nurse at Northwestern Medicine for the past 13 years, and has been a Movement Disorders nurse for the past 3 years. Her favorite part of this job is interacting with patients and their families.

Eligible patients include those with Parkinson's Disease, Lewy body dementias, atypical parkinsonian syndromes (progressive supranuclear palsy, multiple system atrophy, corticobasal degeneration) and others. The clinic's team-based approach includes evaluations and individualized recommendations by the movement disorder neurologist, neuropsychologist, nurse and social worker. Colleagues in psychiatry, rehabilitation medicine and palliative care are available for consultation and referrals as well.

Evaluations and team discussion will be performed in a same-day visit at our Northwestern University Movement Disorder clinic location, thereby enabling comprehensive, collaborative and convenient care. We provide diagnostic consultations for new patients (one-time referrals, second opinions or continued management) and ongoing clinical management for return patients. Patients who are already part of our Northwestern clinic may be eligible for this program after discussion with their neurologist.



IMPROVing Communication

An Improvisation Theater Based Program for Addressing Communication Difficulties in Parkinson's Disease

The *IMPROVing Communication in Parkinson's Disease* program is a novel 8-week program addressing communication skills, communication confidence and communication participation through improvisation theater techniques.

"I had a lot of fun and the course made me aware of my need to slow down and speak louder."

As human beings, we weave our lives together through communication. It is the foundation on which we build interactions with our family, friends, co-workers and society at large. As a support group leader, I often hear that people with Parkinson's experience their world become smaller. They interact less, participate less and become more isolated. This class hopes to counter that reality. As one of the care partners relates, "improving communication in a social setting was great."

For the past three years, I have had the good fortune to participate in the improv classes at Second City with our patients. This experience has taught me skills related to listening, building on a conversation and seeing communication as an exchange of gifts. Specifically, using the tenant of "yes, and" from Second City, we can create a space in which mistakes are accepted and

even welcomed. The most important aspect is to participate.

"You can play with who you are and don't have to be perfect. You're not beat down for not being right. There's no criticism."

Speech therapy is an invaluable intervention for people with Parkinson's. It specifically teaches speech, voice and communication strategies to address communication difficulties in PD. It focuses on building an individual's confidence and enhancing their participation in conversations. As the PDMDC clinical social worker, I have heard multiple presentations from speech therapists that emphasize both verbal and non-verbal strategies to facilitate successful communication.

From these two worlds, I wanted to develop a program that would integrate both of these approaches into a single intervention. Thus, an 8-week program to improve communication was born. In improvisation theater, actors generate spontaneous content that is unplanned and unscripted. Improvisation acting shares goals with, has a similar structure as, and has similar demands to everyday conversation activities. Improvisation theater training programs use a number of exercises to improve the spontaneity, dynamic content building, and on-line

problem-solving skills required of improvisation actors.

"Great environment with people from different places, great connections in class."

The exercises in *IMPROVing Communication in PD* present unique opportunities for people with PD to learn and practice communication strategies within dynamic and spontaneous events where the language content, speaker intent and conversation partners are constantly changing. This contrasts with the fixed practice materials (e.g., reading sentences, scripted exchanges) used in some traditional PD speech-language pathology programs. One of the Parkinson's patients shared this perspective: "The sessions combined improv with communication techniques. The five points were very helpful (slow down, pause, eye contact, speak louder, etc.)"

Essentially, communication serves to **inform**, to **express** feelings and to **meet** social expectations. *IMPROVing Communication* strives to fulfill those to its fullest potential for people with Parkinson's and their care partners.

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Research, Diversity and Advocacy

by **Claudia Revilla**

My life, actions and beliefs have changed since I became a Parkinson's disease patient.

It wasn't a disease like cancer, when doctors tell you to fight it and lay out an array of options and opportunities to participate in research. They tell you to fight because your life depends on it.

With a Parkinson's diagnosis, many patients are not aware that they too can fight, that there is more than a prescription on one hand and a pamphlet on the other. That they can change not only their future, but also the future of the other patients with PD.

Yes, there are ways to fight! Activities such as advocacy and awareness, along with information about opportunities to participate in research, should become part of the standard treatment for Parkinson's—just like a carbidopa-levodopa prescription.

I understand why some PD patients slowly lose the joy for life. We all need a goal, a reward. And that would be living the rest of your life the way it is meant to be: without PD.

The journey is as important as the final destination. Advocacy and research are part of the journey. Ask your care team about how to participate. This will keep you active, alert and informed—and you will be



Claudia Revilla

empowered to make better decisions about your health. You will be helping other patients too, no matter what race or color, man or woman, young or old.

Parkinson's is not just a white people's disease, or a disease for older men. I am a Hispanic woman diagnosed in my early 40's. Advocacy and research need representation and participation from every ethnic group in order to reach our goal. Ask your doctor how you can become an agent of change.

While we are looking for a cure, yes, the road is long and challenging—but we must use our energy in a positive way. By not giving up, staying active both physically and mentally, and by participating in advocacy and research, we will be able to live a better life until we reach our destination. Our lives will be more meaningful if we try to make a difference not just for us, but also for future generations.



"I won't let Parkinson's define me, and exercise is the key."

- **Bill Bucklew**



Words of Wisdom

FROM OUR PATIENTS



"Our lives go by so fast in our modern world, and then medical conditions inevitably occur to slow you down. Most of us are not ready. However, Parkinson's is unique because it can quickly accelerate these life-threatening issues. I learned to immediately fight back both physically and mentally. For me, this includes expanding the daily rigorous exercise routine I had established years before to lose 100 pounds.

"Also, I challenge my mind with 'bucket list' activities, such as running my blue water boat and writing a book. Although I think about my health daily, I have little time to become depressed. Pushing myself to actualize our bucket list has been a key element for me. I like people around me focused on what we are accomplishing, while keeping my Parkinson's as a footnote."

- **Warren Johnson**

New Team Members

Kathrin LaFaver, MD joins us as an Associate Professor of Neurology in the division of Movement Disorders. Dr. LaFaver completed a neurology residency at Mayo Clinic in Rochester, MN, and movement disorder fellowships at Beth Israel Deaconess Medical Center in Boston, MA, and the National Institutes of Health in Bethesda, MD.

Dr. LaFaver joins us from the University of Louisville, where she was the Director of the Parkinson's and Movement Disorders Clinic. In Louisville, she established a multi-disciplinary Functional Movement Disorder (FMD) clinic and an inpatient motor retraining (MoRe) rehabilitation program at Frazier Rehab Institute in Louisville, KY,



which has gained a national reputation. Her clinical research is focused on optimizing quality of life in patients with Parkinson's disease and the pathophysiology and treatment of functional movement disorders. Dr. LaFaver plans to establish a similar FMD clinic here in Chicago in collaboration with Shirley Ryan AbilityLab.

Neil Shetty, MD completed his medical internship and neurology residency at McGaw Medical Center of Northwestern University. After finishing residency in 2019, he began a two-year movement disorders fellowship at Northwestern



University's Parkinson's Disease and Movement Disorders Center, funded by a prestigious Safra Foundation grant from the Michael J. Fox Foundation.

Dr. Shetty has a special interest in deep brain stimulation and atypical parkinsonian syndromes. He is also a member of the McGaw Medical Education Clinical Scholars program.

Tips & Strategies for Cognitive / Behavioral Challenges in Huntington's Disease

by Danny Bega, MD

Huntington's disease (HD)

is characterized by the triad of motor, cognitive and behavioral disturbances. The cognitive disorder becomes more pronounced as the disease becomes more advanced, and it is characterized by slower processing and difficulty organizing information, trouble with learning and memory, trouble recognizing emotions, impulsivity, and impaired insight. Changes in behavior often go along with these cognitive changes, and the root of many of the behavioral problems is frustration.

The following are a few tips that caregivers, family members and friends may consider using to help reduce some of the burden of these symptoms:

1 Patience & Understanding: Some people with HD need extra time. They may be capable of performing a certain task, but pressure makes it more challenging. Allow extra time for tasks to be completed whenever possible. This goes for conversation as well—allow additional time for responses to questions. For those with more impairment, it is useful to use short sentences that convey no more than one or two pieces of information, and offer yes/no choices whenever possible. It is also important to remember that even if a person with HD is not speaking, they may understand what is being said. Finally, don't demand insight into every problem. Instead, focus on achieving behavioral goals rather than pushing a person with HD to see things the same way as you.

2 Optimizing the Environment: Multi-tasking poses an added challenge for people with cognitive impairment. Reducing distractions as

much as possible when interacting with someone with cognitive problems can help set them up for success. Also, reduce physical obstacles in the house by keeping pathways clear and pad furniture wherever possible.

3 Schedules & Routines: Prevent irritability, confusion and fear by introducing predictable daily schedules. Keep a structured environment that minimizes surprises. Routines make it easier for the person with HD to initiate tasks without guidance and lead to less frustration. Finally, when decision-making leads to conflict, offer limited choices rather than forcing decisions or allowing open-ended options.

4 Outbursts: Some people with HD have sudden outbursts or a "short fuse" that can be hard for them to control. Try not to react emotionally in response to the outburst. Although hurtful or embarrassing things may be said, try to remain calm knowing that in general, the person with HD is not doing this intentionally. Attempt to anticipate and avoid triggers that lead to frustration and outbursts. If someone is having an outburst, try to avoid confrontation and try to redirect them away from the source of anger. Acknowledge the irritability as a symptom of frustration. Try not to take cruel words personally, and leave the area if there is a threat of violence or concern for your own safety.

Several studies have shown that cognitive impairments are a significant source of impaired function in HD and can create a greater burden than the motor disorder does for patients and families. It is important to alert a physician to changes in cognitive processes, but family members can adopt strategies that help the person with HD optimize their functioning.



Motor and Non-Motor Fluctuations in Parkinson's Disease

by Danielle Larson, MD

What are "Fluctuations"?

A significant challenge for patients with Parkinson's disease (PD) is fluctuation in their motor and non-motor symptoms through the course of the day. These fluctuations occur as the disease progresses and as higher doses of Levodopa are needed to manage PD. The main kinds of fluctuations are "wearing-off," "early morning off-periods" and "off-episodes."

"Wearing-off" occurs between doses of Levodopa, when motor symptoms (i.e. tremor, walking impairment), or non-motor symptoms (i.e. anxiety, restlessness) return before the next dose is due. Wearing-off typically improves with the next dose of medication. At 3-5 years into the disease, 55-65% of PD patients experience wearing-off, and nearly 80% experience it after 10 years.

Another frequent fluctuation is "early morning off-periods," when PD symptoms return in the morning before taking the first Levodopa dose for the day.

The third type of fluctuation, "off-episodes," are periods when PD symptoms suddenly return. PD patients fluctuate from "off-episodes" to feeling "on," which is when medications are working and PD symptoms are controlled. "On" states can include extra unwanted movements, termed "dyskinesias," which can be troublesome (get in the way of tasks) or non-troublesome. How often and how severe fluctuations are varies

from day-to-day, and can depend on sleep, diet, specific activity or particular mood. In general, fluctuations are caused by complex brain changes in how dopamine is stored, processed and used in PD.

How do we recognize "Fluctuations"?

The best way to tell if someone with PD has fluctuations is with a detailed report of his or her hour-by-hour symptoms. Using Dr. Hauser's "PD Diary," PD patients can record how they are feeling throughout the day. In 30-minute time periods, a PD patient marks which of five states they are feeling: asleep, "OFF," "ON," "ON without dyskinesias," "ON with non-troublesome dyskinesias," and "ON with troublesome dyskinesias." This detailed diary tells the patient's doctor if they have fluctuations and how severe they are.

How can we manage "Fluctuations"?

There are multiple tools that can be used to manage fluctuations:

Levodopa Adjustment

To decrease "wearing-off" time, Levodopa doses in the form of Sinemet ("immediate release Levodopa") can be given more frequently throughout the day. As PD progresses, each dose of Sinemet lasts a shorter period of time. In this case, the longer-acting form of Levodopa, Rytary, can be used. Rytary capsules contain both immediate and extended-release Levodopa for a

longer benefit and reduction of total daily "off time" by up to 2 hours. To resolve "early morning off-periods," controlled-release Levodopa (Sinemet CR) can be given at bedtime, as the longer-acting formula lasts into the morning to prevent PD symptoms.

Adjuvant Therapy for Wearing-off

Multiple medications can be added to Levodopa in order to reduce fluctuations. Long-acting Dopamine Agonists can be added to reduce "wearing-off" time. Medications that prevent the breakdown of dopamine can extend the effect of each Levodopa dose. These medications include Monoamine Oxidase B (MAO-B) inhibitors and Catechol-O-methyl-transferase (COMT) inhibitors.

Adjuvant Therapy for Off Episodes: "Rescue Therapies"

There are several medications that can be used to quickly end an "off episode." Apomorphine injections (brand name Apokyn) can be used to treat the sudden return of PD symptoms, such as freezing of movements. Injections improve PD symptoms within 10-20 minutes. A new alternative to injections is an inhaled form of Levodopa (brand name Inbrija), which is delivered by inhaler with symptom improvement after 20-30 minutes and lasting up to 60 minutes.

Advanced Therapies

When medication adjustments no longer improve symptom fluctuations, patients should see specialized

Movement Disorder neurologists to discuss the potential use of advanced therapies. Currently, there are two main advanced therapies that can help with fluctuations in advanced PD patients: Levodopa Intestinal Gel (Duopa) and Deep Brain Stimulation. Duopa, FDA approved in 2015, is a continuous infusion of Levodopa through a G-tube in the stomach, which delivers Levodopa more evenly throughout the day. Duopa can reduce "off time" by up to 2 hours. Alternatively, Deep Brain Stimulation improves symptom fluctuation by delivering continuous electrical stimulation and reducing the total amount of PD medications needed.

Therapies In Development

There are several research studies underway to test new modes of delivering dopamine replacement in order to treat "off times." An apomorphine film, which can be placed under the tongue for fast absorption, is currently in clinical trials. Additionally, two new Levodopa formulas in clinical trials are under-the-skin infusions and longer-lasting pill dosing in an "Accordion Pill."TM

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PARKINSON'S DISEASE DIARY

NAME _____

DATE _____

Instructions: For each half-hour time period place one check mark to indicate your predominant status during most of that period.

ON = Time when medication is providing benefit with regard to mobility, slowness, and stiffness.

OFF = Time when medication has worn off and is no longer providing benefit with regard to mobility, slowness, and stiffness.

Dyskinesia = Involuntary twisting, turning movements. These movements are an effect of medication and occur during **ON** time.

Non-troublesome dyskinesia does not interfere with function or cause meaningful discomfort. **Troublesome dyskinesia** interferes with function or causes meaningful discomfort.

Tremor is shaking back and forth and is not considered dyskinesia.

time	asleep	OFF	ON without dyskinesia	ON with <u>non</u> -troublesome dyskinesia	ON with troublesome dyskinesia
6:00 AM					
:30					
7:00 AM					
:30					
8:00 AM					
:30					
9:00 AM					
:30					
10:00 AM					
:30					
11:00 AM					
:30					
12:00 PM					
:30					
1:00 PM					
:30					
2:00 PM					
:30					
3:00 PM					
:30					
4:00 PM					
:30					
5:00 PM					
:30					

time	asleep	OFF	ON without dyskinesia	ON with <u>non</u> -troublesome dyskinesia	ON with troublesome dyskinesia
6:00 PM					
:30					
7:00 PM					
:30					
8:00 PM					
:30					
9:00 PM					
:30					
10:00 PM					
:30					
11:00 PM					
:30					
12:00 AM					
:30					
1:00 AM					
:30					
2:00 AM					
:30					
3:00 AM					
:30					
4:00 AM					
:30					
5:00 AM					
:30					

Research Participation Opportunities at Northwestern Medicine

For more information call (312) 503-0755 or email: pdclinicaltrials@northwestern.edu

For more information about Parkinson's disease research at Northwestern, visit our website at: http://www.parkinsons.northwestern.edu/clinical_trials.htm

Research Study Title: Phase 2 Study in Early Parkinson's Disease Patients Evaluating The Safety And Efficacy Of Abl Tyrosine Kinase Inhibition Using K0706 (SPARC)

ClinicalTrials.gov Identifier: NCT03655236

Funded by: Sun Pharma Advanced Research Company Limited

Clinical Trial Investigator: Tanya Simuni, MD

Clinical Trial Description: This is a randomized, multicenter, double-blind, placebo-controlled, parallel-group study, to evaluate the efficacy, safety and tolerability of two doses of K0706 compared to placebo in subjects with early PD who are not receiving dopaminergic therapy. The investigational drug is being studied to see if it may potentially help to slow or reduce disease progression.

Research Study Title: Multi-center, Prospective, Longitudinal, Digital Assessment Study of Disease Progression in Subjects with Early, Untreated Parkinson's Disease (PD)(WATCH-PD)

ClinicalTrials.gov Identifier: NCT03681015

Funded by: University of Rochester/Biogen

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. This study will be used to better understand the relationship between standard clinical assessments and novel digital markers of disease progression in an early, untreated Parkinson's population, as well as understanding operational issues and limitations around the use of these devices in multisite progression studies or clinical trials.

Research Study Title: A Randomized Controlled Study to Compare the Safety and Efficacy of IPX203 with Immediate-Release Carbidopa-Levodopa in Parkinson's Disease Patients with Motor Fluctuations

ClinicalTrials.gov Identifier: NCT03670953

Funded by: Impax Laboratories, LLC

Clinical Trial Investigator: Tanya Simuni, MD

Clinical Trial Description: This is a multicenter, randomized, double-blind, double-dummy, active-controlled, parallel-group study. The purpose of this study is to evaluate the safety and efficacy of IPX203 (carbidopa and levodopa) extended-release capsules (IPX203 ER CD-LD) in comparison to immediate release (IR) CD-LD in the treatment of CD-LD-experienced subjects with Parkinson's disease (PD) who have motor fluctuations. The study will consist of a 3-week, IR CD-LD dose adjustment period; a 4-week, open-label period for conversion to study drug IPX203; followed by a 13-week double-blind treatment period with subjects randomized to receive either IPX203 or IR CD-LD.

Research Study Title: Multicenter, randomized, double-blind, placebo controlled study to assess the efficacy, safety, pharmacokinetics, and pharmacodynamics of GZ/SAR402671 in patients with early-stage Parkinson's disease carrying a GBA mutation or other pre-specified variant.

ClinicalTrials.gov Identifier: NCT02906020 >

Funded by: Sanofi, US

Clinical Trial Investigator: Tanya Simuni, MD

Clinical Trial Description: The purpose of this study is to evaluate the possible risks and effectiveness of the study drug called GZ/SAR402671 in PD patients carrying the GBA gene mutation. The study will provide an evaluation of the study-drug for the treatment of GBA-PD as well as enable a better understanding of the role of GBA as a risk factor in the development and progression of PD. The effects of the study drug will be compared to placebo, an inactive substance made to look like an active medicine. Participants will either get the study drug or placebo.

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

ClinicalTrials.gov Identifier: NCT03562494

Funded by: Voyager Therapeutics

Clinical Trial Investigator: Avram Frait, MD

Clinical Trial Description: The purpose of this study is to assess 1) the delivery and resulting enzyme activity of VY-AADC02 gene therapy delivered bilaterally to an area of the brain called the putamen, using convection enhanced delivery (CED) with MRI guidance and 2) the efficacy and safety of a single dose of VY-AADC02. Participants will be randomized to VY-AADC02 or placebo (sham) surgery.

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: FoxBioNet: LRRK2-002: Detection of LRRK2 Activity in Human Biospecimens

ClinicalTrials.gov Identifier: NCT03545425

Funded by: Michael J. Fox Foundation for Parkinson's Research

Clinical Trial Investigator: Tanya Simuni, MD

Clinical Trial Description: The overall objective of this study is to determine whether LRRK2 gene levels and LRRK2 gene kinase activity differs between LRRK2 PD, idiopathic PD, non-manifesting LRRK2 mutation carriers and healthy controls.

Research Study Title: Biomarkers Discovery in Parkinsonism

Clinical Trial Investigator: Daniel Corcos, PhD

Clinical Trial Description: The purpose of this study is to investigate how the brain and motor behavior change in movement disorders and healthy individuals over time. Structural MRI, functional MRI, blood draws, and behavioral motor and cognitive assessments will be taken in people with Parkinson's Disease (PD), progressive supranuclear palsy (PSP), multiple system atrophy (MSA), and healthy controls.

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

ClinicalTrials.gov Identifier: NCT03667404

Funded by: Northwestern University

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: Clinical Trial Readiness for SCA1 and SCA3

ClinicalTrials.gov Identifier: NCT03487367

Funded by: Tetsuo Ashizawa, MD, The Methodist Hospital System

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

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

ClinicalTrials.gov Identifier: NCT03701399

Funded by: Biohaven Pharmaceuticals, Inc

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).

Parkinson's Disease and Movement Disorders Program at the **Shirley Ryan AbilityLab**

Article contributors: Jennifer G. Goldman, MD, MS • Shari Marchbanks, PT, DPT, NCS
Miriam Rafferty, PT, DPT, PhD • Jillian MacDonald PT, DPT, NCS • Laura Sloan PT, DPT

The Parkinson's Disease and Movement Disorders (PDMD) program at the Shirley Ryan AbilityLab provides comprehensive and personalized care in neurorehabilitation for people with Parkinson's disease and other movement disorders. The PDMD program offers interdisciplinary clinical visits, customized early-stage PD evaluations, individualized outpatient rehabilitation therapy services, fitness center classes, educational sessions and a broad range of research opportunities.

Parkinson's Open House at Shirley Ryan AbilityLab

On April 16, 2019, we hosted a Parkinson's Open House in celebration of Parkinson's Awareness month. We had an exciting and engaging day of presentations and demonstrations. The resource fair featured many services that we have to offer for people with PD and their care partners, as well as local community organizations and Parkinson's foundations. Representatives were on hand to answer questions and provide information on the Shirley Ryan AbilityLab Adaptive Sports and Fitness Center; Occupational, Physical, and Speech therapy; the LIFE Center; Nutrition; Psychology; Spiritual Care; Technology Center; Therapeutic Recreation; and Vocational Rehabilitation. Richard Lieber, PhD, Chief Science Officer and Senior Vice President and Jennifer G.

Goldman, MD, MS, Section Chief of PDMD at Shirley Ryan AbilityLab, spoke to the audience of more than 100 people who attended. Thank you for joining us, and we look forward to seeing you at future events!

Did you know that October is National Physical Therapy Month?

Here at Shirley Ryan AbilityLab, physical therapists (PT's) are part of your interdisciplinary care team.

Have you ever seen a PT? Did you know that much like physicians, PT's can have specialties, including neurology? Our PT team has board certified neurologic and orthopedic clinical specialists to help with all of your needs. Our facility offers PT in the inpatient, Day Rehabilitation and outpatient settings to best provide personalized care for you.

Shirley Ryan AbilityLab Top 10 Physical Therapy Tips for PD:

1. A PT can and should be a part of your care team
2. Shirley Ryan AbilityLab has an early intervention PT program for those who are newly diagnosed with PD or early in the disease
3. A PT can see and offer assistance to people at any stage of PD
4. Exercise at 150 minutes per week at moderate-vigorous intensities is



recommended for all adults, including people with PD. Check with your doctor to make sure it is safe for you. A PT can help you find the best exercises for you

5. If you don't know how to exercise, or are concerned or bored with your current program, you can see a PT to help with your exercise program
6. Exercise with your loved ones, friends, or others with PD—keep each other accountable!
7. A PT can help you find ways to challenge your balance and mobility in order to improve or maintain current function and reduce the risk of falls
8. PT is not a one-time occurrence and may change with different stages of PD. It should be an ongoing relationship over the course of your PD
9. If needed, a PT can help with equipment (walkers, wheelchairs, etc.) prescription and care partner training to promote functional mobility and safety for all
10. In whatever way is safe for you, keep MOVING and make those movements BIG!

Parkinson's NM Programs

Call 312.503.4397 for More Information • Chicago - Northwestern Medicine (251 E. Huron, Chicago IL)

Monthly Parkinson's Disease Support Group

Location: Northwestern Medicine,
Feinberg Pavilion, Room A

Date: First Tuesday of month

Schedule of Activities:

10:30 a.m. – Dance/Music Therapy & Movement
11:15 a.m. – Group Physical Therapy
12:00 p.m. – Box lunch (provided)
12:30 p.m. – Guest Speaker

Care Partner Support Group

Location: Northwestern Medicine,
Prentice Pavilion, Room Q

Date: 2nd Tuesday of month

Time: 3:30 p.m. to 4:30 p.m.

Parkinson's Disease 101

Location: Northwestern Medicine, Prentice Pavilion,
Room P (250 E. Superior)

Date: First Wednesday of the month

Time: 3:00 p.m. to 4:30 p.m.

Contact: Carolyn Taylor, APN, at 312.695.1822

Art and Yoga

Location: Northwestern Medicine,
Prentice Pavilion, Room Q

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

Schedule of Activities:

1:00 p.m. Art Therapy & 2:00 p.m. Yoga

Young Onset Parkinson's Group

Location: Lavin 13th floor conference room; Lavin
Pavilion 259 East Erie.

Date: 4th Wednesday of every month from 6:00 p.m. to
8:00 p.m.

Contact: Pam Palmentera, LCSW for more information or
registration by calling 312.503.4397

Improve Communication using Improv and Speech Therapy for Parkinson's & Care Partners

Dates: An 8-session series

Contact: Pam Palmentera, LCSW for more information or
registration by calling 312.503.4397

Parkinson's & Women On-line Support Group

Date: Second Tuesday of the Month

Time: 11:30 a.m. to 12:30 a.m.

Contact: Pam Palmentera, LCSW for more information or
registration by calling 312.503.4397

Requirements: Must be a patient of a PDMDC
Neurologist & sign a consent form

Once registered you will be given the URL web address to
sign on.

Second City's Improv for People with Parkinson's & Care Partners

Location: Second City, Inc. 1616 N. Wells, Chicago IL
(in their training center)

Dates: An 8-session series

Cost: \$80 due on the first day of class (check made out
to PDMDC)

Contact: Pam Palmentera, LCSW for more information or
registration by calling 312.503.4397

Parkinson's Wellness Initiative

Contact: Emily Zivin, LCSW at 773.516.5864

Cost: \$40 monthly

This program is supported by a community grant from the
Parkinson's Foundation

Programs continue on the next page. >

Hyde Park JCC, Exercise Class

Location: 5200 S. Hyde Park Avenue

Schedule of Activities: PD Strength and Balance on Tuesdays, 11:00 a.m. to 12:00 p.m.

Silver Sneakers classes on Mon., Wed., & Fri from 9:00 a.m. to 10:00 a.m.

Support Group for PD is on the 2nd Wednesday of every month, 10:30 a.m. to 11:30 a.m.

Lake Forest (Lake Forest Health & Fitness)

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

Contact: 847.535.7000 for more information about class times or visit their website at lakeforesthfc.com/parkinsons-programming

Exercise Classes:

RX for Parkinson's Levels 1 & 2
Pedal for Parkinson's Levels 1 & 2
Strength & Balance Levels 2 & 3
Pilates for Parkinson's Levels 2 & 3
Yoga for Parkinson's Levels 3 & 4
Functional Fitness Levels 3 & 4
Dance for Parkinson's Levels 3 & 4
Rock Steady Boxing For All Levels

Support Group: 2nd Wednesday of the month from 10:00 a.m. to 12:00 p.m.

Northwestern and Huntington's Disease Society of America (HDSA) Support Group

Location: Logan Square Library –
Conference Room, 3030 West Fullerton
Avenue, Chicago, IL 60647

Date: Saturdays (call for schedule)
10 am to 11:30 am

Cost: None

Contact: Emily Zivin, LCSW, at 630.443.9877

**To receive mailings & e-mail
notifications, please send your
information to jessenia.erickson@nm.org**

Upcoming Symposiums

You're invited to a patient and family symposium

Sponsored by
**Northwestern Medicine
and the Parkinson's Foundation**

Saturday, October 12, 2019
8:30 am – 12:30 pm
Northwestern Medicine's Downtown Campus

Northwestern Medicine is recognized by the Parkinson's Foundation as a Center of Excellence. The Parkinson's Foundation leads the development of new treatments and care models through its Centers of Excellence network. Each Center of Excellence is staffed by some of the world's foremost specialists in every aspect of the complex, multidisciplinary care that delivers the best results for people with Parkinson's.

REGISTER FOR OUR UPCOMING SYMPOSIUMS: 877.926.4664

You're invited to a patient and family symposium

Sponsored by **the Huntington's Disease Center of
Excellence at Northwestern Memorial Hospital**

Saturday, November 23, 2019
8:30 am – 12:00 pm
Northwestern Medicine Parkinson's Disease
and Movement Disorders Center