

Talking about PD with Your Family

By Diane B. Breslow



No one knows and understands Parkinson's disease like the people who have the diagnosis and those who live with and help care for them. Even so, you yourself, whether patient or caregiver, may not yet accept the reality of the disease, or you may feel frightened, burdened, or sad. At the same time, you have family members—adult children, young children, siblings—who are affected and perhaps confused but want to understand and help. How do you even begin to explain this life-altering condition to them?

The devoted and compassionate care partners in Northwestern's Parkinson's Disease Caregiver Support Group frequently discuss this issue with one another and have some ideas about "what we want our children to know."

The caregivers' first concern is that family members know what Parkinson's disease is and how it is diagnosed. PD is a slowly progressive neurological

disorder that occurs when dopamine-producing nerve cells die or become impaired. The four major motor symptoms that are key to diagnosis are resting tremor, slowness, stiffness, and trouble with balance. Other motor symptoms may include small handwriting, reduced arm swing, soft voice, and loss of facial expression. Nonmovement symptoms may include sleep disturbances, depression, anxiety, and slowed thinking.

Caregivers say that they want to allay their children's fears about PD and genetics. Some young-onset cases may demonstrate a genetic pattern, but for the vast majority of people, PD is not inherited. Most scientists feel that PD results from a tendency or predisposition to develop the disorder coupled with a trigger such as environment, past illness, or trauma. At this time, however, there is no test that can accurately predict who will develop PD. Extensive gene and "biomarker" research is under way. The purpose of biomarker research is to uncover the possible precursors—not necessarily causes—to disease development.

Although no reversal or cure exists, exercise is valuable in symptom management and overall physical and emotional well-being. Lastly, caregivers want their families to understand that while PD may be progressive, it is not fatal.

Caregivers want their family members to understand not just the symptoms of PD but also the daily impact of those symptoms on the patient and the caregiver. To that end, here are suggestions for the patient's adult children or significant family members:

continued on next page

Talking about PD

continued from front cover

- Spend a sizable block of time with the caregiver and the person with Parkinson's. This will give you a firsthand look at specific challenges and issues and help you think about how to be involved.
- Recognize that PD can affect cognition as well as mobility.
- Open your doors to your relative with PD and caregiver. This will give them a change of environment, decrease a sense of isolation, and help them feel valued.
- Understand that a couple's relationship dynamics have changed. One person may now be taking on a greater share of responsibilities.
- Attend a physician visit with the patient.
- Express vocal support to the patient for the healthcare team's care and safety recommendations, e.g., using a walker, not driving, accepting additional help with personal care, wearing a medical identification bracelet.
- Participate in PD advocacy, fundraising, and awareness building.

In addition, caregivers suggest to one another:

- Involve your children. Ask them for their observations about how their parent with PD is doing. Include your family in care planning discussions.
- Make specific, concrete requests to your children and other family members about how they can help you or the person with PD.
- Accept offers of help. Allow people to cook a meal, run an errand, or drive you to the doctor.
- Attend a PD/caregiver support group and invite your children to join you.



- If your children live out of town, provide them with information about PD and tell them about support groups in their area or places they can go to learn more about PD.

As with all of life's challenges, PD is an ongoing journey, one in which we need to face realities little by little, make adaptations, stay connected to who and what are important, and live each day in the best way possible.

Diane Breslow, MSW, LCSW, is the leader of the Northwestern PD Support Group.

Researchers Look at Role of Serotonin Loss in PD

The motor symptoms of Parkinson's disease are attributed to a loss of dopamine-producing cells, but recent research has shown that cells producing the neurotransmitter serotonin are also lost. The loss of serotonin may contribute to PD's motor symptoms—a subject of two research studies in the Feinberg School of Medicine's Department of Physical Therapy and Human Movement Sciences.

“Neuromodulation of Motor Neurons in Parkinson's Disease” is testing participants' reflexes. To elicit reflexes in the arm, researchers apply a vibration to the bicep muscle and then use a robotic device to bend and extend the arm at the elbow.

In “Pathophysiology of Rigidity in Parkinson's Disease,” sensors are placed on the participants' bicep muscles while they bend and extend their arms. The sensors record the pattern of activity of the arm muscles during a muscular contraction.

Besides increasing understanding of what causes the motor symptoms of PD, both studies may contribute to development of therapies.

Each study involves a single morning visit to the physical therapy and human movement sciences department, which is located near Northwestern Memorial Hospital in Chicago. Participants must be diagnosed with idiopathic Parkinson's disease and must not be taking antidepressants that affect the body's serotonin level. Transportation is provided, and participants are compensated.

The study team members are principal investigator Jules Dewald, Alexis Kuncel, and Jessica Wilson. For more information please call 312-503-5843.

Ongoing Programs

PROGRAMS AT NORTHWESTERN

(312-503-4397)

Patient and Caregiver Support Group (dance and exercise and a separate caregiver group): 10:30 a.m.–2 p.m., first Tuesday of every month, Northwestern Memorial Hospital, Feinberg Pavilion, third floor, Room A

PD 101: quarterly class for people newly diagnosed with Parkinson's

Creative Arts (art and music): 1–3:30 p.m., second and fourth Mondays, Prentice Women's Hospital, third floor, Room Q

Patient-Family Educational Symposia: every spring and fall (see page 6)

Caregiver Programs: conferences, coffees, and classes

National Parkinson Foundation–Chicago

Moving Day: October 20 this year (see page 7)

REHABILITATION INSTITUTE OF CHICAGO EXERCISE CLASSES (312-238-5001)

Amplitude-Based Training for Early-Stage PD

Integrated Exercise for Parkinson's: Chicago and suburban locations

DANCE CLASSES IN CHICAGO AND EVANSTON (847-563-8719)

Taught by Citlali Lopez-Ortiz

Chicago: 10–11 a.m. Mondays and Wednesdays, Joffrey Tower, 10 East Randolph Street, third floor, Studio D

Evanston: 9:30–10:30 a.m. Fridays, Dance Center Evanston, 1934 Dempster Street

Dimitri Krainc Is New Neurology Chair

Dimitri Krainc, MD, is the new Aaron Montgomery Ward Professor and chair of the Ken and Ruth Davee Department of Neurology.

Krainc has been awarded numerous honors for his influential research in neurology and neuroscience. A native of Slovenia and graduate of Zagreb Medical School, he spent the past 21 years at Harvard Medical School. He completed research training, a neurology residency, and a



fellowship in movement disorders at Massachusetts General Hospital and Brigham and Women's Hospital. He then served on the neurology faculties at Massachusetts General and Harvard.

Krainc has been credited with uncovering many of the molecular underpinnings of neurodegenerative diseases. His work has focused on the key molecular pathways in the causes of neurodegeneration in order to develop therapies for Parkinson's, Huntington's, and related pathologies.

His numerous professional service affiliations have included

the Society for Neuroscience and the National Institutes of Health's Neurological Sciences and Disorders Committee. An elected member of the American Neurological Association and American Academy of Neurology, he has also been on the editorial board for the *Journal of Neuroscience*. He was named a 2013 Massachusetts General Hospital Research Scholar; the award provides unrestricted funding to allow researchers to pursue projects that may open doors in medicine.

Coordinator Hired to Oversee Research Studies

Ilse Salinas has joined the Parkinson's Center as a clinical research coordinator managing and overseeing multi-disciplinary clinical research studies. Besides coordinating clinical drug trials for advanced PD patients, she oversees a patient registry for the National Parkinson Foundation Quality Improvement Initiative that aims to improve quality of care through research, education, and outreach.

Salinas received a bachelor's degree cum laude from the University of Illinois at Chicago with a major in applied psychology and a minor in sociology. Experienced in crisis counseling and clinical research in academic and hospital settings, she plans to pursue a doctorate in cognitive neurosciences.

New Fellow Joins Center



Danny Bega, MD, has a two-year clinical fellowship at the Parkinson's Center and sees patients with movement

disorders. After earning a medical degree at Rush University in 2009, Bega completed a residency in neurology at Harvard's Massachusetts General Hospital and Brigham and Women's Hospital. He is also pursuing a master of science in clinical investigation at Northwestern; his research focus is complementary and alternative medicine for PD and other movement disorders.



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.



A kit includes the following:

- 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 for displaying it in the hospital room
- PD ID bracelet
- 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

Annual patient and family symposium

Knowledge and know-how for living with Parkinson's disease

Saturday, October 19 • 8 a.m.–12:30 p.m.

Northwestern Memorial Hospital

251 East Huron Street, Chicago, Conference Room A

8 a.m. Registration, continental breakfast, and "Art of Parkinson's" exhibit

9 a.m. Welcome

**9:05 a.m. Keynote address: "Frontiers of Genetic Research in Parkinson's Disease—
How Can We Translate It to the Clinic?"**

Dimitri Krainc, MD, PhD, Aaron Montgomery Ward Professor and chair,
Ken and Ruth Davee Department of Neurology, Feinberg School of Medicine

9:30 a.m. "New Treatment Pipeline"

Tanya Simuni, MD, medical director, Northwestern Parkinson's Center, and
Arthur C. Nielsen Professor of Neurology, Feinberg School

9:50 a.m. "Neurosurgery for Parkinson's Disease: Is It Right for Me?"

Cindy Zadikoff, MD, movement disorders neurologist, Northwestern Parkinson's Center,
and assistant professor of neurology, Feinberg School

10:10 a.m. Break

10:30 a.m. "Sleep and Parkinson's Disease"

Roneil Malkani, MD, movement disorders neurologist, Northwestern Parkinson's Center,
and assistant professor of neurology, Feinberg School

10:50 a.m. "Exercise and Rehab"

Santiago D. Toledo, MD, medical director, Movement Disorders Rehabilitation Program,
Rehabilitation Institute of Chicago

11:10 a.m. Physician panel: questions and answers

11:50 a.m. Break-out sessions

- Young-Onset Networking—Diane Breslow, MSW, LCSW
- Living with Advanced PD—movement disorders physicians
- Exercise
- Therapy through Art and Music

• **To register**, please call Northwestern Memorial Hospital's Health Resources and Physician Referral Service at 312-926-8400.

• **To display your artwork at the the "Art of Parkinson's" exhibit**, please contact Trupti Patel at trupti@northwestern.edu.

Parkinson's Disease Weekend: Annual Symposium and Moving Day®

At the Parkinson's Disease and Movement Disorders Center's symposium on October 19, Northwestern physicians will review the latest PD research and treatment options (see previous page for details). The National Parkinson Foundation's Moving Day Chicago fundraising walk will follow on October 20. The weekend's participants will be able to interact with both physicians and their peers to better understand the disease as well as work together to raise funds for programs and research.

The symposium's topics will include genetic research, neurosurgery, and research on REM sleep behavior disorder in PD; physicians will take questions following their presentations. The conference will end with a series of workshops. The free event includes complimentary continental breakfast and parking. For more information and to register, please call 312-926-8400.

Moving Day unites families, friends, and communities in the fight against Parkinson's disease. This year's celebration of movement will include a family-friendly walk course, a kids area, a caregivers relaxation tent, and a pavilion featuring yoga, dance, tai chi, and pilates, all of which help in managing PD symptoms. To participate, call 312-505-7602 or visit www3.parkinson.org/site/PageServer?pagename=moving_day_Chicago_Event_page.

To take advantage of discounted hotel rates, email Trupti Patel at trupti@northwestern.edu or call 312-503-3320.



Katie Couric

is the Honorary National Chair of Moving Day® in memory of her father who had Parkinson's.

WALK FOR PARKINSON'S



Sunday, October 20, 2013 Lincoln Park, Grove 2

It's a new day for people with Parkinson's! Moving Day® is your chance to unite in the fight against Parkinson's disease. Join us by moving any way you can – by walking, stretching or doing yoga in our signature Movement Pavilion. Together we can raise awareness and celebrate the importance of movement for all of us.

**Visit MovingDayChicago.org
or call 312-505-7602 to register.**

**A day to move.
A day to move others.
A day that moves you!**



Founded in 1957, the National Parkinson Foundation's mission is to improve the quality of care for people with Parkinson's disease through research, education and outreach. NPF has funded more than \$172 million in research and support services to improve the lives of people with Parkinson's.

National Moving Day Partners



Medtronic



www.parkinsonshealth.com

Why Advocate?



By Roger Halleen

Why advocate for Parkinson's research and education? I'm asked this many times in my role as Illinois director for the Parkinson's Action Network. I normally give a two-part answer:

The first part is that I want to build on the foundation started by those who have advocated before us: to improve the quality of life, to work toward finding a cure, and to prevent further generations from suffering with Parkinson's. I then ask people whether they have Parkinson's or know someone who does. If I get a yes reply, I ask why they wouldn't want to do everything they can to improve their own lives or the lives of those with Parkinson's disease.

The second reason for my advocacy work has to do with research. Most people don't realize how much the federal government does to fund research on Parkinson's and help find ways to improve the lives of those living with the disease.

First and foremost, the National Institutes of Health is the largest single funder of Parkinson's research in the world. The NIH supported \$154 million in Parkinson's research in fiscal year 2012 and spends almost \$8 million of that amount right here in Illinois.

Number two on the federal support list is the Department of Defense Neurotoxin Exposure Treatment (Parkinson's) Research Program. Since its inception in 1997, the NETPR program has funded more than \$350 million in Parkinson's research.

Third on the list is the Food and Drug Administration, whose role is essential in speeding access to safe and effective therapies for Parkinson's and other diseases.

The Parkinson's Action Network continues to be the leading voice for patient advocacy in Washington, DC. PAN educates government leaders and the public on better policies for research and improved quality of life for people living with Parkinson's. Advocacy issues include Social Security Disability Insurance and Medicare, Department of Veterans Affairs benefits, and Telemedicine therapy caps.

How can you be involved? Join the PAN grassroots team. We hope that with greater understanding, we will make strides in finding better treatments and a cure for Parkinson's disease. For more information visit www.parkinsonsaction.org or contact me at rogfish@comcast.net or 309-219-1210.

Get Involved

Interested in supporting the Northwestern Parkinson's Disease and Movement Disorders Center?

- Make a gift to support Parkinson's research and clinical care by visiting foundation.nmh.org or contacting Jorie Parwani at 312-926-4198.
- Join the Northwestern Parkinson's Disease and Movement Disorders Center Advisory Council of donors and community and corporate leaders who promote charitable support of Parkinson's research at Northwestern. Contact Jorie Parwani at 312-926-4198 or jparwani@nmh.org.
- Attend an event that supports Parkinson's research at Northwestern, such as the third annual Sub-5 Century on September 8. Participants either bicycle 100 miles in less than five hours or do a 25-mile recreational ride. Visit www.sub5century.org for more information.

YOU'RE INVITED!

What: **CHICAGO CLINICAL TRIALS FAIR presented by
The Michael J. Fox Foundation and Fox Trial Finder**

Who: **Parkinson's patients, their families and friends**

Where: **The Palmer House Hilton Hotel, Chicago, Illinois**

When: **Saturday, September 7 | 8:30 a.m. – 1 p.m.**

This event is a prime opportunity to learn about PD research going on near you. It will **feature an expert panel presentation** led by Todd Sherer, PhD, CEO of The Michael J. Fox Foundation, and provide you with a forum to get your questions answered:

- Can I participate even if I don't have PD?
- How can I fit this into my busy schedule?
- What's required of me if I participate?
- How do I get started?

Join us on September 7 to interact with representatives from all of the leading research centers in the area who are currently recruiting for PD clinical trials and learn more about how **you can play a part** in accelerating this critical research.

PLEASE RSVP BY FRIDAY, AUGUST 23

WWW.MICHAELJFOX.ORG/CHICAGOTRIALSFAIR

This event is free of charge and includes free parking and refreshments.

Questions? Email trialsfair@michaeljfox.org

"The cures we want aren't going to fall from the sky. We have to get ladders and climb up and get them." – Michael J. Fox

Movement Disorders **Clinical Trials** *For information on participating in any of the following movement disorders clinical trials, please call 312-503-0755.*

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 study is recruiting non-PD subjects with sleep disorders and non-PD subjects who have lost their sense of smell. *Funded by the Michael J. Fox Foundation.*

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.

COGNITION

TVP-1012/PM106 (Moderato)

This 24-week study is investigating whether 1 milligram a day of rasagiline (Azilect) is more effective than a placebo in improving cognitive function in mild cognitive impairment. *Funded by Teva-Branded Pharmaceutical Products R&D.*

FATIGUE

Selegiline This study is measuring the efficacy of Selegiline in reducing fatigue symptoms in PD patients.

CERVICAL DYSTONIA

CD-FLEX The purpose is to evaluate the relative efficacy of short, flexible dosing and long, flexible dosing of Xeomin in subjects who report they received therapeutic benefit from onabotulinumtoxinA (Botox®) for less than 10 weeks. Patients are asked to complete questionnaires daily or weekly at home and during 12 to 17 clinic visits. *Funded by Merz Pharmaceuticals.*

The Parkinson's Disease and Movement Disorders Center participates in preclinical and clinical research in order to extend the knowledge and treatment of movement disorders. Recognized by the National Parkinson Foundation as a Center of Excellence, the center's multidisciplinary group of neurologists and neurosurgeons are continuously engaging in cutting-edge research.

Consider making a personal contribution to research by participating in a clinical trial. Clinical research may lead to the discovery of new possibilities in the control or the delay of Parkinsonian symptoms. All study-related care is provided at no charge. For information about participation in clinical trials, please contact the Movement Disorders Research Office by email at parkinsons@northwestern.edu, by phone at 312-503-0755, or by fax at 312-503-0787.

Event Informs Korean Community about PD

In memory of her late mother, Northwestern PD Caregiver Support Group member Rosa Kim (below right) organized and hosted a Parkinson's disease conference for the Korean community at the Korean Cultural Center in suburban Wheeling in May.

More than 100 people attended the event, which was funded by the Parkinson's Disease Foundation and conducted entirely in Korean. It informed people about many aspects of PD, including diagnosis, treatment, and sources of support. The two guest speakers were Sun Ha Park, a neurosurgeon specializing in deep brain stimulation surgery at Seoul National University, whose areas of expertise include stereotactic functional neurosurgery, neurooncology, and gamma knife radiosurgery; and Un Jung Kang (above right), a neurologist who recently left the University of Chicago to become chief of movement disorders and director of the Parkinson's Disease Foundation Research Center at Columbia University.

Printed materials in Korean were distributed, and Seoul National University Hospital



sent a representative. The event was featured in Chicago's Korean news media.

Kim said that when she and her sister were caring for their mother, they "received a lot of help and support from organizations such as the National

Parkinson Foundation and Northwestern's support group. I wanted to provide the Chicago Korean community with the same kind of support that I received."

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Calendar

PARKINSON'S DISEASE ANNUAL PATIENT AND FAMILY SYMPOSIUM

Saturday, October 19, 9 a.m.–12:30 p.m.
Northwestern Memorial Hospital
251 East Huron Street, Chicago

See page 6 for more information.

Call 312-926-8400 to register now.

Contact Trupti Patel at trupti@northwestern.edu to display your artwork at the "Art of Parkinson's" exhibit.

MOVING DAY CHICAGO

Sunday, October 20, 9 a.m.–12:30 p.m.
Lincoln Park, Grove 2, Chicago
Call 312-505-7602
www.parkinson.org