# Parkinson's Update

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

Fall 2012 Vol. 15



holistic approach to care has always been front and center in the mission and activities of the Northwestern Parkinson's Disease and Movement Disorders Center, both in the clinic and in programs. Holistic care is a philosophical approach to healthcare, i.e., a belief that all aspects of a person's needs—physical, psychological, social, familial, environmental, and spiritual—should be taken into account and viewed as a whole and as interdependent. In brief, evaluation and treatment should focus on the entire person. This holistic view is widely accepted in medicine yet not as widely implemented.

Complementary medicine refers to a group of diagnostic and therapeutic disciplines that are used together with conventional medicine. These can include acupuncture, biofeedback, diet therapy, massage, tai chi, and yoga,

# Center Takes Holistic Approach to Care

among others. Complementary therapies offer Parkinson's disease patients a wide avenue for disease management and enhanced quality of life. Living with Parkinson's disease poses unique motor challenges—including voice and swallowing difficulties, involuntary motor control, stiffening of joints, and slowing down of gait—as well as myriad nonmotor, psychological, and social changes. Many of these symptoms can be mitigated by participation in creative arts, various exercise modalities, and positive psychology—all of which are offered at Northwestern.

#### **CREATIVE ARTS**

Expressing oneself creatively is an art—but it's not only for the naturally artistically inclined. Everyone can reap benefits from engaging in such activities as dance, crafts, singing, and drama. Creative arts therapies offer an opportunity for people with Parkinson's disease to discover new strengths and

abilities. Therapeutic intervention may enhance and maintain these abilities when other functions decline. Participation in the arts allows for growth and self-expression as one experiences life changes. It promotes maintenance of cognitive abilities, and research has shown that cognitive stimulation may increase mental alertness in Parkinson's patients and may even slow the progression of the disease.

The center's creative arts classes meet the second and fourth Mondays of the month from 1 to 3 p.m. Contact Trupti Patel at trupti@northwestern.edu.

Art Therapy—Through the artmaking experience and relationship with the art therapist, people
express and examine feelings,
learn causes and effects, enhance
social and verbal skills, hear
how others react to symptoms,
and practice coping lessons. The
therapist asks participants to
work with a wide variety of art

continued on next page

# Center Takes Holistic Approach to Care

... continued from cover page



materials to create a free-form work or one related to a particular topic. The therapist provides assistance, encourages reflection, and allows the creative process to unfold. "I am very impressed by the way the therapist establishes a theme for the art project and encourages everyone to engage in the activity," a spouse of a PD patient attests, "and impressed by how she draws out from each artwork a lesson or realization about how one can cope with life challenges."

#### **Drama and Music Therapy—**

Drama therapy uses creative expression, dramatic processes, and performance to help patients experience symptom relief. Voice, swallowing, and elocution are strengthened. Music therapy is designed to enhance speech, memory, and listening skills. Exercises target certain speech and vocalization difficulties that people with PD might have.

#### **EXERCISE**

Research has shown that patients with Parkinson's greatly benefit from participating in routine exercise that stimulates muscle tone and works on balance impairment. Symptomatic benefits to exercise include improvements in motor performance, gait speed, and sit-and-stand tasks. Tai chi, dance, and yoga are all effective for achieving these benefits.

**Tai Chi—**According to an article in the February 9 issue of the New England Journal of Medicine, researchers have found that tai chi encourages and improves control of balance impairments and posture and also reduces stress. The positions and postures involve slow, fluid, deliberate movements and breath control. Parkinson'sspecific tai chi is offered through Northwestern Integrative Medicine. For information call 877-926-4664 or visit nmh.org and click on View Classes and Support Groups.

**Dance and Movement—**Dance and movement therapies are based on the belief that the body, mind, and spirit are interconnected. The psychotherapeutic use of movement as a process furthers emotional, cognitive, social, and physical integration. Therapists help clients improve self-esteem and body image, develop effective communication skills and relationships, expand their movement vocabulary, gain insight into patterns of behavior, and create options for coping with problems. The center's dance class is offered by Citlali Lopez-Ortiz at the Joffrey Tower. For more information contact Lopez-Ortiz at c-lopez-ortiz @northwestern.edu.

#### Yoga and Meditation—

Parkinson's patients use yoga to combat tremors and rigidity. Anecdotal evidence has shown that yoga poses and postures improve balance. The complementary practice of meditation is a wonderful way to relax and encourage happiness. Yoga is



offered through Northwestern Integrative Medicine. For more information call 877-926-4664 or visit nmh.org and click on View Classes and Support Groups.

#### **POSITIVE PSYCHOLOGY**

Positive psychology is a cognitivebehavioral approach that not only addresses behavioral and psychological symptoms but also can provide greater life satisfaction and well-being. A positive perspective encourages people to use their strengths to enhance their lives, manage the disease, and develop constructive attitudes. Sessions in positive psychology incorporate the principles and goals of developing oneself in five ways: positive feelings, positive engagement in activities, positive relationships and sense of belonging, feeling that one's life has meaning, and feeling a sense of accomplishment. Positive psychology classes are offered through Northwestern Integrative Medicine. For more information call 877-926-4664 or visit nmh.org and click on View Classes and Support Groups.

#### From a Patient's Perspective



"Both music and art therapies have made a very positive impact on me and, I believe, on the others who attend. Every time we meet, I notice

positive changes in the people in our group. Having the same professionals and familiar activities week after week allows continuity and comfort. Leslee [art therapist] and Jenni [music therapist] are outstanding therapists. Leslee makes us feel like we have created a masterpiece, and Jenni makes us believe that we can sing. We sometimes use our artwork in music therapy. I never thought I would sing a solo, but I do now. Members leave the classes happier and more self-confident than when they walked in. With the help of the therapists, I have gained valuable insight from my own artwork. The amount of time for the two classes is right. No one has complained that they are tired. I don't see any restlessness like I have in other groups or classes I've attended. I encourage others to get involved in the art and music therapy programs offered by Northwestern's Parkinson's Disease Center."

—Brenda Allison, artist and arts advocate, talking about the center's music and art therapy classes



OCT. 14, 2012 CHICAGO, IL

### Join us for Moving Day Chicago

October 14, 2012, in Lincoln Park

Taking place in cities across the United States, Moving Day is your chance to speak up about Parkinson's disease and move others to take action. It is a movement for change—toward more awareness, more funding, and more understanding of a disease that affects so many.

For more information or to register, call 1-800-327-4545 or email movingday@parkinson.org.



# BECOME A TEAM CAPTAIN. START BUILDING YOUR TEAM NOW.

# Movement Disorders Clinical Trials For information on participating in any of the following movement disorders clinical trials, please call 312-503-3320.

## 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 diseasemodifying therapies. The 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.

**FS-Zone** The primary objective is to assess the impact of prioglitazone on the progression of PD in order to determine whether to proceed with further study of this agent. Funded by the National Institute of Neurological Disorders and Stroke.

#### Circadian Rhythms in Early PD

This study is looking at how the biological clock works in patients with PD. Sleep patterns, daytime sleepiness, and melatonin and cortisol blood levels are being examined. Participation lasts two weeks and includes two sleep studies and one 24-hour period of blood draws. Participants are compensated for their time and travel. Funded by the Paul Ruby Foundation for Parkinson's Research.

#### ADVANCED DISEASE

Amantadine This study is looking at the potential benefits of the FDA-approved medication amantadine on freezing of gait. Patients are required to be both on and off medication. Participation includes four clinic visits and one telephone interview. Funded by the Rettinger Foundation.

Light/Circadian Study The purpose is to evaluate the effectiveness of light treatment on excessive daytime sleepiness in patients with PD. This study requires one clinic visit, two to six weeks of home journaling, two to four sleep studies, one or two 24-hour periods of blood draws, and up to four weeks of light-box treatment in the subject's home. Participants are compensated for their time and travel. Funded by the National Institute of Neurological Disorders and Stroke.

Circadian Rhythms in PD This study is looking at how the biological clock works in patients with PD.

Sleep patterns, daytime sleepiness, and melatonin and cortisol blood levels are being examined.

Participation lasts two weeks and includes two sleep studies and one 24-hour period of blood draws.

Participants are compensated for their time and travel. Funded by the National Parkinson Foundation and the American Academy of Neurology Foundation.

#### CERVICAL DYSTONIA

**CD-Probe** This observational study is designed to capture current diagnosis and treatment approaches for CD and their effects on patients' quality of life. Patients are asked to complete questionnaires during four clinic visits and two telephone interviews after Botox injections. *Funded by Allergan*.

**XCiDaBLE** This observational study is designed to collect, evaluate, and report data about the clinical use of Xeomin in a "real-world" setting to determine injection patterns (muscles injected, dose, and dilution) and use of guidance techniques. Patients are asked to complete questionnaires during three clinic visits as well as outside the clinic. *Funded by Merz*.

**CD-FLEX** The purpose is to evaluate two dosing schedules of Xeomin (short-flex and long-flex) in subjects who have reported a therapeutic benefit from Botox injections for cervical dystonia. Patients are asked to complete questionnaires during 17 short-flex visits and 12 long-flex visits. *Funded by Merz*.

# Out of the Park for PD in Third Year

atients and family members from Northwestern's Parkinson's Disease and Movement Disorders Center joined Chicago White Sox infielder Gordon Beckham at U.S. Cellular Field on June 22 as he launched his 2012 Out of the Park for Parkinson's awareness and fundraising campaign to benefit the National Parkinson Foundation (NPF).

The White Sox organization, in partnership with the NPF, hosted a luncheon and meet and greet with the ballplayer. Beckham led the group in a series of stretches on the field.

Beckham, whose grandfather has been living with PD for nearly a decade, launched Out of the Park in 2010. To date, the campaign has raised more than \$120,000 for the National Parkinson Foundation, To learn more or support the campaign, visit www.outofthepark.org.







# Northwestern One of Four Wilson's Disease **Centers of Excellence** in United States

orthwestern has had the designation "Wilson's Disease Association
Center of Excellence" since 2008 and is one of four such centers in the United States. Wilson's disease is an inherited disorder in which there is too much copper in bodily tissues. The excess copper damages the liver and nervous system, possibly leading to wide-range movement disorders.

Northwestern's WD center is directed by Dr. Aleksandar Videnovic, movement disorders specialist, and Dr. Richard Green, liver diseases specialist. Under the comprehensive care model, the team includes specialists in neurology, hepatology, psychiatry, physical medicine and rehabilitation, and social work.

A recent development will further center growth. The relocation of the Ann and Robert H. Lurie Children's Hospital of Chicago to the Northwestern medical campus will allow the integration of pediatric and adult care for WD patients and their families.

In 2009 Northwestern hosted the annual WDA Conference, attended by people from across the United States and five foreign countries.

More information about the center can be found at www .parkinsons.northwestern.edu or by calling 312-503-4397.



#### Parkinson's Disease Classes

## Integrated Fitness for Parkinson's *Monday, Wednesday, and Friday*

11-11:45 a.m.

Rehabilitation Institute of Chicago Center for Health and Fitness Call 312-238-5001

#### **Tuesday and Thursday**

4-5 p.m.

RIC Northshore Day Rehab and Outpatient Center Call 312-238-5007 or 312-238-5009

# Amplitude-Based Training: Advanced Exercise Class for People with Early-Stage Parkinson's Disease *Time varies by location*

Downtown Chicago, Willowbrook, and Deerfield Call RIC Center for Health and Fitness, 312-238-5001

## Neurology Arts Lab: Express Yourself through Art and Music **Second and fourth Mondays**

1-3:30 p.m.

Room Q, third floor, Prentice Women's Hospital 250 East Superior Street, Chicago Call 312-503-3320 or email trupti@northwestern.edu

**Integrated Medicine Classes: Tai Chi, Yoga, Positive Psychology** Call Northwestern Integrated Medicine, 312-926-3627

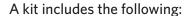


### Center Uses NPF's "Aware in Care" Kits

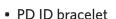
Northwestern's Parkinson's Center is providing the National Parkinson Foundation's "Aware in Care" hospitalization kits free of charge to patients in our clinic and support groups.

NPF introduced the "Aware in Care" kits at the 2011 NPF Centers Leadership Conference. Intended to improve delivery of care, the kits help hospitalized PD patients share information about their symptoms and needs with hospital staff.

NPF produced the kits in response to alarming findings that during a hospital stay three out of four people with PD do not get their medications on time and that patients with PD suffer more avoidable complications than do other patients.



- action plan with information about how to prepare for one's next hospital visit
- medical alert card with emergency contact information
- medications form and a magnet to display it in your hospital room



- PD fact sheet for the hospital chart and staff
- "I Have Parkinson's" reminder slips for the hospital care team
- thank-you card to give to hospital staff who provide high-quality care



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

## Parkinson's Disease Moving Forward

### Annual Patient and Family Symposium

Saturday, September 29 • 8 a.m.-12:30 p.m. Feinberg Pavilion, Third Floor, Room A Northwestern Memorial Hospital 251 East Huron Street, Chicago

8-9 a.m. Registration and continental breakfast; patient art exhibit:

The Art of Parkinson's

9-9:30 a.m. Opening address: Positive Psychology—A Path to Greater Well-Being

Helene Moore, PsyD, MAPP, health psychologist, Northwestern Integrative Medicine

9:30-9:50 a.m. Parkinson's Disease: Present and Future

Tanya Simuni, MD, medical director, Northwestern Parkinson's Center, and associate professor of neurology, Feinberg School of Medicine

9:50-10:10 a.m. Nonmotor Symptoms of PD

Cindy Zadikoff, MD, movement disorders neurologist,

Northwestern Parkinson's Center, and assistant professor of neurology, Feinberg School of Medicine

10:30-10:50 a.m. REM Sleep Behavior Disorder in Parkinson's Disease

Aleksandar Videnovic, MD, movement disorders neurologist, Northwestern Parkinson's Center, and assistant professor of neurology, Feinberg School of Medicine

10:50-11:10 a.m. Surgery for Parkinson's Disease: Is It Right for Me?

Joshua M. Rosenow, MD, neurosurgeon and director of functional neurosurgery, Northwestern Memorial Hospital, and associate professor of neurology, Feinberg School of Medicine

11:10-11:40 a.m. Physician panel: question and answer

11:50 a.m.-12:30 p.m. Breakout sessions

- Medications and surgery—Q and A with the physician speakers
- Exercise—Santiago Toledo, MD
- Therapy through art and music—Leslee Goldman, LPC, ATR-BC; Jenni Rook, LPC, MT-BC
- Care partners and children of people with PD—Diane Breslow, MSW, LCSW

RSVP: Northwestern Memorial Hospital's Health Resources and Physician Referral Service, 312-926-8400

### Parkinson's Disease

### **Support Group Corner**

Second Saturday of every month 11:30 A.M.-1 P.M.

#### Mather's More than a Café

33 East 83rd Street, Chicago Call 773-488-2801

At the following free support group provided by Northwestern's Parkinson's Center, participants are offered social interaction and discussion as well as professional presentations. A session for caregivers also takes place. Refreshments and parking validation are provided. Family members, visitors, and guests are always welcome.

First Tuesday of every month 10 A.M.-2 P.M.

#### **Northwestern Memorial Hospital**

Feinberg Pavilion, Third Floor, Conference Room A 251 East Huron Street

Free parking at Huron/St. Clair Self-Park

10-11 A.M. Dance 11 A.M.-noon Exercise

noon-1 P.M. Lunch and discussion groups

for patients and caregivers

1-2 P.M. Discussion topic (whole group)

#### **Contact:**

Diane Breslow, MSW, LCSW, center coordinator dbreslow@nmff.org 312-503-4397

Trupti Patel, MPP, program associate trupti@northwestern.edu 312-503-3320

### Clinic Offers Treatment for **Sleep-Movement Disorders**

he Northwestern Parkinson's Disease and Movement Disorders Center has clinical and research programs dedicated to the management of the common and undertreated problems of poor sleep and impaired alertness in PD. The Sleep-Movement Disorders Clinic programs are directed by Dr. Aleksandar Videnovic, movement disorders and sleep specialist.

One of the newest initiatives is the Restless Legs Syndrome Clinic. This common disorder is characterized by an irresistible urge to move one's body to stop uncomfortable or odd sensations. It most commonly affects the legs, mainly in evening hours. While the diagnosis may be delayed, several good treatment options exist.

If you have problems with RLS or any sleep and daytime alertness issues, you may consider a consultation. Call 312-695-7950 to schedule an appointment.



#### WE'RE GRATEFUL FOR SUPPORT

The Northwestern Parkinson's Disease and Movement Disorders Center is grateful for the generous efforts of volunteers, donors, and grateful patients, many of whom are members of the Northwestern Medicine Parkinson's Disease and Movement Disorders Center Advisory Council.



The **Paul Ruby Foundation for Parkinson's Research** hosts its sixth **Concert for a Cure** on August 25 at Tanna Farms in Geneva, Illinois. The all-day, family-friendly music festival features excellent bands, silent and live auctions, great food, and a "kid zone." For more information please visit www.paulrubyfoundation.org.

The **Ruby Foundation** will be the beneficiary of the **Sub5 Century Challenge** for the second year in a row.

On September 9 riders will cycle 25, 75, or 100 miles to support Parkinson's research. See www.sub5century.org for more information.

With the proceeds from both events, this fall the Ruby Foundation again will conduct a formal grants initiative to support Parkinson's research projects at Northwestern through Northwestern Memorial Foundation. The Ruby Foundation has committed to donating \$80,000.

The Northwestern Medicine Parkinson's Disease and Movement Disorders Center Advisory Council continues its competitive grant initiative to fund Parkinson's research by junior investigators. Two grants of \$25,000 each will be available this academic year.

Gifts of all sizes and forms play a direct and significant role in the center's ability to offer a wide variety of services to patients and families as well as to pursue cutting-edge basic and clinical research studies.

If you have an interest in becoming involved with the advisory council or supporting our programs in your own way, please contact Jorie Parwani of Northwestern Memorial Foundation at 312-926-4198 or Barbara Monroe of the Feinberg School of Medicine at 312-503-0761.

Parkinson's Disease and Movement Disorders Center 710 North Lake Shore Drive, 11th floor Chicago, Illinois 60611-3006 www.parkinsons.northwestern.edu

Nonprofit Organization U.S. Postage **PAID** Evanston, Illinois







Northwestern Parkinson's Disease and Movement Disorders Center is proud to be a National Parkinson Foundation Center of Excellence.

CONTACT US 312-503-4397 or 312-695-7950 parkinsons@northwestern.edu

Medical director: Tanya Simuni, MD

Parkinson's Update editors: Diane Breslow, MSW, LCSW, d-breslow@northwestern.edu; Trupti Patel, MPP, trupti@northwestern.edu; Aleksandar Videnovic, MD, MS, a-videnovic@northwestern.edu

Please notify us to be added to our mail or email lists or to update your address. We also welcome your comments and letters.

Northwestern University is an equal opportunity, affirmative action educator and employer. © 2012 Northwestern University. All rights reserved. Produced by University Relations. 8-12/1.6M/AE-VL/1360-1

#### Calendar

#### **SUB5 CENTURY CHALLENGE**

Sunday, September 9 See www.sub5century.org

#### PARKINSON'S DISEASE MOVING FORWARD— ANNUAL PATIENT AND FAMILY SYMPOSIUM

Saturday, September 29, 8 a.m.–12:30 p.m. Northwestern Memorial Hospital 251 East Huron Street, Chicago Call 312-926-8400

#### **MOVING DAY CHICAGO**

Sunday, October 14 Call 1-800-327-4545