Parkinson's Update

Parkinson's Disease and Movement Disorders Center Feinberg School of Medicine Northwestern University

Spring 2016 Vol. 22

April is Parkinson's Awareness Month

arkinson's disease (PD) is a slowly progressing disorder of the nervous system marked by slowness of movement, tremor at rest, muscle stiffness, and gait problems. PD symptoms are triggered by declining levels of dopamine in the brain.

"Parkinson's is the disease of aging," says Tanya Simuni, MD, director of Northwestern's Parkinson's Disease and Movement Disorders Center. "With our aging population, we expect there will be twice as many people living with Parkinson's over the next 20 to 40 years."

Our mission is to provide innovative, multidisciplinary care for patients and families affected by Parkinson's disease and other movement disorders. We promote health, education, and support for patients, caregivers, family members, healthcare providers, and the community.

To see our work in action, visit impacteverydaynm.org /wednesday.

JOIN US IN OUR EFFORTS BY

- Getting the latest information about Parkinson's from our center at parkinsons.nm.org or from our partner, the National Parkinson Foundation, at www.parkinson.org.
- Sharing what you've learned with your family, friends, and community.
- Making an impact. Donations are gratefully accepted at 312-926-2033.
 Our representatives will ensure your gift is designated to the Parkinson's Disease and Movement Disorders Center. Or support our fundraising efforts, such as Moving Day Chicago, by calling 312-505-7602.
- 60,000 people are diagnosed with PD each year 1 in 100 people over age 60 have PD
 - Approximately 2 percent of people with PD are below age 40
 - Men are one and a half times more likely than women to have PD •
 - In the early stages of PD your arms may not swing when you walk
 - Loss of smell is a common sign of Parkinson's •
 - Parkinson's has nonmotor symptoms like trouble sleeping and constipation
 - Exercise is vital in managing PD Stress can make PD symptoms worse
 - The causes of PD are unknown •

Research Participation Opportunities at Northwestern Medicine

MOVEMENT DISORDERS CENTER BIOREPOSITORY

The objective of the **Movement Disorders Center Biorepository** is to create a repository of DNA, plasma, iPS-derived cell lines, and clinical information from patients, familial controls, and healthy control subjects for future research.

EARLY PARKINSON'S DISEASE

PPMI Study: The objective is to identify clinical, imaging, and biologic markers of PD progression for use in clinical trials of disease-modifying therapies. The five-year study is recruiting PD subjects who do not require therapy for at least six months, as well as non-PD subjects.

Funded by the Michael J. Fox Foundation.

MODERATE TO ADVANCED PARKINSON'S DISEASE

Sublingual Apomorphine Thin Films: The objective is to determine the efficacy, safety, and tolerability of sublingual apomorphine thin films in levodoparesponsive PD patients with motor fluctuations (wearing off of medication). Requires 13 visits over 12 weeks; patients who complete the study will be eligible for the 24-week open-label study. *Funded by Cynapsus Therapeutics Inc.*

Levodopa Inhalation Powder: This multicenter study is evaluating inhaled CVT-301 for the treatment of PD patients experiencing up to five off-episodes of motor fluctuations (wearing off of medication) per day. Participants are between 30 and 80 years old. Requires 8 visits over 12 weeks.

Wearing Off in Patients Using Levodopa: The purpose of this study is to test the effect of tozadenant tablets in patients using levodopa, whether the drug decreases end-of-dose wearing off, and what side effects can be expected. Participants will maintain an accurate record of on- and off-time in a home diary. Other symptoms that some PD patients experience will be evaluated during clinic visits. Requires 15 visits over a year and a half.

Funded by Biotie Therapies, Inc.

INTREPID (implantable neurostimulator for the treatment of Parkinson's disease): The objective is to evaluate the safety and efficacy of bilateral stimulation of the subthalamic nucleus as an adjunctive therapy for improving the number of waking hours per day with good symptom control and no troublesome dyskinesia. Subjects are adults with advanced, levodopa-responsive bilateral PD that is not adequately controlled with medication. Requires 14 clinic visits and one phone call over 5½ years. *Funded by Boston Scientific Corporation*.

PARKINSON'S DISFASE DEMENTIA

SYNAPSE (safety, tolerability, and efficacy in Parkinson's disease dementia): The objective is to assess the efficacy of a fixed dose of SYN120 on cognition in patients with Parkinson's disease dementia. Requires 6 visits over 24 weeks. Funded by Biotie Therapies, Inc.

WILSON'S DISEASE

The objective of the **Wilson's Disease Study** is to evaluate the efficacy and safety of WTX101 administered with a proton pump inhibitor for 24 weeks in newly diagnosed Wilson's disease patients older than age 18 with above-normal nonceruloplasmin-bound copper levels. Requires 15 visits over 28 weeks. *Funded by Wilson Therapeutics*.

For more information about Parkinson's disease research at Northwestern, visit www.parkinsons.northwestern.edu /clinical_trials.html, call 312-503-0755, or email PDclinicaltrials@northwestern.edu.

Why Join a Trial?

"When I'm asked why I volunteered to be part of a research study, my answer is, why not? The medications available today for those of us with PD are directly due to the fact that someone in the past willingly stepped up.

"I drive 350 miles round-trip to be part of a study here at Northwestern Memorial Hospital, and I feel empowered by each visit. I don't know if I am taking the medicine or the placebo, and it doesn't really matter. Either I can have Parkinson's, or Parkinson's can have me. I have no intention of letting PD define who I am, so I hope you'll join me and give thoughtful consideration to volunteering for upcoming research studies—you owe it to yourself."

—M. Ellinger, study participant



For more information or to register, call 312.926.8400

Northwestern Medicine's Parkinson's Disease and Movement Disorders Center National Parkinson Foundation Center of Excellence

Beyond the Medications: Taking Control of Parkinson's

Sunday, April 10, 2016 • 10:30 a.m.-1:30 p.m. CJE SeniorLife Weinberg Community for Senior Living 1551 Lake Cook Road • Deerfield, Illinois 60015

Registration
Welcome
Michelle Bernstein, CJE SeniorLife
Beyond the Medications: Taking Control of Parkinson's
Danny Bega, MD, Parkinson's Disease and
Movement Disorders Center
A Few Words from the National Parkinson Foundation
Sara O'Hare, Community Development Director
Luncheon Panel
Moderated by Pamela Palmentera, LCSW, Coordinator
and Clinical Social Worker, Parkinson's Disease and
Movement Disorders Center
Optional Tour of the CJE SeniorLife Facility

We would like to thank our sponsors for making this program possible:







For more information or to register, call 312-505-7602.

Exercise as Medicine for Parkinson's Disease

By Daniel M. Corcos

ne consequence of Parkinson's disease is a natural tendency to move less and do less. Although the disease itself causes many symptoms, part of a patient's decline in movement and cognition may be due to reduced physical activity. This is a vicious circle, as less physical activity leads to a further reduction in physical and mental performance.

The evidence that regular exercise is good for health and can reduce the burden of disease is beyond dispute. Every week new research documents the benefits of exercise at every level of the mind-body continuum.

General guidelines published by the Centers for Disease Control and Prevention, the American College of Sports Medicine, and others focus on endurance exercise, strength training, balance, and flexibility. There is mounting evidence that exercise helps with both the motor and nonmotor symptoms of PD. Strong evidence from animal models shows that exercise may protect the nervous system, slowing the progression of the disease.

Exercise benefits people with PD in a number of ways:

- Progressive resistance exercises, such as lifting weights and using resistance bands, lessen motor symptoms and improve attention and memory.
- Endurance exercises, such as running, jogging, using a treadmill, and cycling, improve walking and mobility.
- Tai chi and similar practices improve balance.

Exercise in general improves quality of life and physical function by increasing dopamine metabolism and oxygen

consumption, improving blood supply and promoting the growth of blood vessels, stimulating nerve growth, reducing inflammation, and increasing brain adaptability.

Often the most difficult part of exercising is finding time for it. The best strategy is to make exercise a priority and put exercise sessions in your calendar before you schedule other activities. Just as medications are taken at specific times, exercise should be done on a consistent schedule.

Multiple studies over the past 20 years tell us that a fitness regimen should consist of progressive resistance exercises twice a week, endurance exercise three times a week, and flexibility training once a week. As not everyone can or wants to exercise six times a week, you should do what you are comfortable with and adjust these amounts accordingly. The most important aspect of an exercise program is consistency, so find

The National Institute on Aging can help you Get Ready, Get Set, and Go!
Visit **go4life.nia.nih.gov**/4-types-exercise
to get started.

exercises that you enjoy so you will keep doing them. Yoga, dancing, swimming, boxing, and even playing movement-oriented video games all have been shown to be beneficial.

Exercise is a therapeutic treatment that has no known adverse side effects, and people who exercise regularly empower themselves to take ownership of their disease. There's a growing trend among people with PD to move more, and we urge you to join them.

Daniel M. Corcos, PhD, is a professor of physical therapy and human movement sciences at the Feinberg School of Medicine.

Lake Forest Resources

disease and other movement disorders continues to grow, more and more patients are seeking therapy services at Lake Forest Hospital. Our Parkinson's Disease and Movement Disorders team, made up of occupational and physical therapists and speech-language pathologists, works closely with patients and their families to provide therapy and support throughout the rehabilitation process. Begun last year at the hospital's Lake Forest Health and Fitness Center, our support group provides an opportunity for people with PD, family members, and caregivers to share ideas, trials, and successes to improve their everyday experience and quality of life.

Each two-hour meeting includes exercise, a discussion, and an educational presentation. Featured topics have included PD 101, PD and nutrition, National Parkinson Foundation resources, Rock Steady Boxing, and voice and swallowing concerns.

Peter Daniel, an active participant, finds tremendous value in sharing his experiences at meetings. "I feel like I fit into this group because we have something in common," he says. "I'm making new friends and like to attend because I never know what I'm going to learn."

In addition to the support group, the Health and Fitness Center also offers dance and stationary bicycle classes at no charge for people with PD and their caregivers.

For more information, contact the Rehabilitative Services Department of Lake Forest Hospital at 847-535-8060.

Now, and Then

By Jean Anderson



Something was wrong. My husband, to whom I had been married for 50 years, was mowing the grass at our little Wisconsin cottage, repeatedly covering the portions he had already mowed. That same evening, he became anxious about feeding people he saw outside the cottage in the summer darkness. These are just two bizarre instances, of which there were many.

After my frustrations with his behavior, his doctor's not heeding my distress calls, and my family's fracture when our adult children did not comprehend (or perhaps, acknowledge) his decline, my husband was finally diagnosed with Parkinson's disease and dementia.

Now we had something to work on! That work began with an invitation to join the Parkinson's support group at Northwestern Memorial Hospital. In the early stages of the disease's progression, my husband participated in exercise classes and art and music therapy. I joined a very special group of Parkinson's caregivers, who lent one another support under the gentle and encouraging guidance of a social worker. Around the table, we shared stories of frustration and sadness and fortitude.

My husband's condition declined rapidly, and he is now cared for in a small, faith-based nursing facility close to my home. He is approaching the end of his second year in hospice, completely bedridden, seldom speaking a word that can be understood. The people who care for him have my deepest gratitude and respect.

After having spent many years with my life partner, I have

been given time for my own choosing, knowing it has come at great expense. We do not always get what we want, but this moment in time has brought the realization that I have a choice going forward. It is my choice to live without regret or blame, to live with intention, to call upon the many resources offered to me so my husband's care is met and I dedicate my time where I feel the greatest reward.

A friend sent me a card with a picture of a woman afloat inside an inner tube covered with patches. The message read, "I hope to be one of those patches." I am grateful for these many patches on my leaky inner tube—family and friends, my faith community with a Stephen Ministry program, opportunities to take classes and volunteer in my neighborhood. When I visit my husband almost daily, I tell him of the precious memories of our life together, I tell him that I love him, and sometimes, he smiles.

Bernard Horwich JCC and Northwestern Medicine **Parkinson's Wellness Program**

By Elizabeth Abrams

rigid winter temperatures didn't cool the spirit of the passionate participants in our new Parkinson's Wellness Programs at the Bernard Horwich JCC in West Rogers Park. JCC Chicago has partnered with

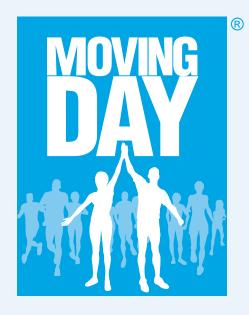


the Parkinson's Disease and Movement Disorders Center to bring innovative movement therapy sessions directly to the community.

JCC Chicago offers three weekly classes: Strength and Balance, Power Flow, and Chair Class: Seated Strength and Stretch. Led by experienced experts, the workshops help those with Parkinson's build strength, increase balance, and develop strong mind-body connections. An additional weekly class for caregivers offers a unique and vital opportunity for partners to connect and learn in a supportive and informative environment.

Made possible by a generous grant from the Edmond J. Safra Philanthropic Foundation, the wellness initiative is "about connecting, inspiring, and empowering individuals and families affected by Parkinson's," says Addie Goodman, chief advancement officer for JCC Chicago. "By partnering with the renowned Parkinson's Disease and Movement Disorders Center at Northwestern, we are redefining what it means to live well with Parkinson's and offering enhanced quality of life, strength, and hope for everyone who participates."

The Parkinson's Wellness Programs at JCC Chicago are \$10 per class and include a free JFit membership to the facility. For more information, visit www.jccchicago.org/parkinsons.



Saturday, September 24 Lincoln Park South Fields

The National Parkinson Foundation's fifth annual Moving Day® **Chicago** fundraising walk returns to Lincoln Park on Saturday, September 24, 2016. Moving Day is a fun and inspiring event that unites families, friends, and communities both large and small in the fight against Parkinson's disease. This celebration of movement will feature a familyfriendly walk course, a children's area, a refreshment tent, and a special movement pavilion where exercises proven to help manage PD symptoms will be taught. In its four-year history, Moving Day Chicago has raised more than \$1.5 million to help improve the quality of care for people with PD.

PEOPLE WHO MOVE CHANGE THE WORLD.

Ajay Kurani



Ajay Kurani, MD, is a postdoctoral research fellow at the Parkinson's Disease and Movement Disorders Center in the Department of Neurology at Northwestern

University's Feinberg School of Medicine.

Kurani's research interests focus on understanding the basis of structural and functional deficits in patients with neurodegenerative diseases. His goal is to use advanced MRI techniques to noninvasively identify changes in brain morphology that are related to cognitive and motor deficits in patients. Identifying these biomarkers can help improve early detection, differential diagnosis, tracking of long-term changes, and understanding of the underlying mechanisms of these diseases.

Kurani earned his BS in electrical and computer engineering at the University of Illinois at Urbana-Champaign, and he completed his MS and PhD in bioengineering at the University of Illinois at Chicago. During that time he conducted brain-imaging research related to movement disorders at the Laboratory for Rehabilitation Neuroscience, University of Florida.

Kurani has developed several analysis methods related to magnetic resonance imaging in PD and related disorders. Before arriving at Northwestern in 2015, he completed a postdoctoral fellowship in the departments of neurology and radiology at the University of Pittsburgh, where he focused on developing techniques for localizing seizure networks in patients with epilepsy as well as on technical developments in high-field MRI analysis.

Art Therapy Classes

By Sophie Canadé



Hello! As the new art therapist with the Parkinson's Disease and Movement Disorders Center, I'm honored to carry on the work of

Leslee Goldman, who passed the torch to me after working with the group for the past three years.

One of the most thrilling experiences for me as an art therapist is seeing people with PD reap enormous benefits by embracing art. As you may know, the dopaminergic drugs used to treat PD have been observed to stimulate creativity in people who hadn't previously considered themselves artistic.

The benefits of art therapy begin with the strength and support that develop in a shared, safe space where making art is a pursuit of pleasure. Visually expressing yourself is known to lift depression, as making art can reduce stress, anxiety, and

repetitive thoughts. In a relaxed state, when you focus on artistic expression rather than physical movements, motion can become more fluid. I've witnessed people drawing themselves into a state of "flow."

The act of creating also increases bilateral activity in the brain. When you're active, cognition is enhanced, and memory and executive function improve.

My goal is that we all find a way to connect creatively with our own experiences and with one another. If you've ever had a thought or feeling you wanted to share but didn't know how to put into words, give art therapy a try. We'll save a space for you.

Sophie Canadé, ATR, LPC, is an art therapist at Gilda's Club Cancer Support Services, Hamdard Healthcare, and the Institute for Therapy through the Arts.

ART THERAPY CLASSES

Second, third, and fourth Tuesdays of the month • 1–3 p.m. Northwestern Prentice Women's Hospital 250 East Superior Street • Third floor • Room Q

The focus is on the process, not the product. You don't have to be an artist to participate.

"Will I Get Dementia?" Concerns about Cognitive Changes in Parkinson's Disease

By Yasaman Kianirad and Danny Bega

arkinson's disease is a neurodegenerative disorder affecting more than four million people older than 50 around the world, with rates expected to double over the next two decades. PD has traditionally been regarded primarily as a motor disorder, but nonmotor signs and symptoms are increasingly recognized as part of the disease.

Nonmotor symptoms of PD include mood disorders, such as depression, anxiety, and apathy; sleep disturbances; gastrointestinal dysfunction; fatigue; cognitive impairment; and dementia. These features can be very disabling and in many patients are the most troubling symptoms. Motor and nonmotor decline generally tend to occur in parallel as the disease progresses.

Cognitive Impairment versus Dementia

The difference between cognitive impairment and dementia is the extent of decline in thinking and memory. Dementia refers to advanced problems in thinking and memory that interfere with daily activities and quality of life. While Alzheimer's disease is the most common type of dementia, the terms are not synonymous, and Alzheimer's is likely not the most common form of dementia among patients with PD. By contrast, mild cognitive impairment describes patients who have demonstrable cognitive difficulties but who remain independent in their day-to-day functioning.

Only about 30 percent of patients with PD have dementia, with advanced disease and age being the greatest risk factors. More severe motor symptoms, depression, and family history of dementia are also associated with an increased risk of PD dementia. Cognitive complaints in the early stages of the illness

typically include slowed processing, difficulty with multitasking or planning, decreased attention and concentration, and difficulty retrieving words.

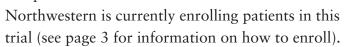
Cognitive impairments in executive function (the ability to plan, organize, initiate, and regulate goal-directed behavior), attention, perception, and memory have also been noted in patients with PD. Other aspects of cognition, such as language ability, orientation, long-term memory, and calculation, are relatively preserved, in contrast to Alzheimer's disease.

Evaluating cognition in patients with PD can be tricky because noncognitive factors may come into play. Depressed mood, confusion, hallucination, and agitation may affect motivation and attention and consequently influence performance in cognitive testing. Severe motor impairment may physically prevent patients with advanced PD from performing many daily activities even though they don't have cognitive impairment. The clinician must judge whether functional deficits result from cognitive problems, motor problems, or both.

Treatment Options for Cognitive Problems

No medical treatment can delay, stabilize, or reverse the biological processes that cause progressive cognitive impairment in PD. However, there is some evidence that medications used to treat Alzheimer's patients, such as cholinesterase inhibitors, can improve cognition and quality of life for both the PD patient and the caregiver and thus allow for possible prolongation of home-based care. These medications, which increase levels of acetylcholine in the brain, include donepezil (Aricept), rivastigmine (Exelon), and galantamine (Reminyl) and are relatively safe for PD patients, with few side effects.

Medications that block certain types of serotonin receptors have also been shown to improve cognition, but none are currently approved by the FDA with this mechanism of action. A clinical trial is assessing the safety and efficacy of one such drug in patients with PD dementia in the hope that it will improve cognitive performance and behavior.



Another treatment for cognitive deficits in PD is cognitive and behavioral therapy, which can be used instead of, or in combination with, medication. Cognitive remediation therapy emphasizes teaching patients ways to use their cognitive strengths to compensate for areas of thinking that are not as strong. Patients learn strategies that help with memory skills, such as organizing day-to-day tasks. This therapy is usually conducted by a neuropsychologist or speech pathologist who is trained in these techniques.

Some studies suggest that nonpharmacologic preventive strategies, such as social interaction, computer use, and artistic and crafting activities, can increase cognitive abilities, maintain brain-cell function, and stimulate brain-cell growth to preserve cognitive function. Studies have also found that people with higher levels of mental activity have a lower risk of getting dementia.

Managing PD dementia should include consideration of the patient, caregiver, and social and physical environments. Competence to work and drive, home



safety, and the need for assistance at home should be evaluated, and caregivers should be educated about dementia and strategies to support and maintain function. Community resources such as day care centers and support groups can provide substantial assistance and address the important issues of caregiver burden and burnout.

Treatment of co-occurring conditions such as depression, anxiety, and sleep dysfunction may also play a role in treating cognitive impairment in PD. Non-PD medications with the potential to impair cognition or cause confusion (e.g., centrally acting medications for pain, bladder function, or sleep) should be avoided or used sparingly.

Although we still have much to learn about how to diagnose and treat these cognitive problems, many more treatment options are available today than just a few years ago. Research increasingly shows that maintaining an active mental and physical schedule can help delay or prevent some cognitive impairment. It seems that remaining mentally active and engaged is good exercise for the brain, and it's never too late to start. As the saying goes, if you don't use it, you lose it.

Yasaman Kianirad, MD, is a movement disorders fellow at the Parkinson's Disease and Movement Disorders Center. Danny Bega, MD, MSCI, is a neurologist and assistant professor of neurology at the Feinberg School of Medicine.

Programs and Educational Opportunities

PD Support Group, Chicago

First Tuesday of the month 10:30 a.m.-2 p.m.

Northwestern Memorial Hospital 251 East Huron Street, Feinberg Pavilion, third floor, room A

May 3: Speech and Swallowing, Kristen Larsen, MA, CCC-SLP

Art and Yoga Therapy

Second, third, and fourth Tuesdays of the month 1–3 p.m.

Northwestern Prentice Women's Hospital 250 East Superior Street, third floor, room Q

PD Support Group, Lake Forest

Second Wednesday of the month 10 a.m.-noon

Lake Forest Health and Fitness Center 1200 North Westmoreland Road For more information call 847-535-6520.

April 13: Guest speakers Bob Baittie, author of Tremors in the Universe, and Sara O'Hare, National Parkinson Foundation

Classes

Registration is required; call 847-535-8060.

Pedaling for Parkinson's

(stationary bicycle therapy)
Tuesdays, 11 a.m.-noon
Lake Forest Health and Fitness Center

Thursdays, 10:15–11 a.m. 3098 Falling Waters Boulevard, Lindenhurst

Dance for Parkinson's

(for all abilities)
Wednesdays, 2-3 p.m.
Lake Forest Health and Fitness Center

Safra Wellness Program, Rogers Park

To register, call 773-516-5864 or email pd@gojcc.org.

Bernard Horwich JCC 3003 Touhy Avenue

Strength and Balance

Mondays, 3-4 p.m.

Power Flow

Mondays, 4-5 p.m.

Chair Class: Seated Strength and Stretch

Wednesdays, 3-4 p.m.

Care Partner Support Group

Wednesdays, 3-4 p.m.

Early Onset/Young Diagnosis Support Group

Saturday, April 30, 9-10:30 a.m.

Northwestern Memorial Hospital, Feinberg Pavilion

Women with Parkinson's Support Group

(inaugural planning session)

Saturday, April 30, 11 a.m.-12:30 p.m.

Northwestern Memorial Hospital, Feinberg Pavilion

Patient and Family Spring Symposium

To register, call 312-926-8400.

Sunday, May 15, 9 a.m.-noon

Bernard Weinger JCC 300 Revere Drive, Northbrook

Parkinson's Disease 101

Tuesday, July 12, 1-4 p.m.

Northwestern Memorial Hospital, Feinberg Pavilion

Music Therapy

By Priya Mhatre

Iterations in speech quality can occur early in the course of PD, adversely affecting a person's self-perception and causing embarrassment during social interactions. Speech therapy is the traditional intervention to target these changes; unfortunately, due to insurance limitations and provider availability, continuous speech therapy is not always possible for people with PD.

Studies show that music therapy is a successful intervention to address impairments in speech intelligibility, vocal quality, and intonation. This therapy has also been shown to combat the mood disorders common in PD and other neurologic diseases, having positive effects on emotional function and quality of life.

Formal music therapy is a partnership between a certified music therapist and the patient, but this form of therapy is not always covered by insurance. However, some simple music-listening interventions at home can have similar effects.

For people with PD, music can be used to

- help focus on a rhythm while walking or performing repetitive tasks
- promote breath support by sustaining syllables while singing
- help coordination by tapping out rhythms with their hands

For more information about music therapy and finding a certified therapist, visit www.itachicago.org, www.musictherapy.org, and www.cbmt.org.

Priya Mhatre, MD, is attending physiatrist at the Rehabilitation Institute of Chicago.

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CONTACT 312-503-4397 or 312-695-7950

CLINICAL TRIALS 312-503-0755 PDclinicaltrials@northwestern.edu

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