Two New Centers of Excellence Join Global Network

When you live with Parkinson's disease (PD) the right care at the right time can mean the difference between a medication adjustment and a hospital stay, which is one of the many reasons the Parkinson’s Foundation has added two new Center of Excellence designations to its global expert Parkinson’s network.

Columbia University Medical Center in New York, NY, and Rush University Medical Center in Chicago, IL, will join the Center of Excellence network in providing new therapies and care models through grant programs and targeted initiatives such as the Parkinson’s Outcomes Project, the largest clinical study of PD. This sought-after designation, based on clinical and research excellence, has achieved world-wide recognition.

“At Parkinson’s Foundation, we are proud that our longtime investment in Columbia and Rush has played a pivotal role in all significant Parkinson’s research advances,” said Parkinson’s Foundation chief executive officer John L. Lehr.

...continued on page 2
Two New Centers of Excellence Join Global Network

...continued from cover

This newest designation recognizes that both institutions are successfully translating those research advancements into improvements in patient care – exactly what our community so urgently needs, John said.

Parkinson’s Foundation Centers of Excellence achieve their designation after adhering to a rigorous application and peer-review process. Currently, there is a worldwide network of 42 leading academic medical centers participating in cutting-edge research and exemplary patient-focused, multidisciplinary care.

More than 100,000 people living with Parkinson’s seek treatment within the network. To qualify for the designation process, centers must meet strict criteria for research, comprehensive care, patient outreach services and professional education. The network is widely credited with developing and promoting the modern Parkinson’s team model of care and ensuring patients the highest standards of care.

Columbia and Rush each bring rich histories and unique strengths to the network. Columbia University brings an illustrious history in cutting-edge translational research. Rush University offers tremendous innovation in clinical research. Both are renowned for their training of academic leaders worldwide.

“This designation is an enormous honor and recognition of the vital program that we have developed to integrate our three-part mission of research, education and patient care excellence,” said Christopher Goetz, MD, professor of neurological sciences and pharmacology and director of the Parkinson’s Disease and Movement Disorders Program at Rush University Medical Center. “With this new designation, the faculty and staff will direct our efforts continually to enhance our services and work in partnership with our patients and families to meet these three missions.”

Every year the Parkinson’s Foundation brings all Centers of Excellence together to provide updates on care activities and research initiatives. This year’s meeting will focus on impacting care for the patients of today and tomorrow. To maintain the high standards of care centers must re-certify every five years. This process includes a review of achievements as well as a team-based peer evaluation, including an on-site assessment.

“Both Columbia and Rush have a long history of research and training that paved the way for the scientific and clinical networks of movement disorders centers,” said Peter Schmidt, PhD, National Parkinson Foundation chief mission officer. “We will change the course of Parkinson’s for tomorrow’s patients by improving care for everyone living with the disease today.”

To find a Center of Excellence near you, visit www.parkinson.org/search.

The 2016 Annual Report is online www.parkinson.org/annualreport
Letter from the Parkinson's Foundation CEO

Dear Friends and Supporters:

I am honored to introduce myself as the Chief Executive Officer (CEO) of the Parkinson’s Foundation, an organization with a rich history of serving the community.

As readers may know, last year, our two legacy organizations, the National Parkinson Foundation (NPF) and the Parkinson’s Disease Foundation (PDF), merged to form the Parkinson’s Foundation. In January of this year, the Board of Directors named me as the new CEO. Thanks to those of you who have already extended such a warm welcome.

Our team at the Parkinson’s Foundation is eager to work on your behalf to advance our mission and better meet the needs of the community. We will continue to invest in the scientific research to end Parkinson’s disease and to improve the lives of people with Parkinson’s and their families, through improved treatments, support and care.

As we look ahead, there are already exciting events on the horizon and many ways for you to get involved and raise awareness during April, Parkinson’s Awareness Month, and beyond. This June, the Parkinson’s Foundation is bringing together the best scientific minds in the field for a cutting-edge event, World Without Parkinson’s: A Look Into the Future, to mark the 200th anniversary of the publication of James Parkinson’s “An Essay on the Shaking Palsy.” We are also bringing together the Parkinson’s community at several spring Moving Day® walks across the U.S., where we hope you will join us in raising awareness and funds for research.

At the Foundation, we know that this is a pivotal time, one in which the needs of the Parkinson’s community and the potential of science are greater than ever. That’s why we are committed to accelerating the science and care for Parkinson’s on behalf of the millions of people across the globe living with the disease.

We look forward to working with you to ensure that people with Parkinson’s and their families have the tools they need to live well with the disease today, and to ending the disease once and for all. We are stronger together.

Yours in the fight,

John L. Lehr
Chief Executive Officer
Parkinson’s Foundation

P.S. – This April, join the Parkinson’s Foundation in spreading Parkinson’s awareness. #Together4PD

#Together4PD

John L. Lehr
Chief Executive Officer
Parkinson’s Foundation

Parkinson’s Foundation presents
World Without Parkinson’s:
A Look into the Future
A cutting-edge scientific event

Thursday, June 1, 2017
New York, NY
www.parkinsonsfoundation.org/wwp
#WorldWithoutPD
Dr. Danny Bega’s favorite part of conducting the first-ever Parkinson’s disease (PD) improvisation comedy clinical research study is when participants told him how good it felt to make people laugh again.

Through Moving Day® grants, the Foundation funded a study analyzing improvisational (also known as improv) humor as an effective therapy for Parkinson’s. The study, conducted by the Northwestern University Movement Disorders Center, a Center of Excellence, recruited 22 participants—men and women spanning in different ages and stages of PD. Caregivers also attended. For 12 weeks, nearly every participant attended a weekly, 60-minute improv class ready to laugh and perform.

“Parkinson’s is a multisystem disorder that affects physical, psychological and social well-being,” Dr. Bega said. “It’s difficult to see some patients only treating their motor symptoms with medication, but ignoring the mental symptoms.”

Dr. Bega and his colleagues worked with Second City® improv to create a specialized class that focused on addressing PD symptoms like anxiety, depression, memory and speech. At first, participants warmed up by introducing themselves with their name and a physical movement that represented themselves. Some attendees immediately used the opportunity to showcase their vibrant sense of humor.

Next came memory games, like throwing invisible balls of different colors to one another, while remembering who was holding which color. After several weeks, the class advanced to full-on improv comedy. Together, with the two comedy instructors, participants took turns acting scenes, calling scenarios to keep the story going, but most importantly keeping each other laughing.

“Each year, Moving Day grants allow us to support new research initiatives that make life better for people with Parkinson’s,” said Sara O’Hare, NPF Chicago Community Development Director.

For his study, Dr. Bega was surprised to see attendance rates stay nearly perfect for all 12 weeks—a feat in the clinical research world. Each week attendees felt happier and looked forward to attending class. “Through improvisation comedy we saw significant improvements in daily living,” Dr. Bega said.

As a researcher, Dr. Bega would like to see the study conducted in larger numbers. If the findings are duplicated, he would one day like to see improv comedy added to weekly treatment regimens for people with PD. He was thrilled to see attendees develop a tight-knit bond among themselves, some even staying after class to form a support group.

One attendee developed speech problems and facial masking due to his Parkinson’s, but performing improv comedy instantly boosted his mood and reminded him how phenomenal it felt to make people smile.
What's Hot in Parkinson's Disease?

Gut Bacteria and H. pylori

Twenty years ago, no one was talking about the connection between the ulcer-causing Helicobacter pylori (H. pylori), gut bacteria, and Parkinson's disease (PD). But many neurologists are increasingly understanding that the association between a healthy gastrointestinal (GI) system and Parkinson's is of mounting importance.

Some even believe that Parkinson's may start in the gut. People with PD have an altered gut microbiome. Additionally, GI problems like constipation are common. Now, emerging research is proving that a major link between gut microbes and PD exists. This is important because two out of every three people have H. pylori.

The discovery that H. pylori—a corkscrew-shaped bacterium that makes its way through the lining of the stomach—could underpin gastrointestinal disease and lead to ulcers was one of the most important observations in modern GI medicine. Today, researchers are conducting studies to determine whether H. pylori and other gut bacteria are a risk factor for the development of PD. Such findings could lead to new treatment options.

In 2006, Italian doctors treated PD patients infected with H. pylori with either an antioxidant pill or a triple therapy antibiotic regimen. After antibiotic treatment, levodopa response significantly improved as did “on” time. Two years later, researchers in Korea confirmed these results.

In 2012, Danish researchers speculated that chronic H. pylori and gastric infections could be related to an increased risk of the development of PD. Their study, which involved more than 4,000 patients, showed that the use of H. pylori-eradicating drugs was associated with a 45 percent decreased risk of developing PD. Similarly, the use of proton-pump inhibitors was linked to a 23 percent decreased risk of PD.

In 2013, Malaysian researchers presented a study at the International Movement Disorders Society Congress showing that men and women with PD who treated H. pylori with antibiotics significantly improved their response to levodopa, in addition to having more “on” time and better quality of life.

Connecting Other Gut Bacteria to Parkinson’s

A 2013 study showed that eradicating the spread of bacteria improved patient symptoms without disrupting the absorption and metabolism of their PD medication. They also concluded that PD patients with isolated small intestinal bacterial overgrowth had more dopaminergic “off” time, more delayed “on” time and more dose failures.

Last year, researchers from the California Institute of Technology reported the groundbreaking link between PD and gut microbes. In their study, mice were designed to overexpress alpha synuclein, the protein deposited in the guts and brains of people with PD. Antibiotic treatment in these mice reduced motor deficits and molecular indicators of PD. The study highlighted an important and previously unknown brain-stomach signaling pathway.

Until future studies can give us more answers, here's what you can do: if you are experiencing motor fluctuations that cannot be controlled by medication adjustment, ask your doctor to test you for H. pylori. If left untreated, H. pylori may affect the absorption of PD medications and the overall response to treatment. However, until robust clinical studies are conducted, we do not recommend that people with PD seek treatment with antibiotics.

Author: Michael S. Okun, MD, National Medical Director

Read Dr. Okun’s monthly column, “What’s Hot in PD?” online at www.parkinson.org/whatshot.
April is Parkinson’s Disease Awareness Month. In this issue, we focus on commonly asked questions about Parkinson’s disease (PD) from our “Ask the Doctor” forum. We encourage all people with Parkinson’s, caregivers and friends of the Parkinson’s community to start a dialogue with us and take advantage of the informative and free online resource at www.parkinson.org/forums.

Q Should people with Parkinson’s consume extra protein since they tend to lose more muscle mass compared to others? Also, is it true that protein could weaken Sinemet absorption and needs to be timed properly?

A In most cases, too much is made of the protein issues associated with PD. Put simply, focus on eating a healthy, balanced diet. That means consuming a variety of foods across all food groups. Eating well and exercising will help you maintain a healthy weight, without increasing protein. As the disease progresses, you may want to consult with a nutritionist or dietitian about PD symptoms and meal planning. Also, if you have wearing off or fluctuations that are increasingly difficult to control, sometimes taking your Parkinson’s medications 30 to 45 minutes before a meal can help. In a small percentage of patients, we may use a protein-restricted diet to prevent competition for medications, but we never recommend this measure unless protein intake is really affecting medication absorption.

Q My mother has Parkinson’s and recently experienced a bad phase while taking an antibiotic. She couldn’t speak or swallow and had a twitch in her arm. Is this due to the antibiotics? Are certain antibiotics better tolerated?

A All antibiotics used to cure infection have the potential to disrupt PD medication absorption, which can cause PD symptoms to get worse. Antibiotics kill off not only the bad bacteria in your gut, but also the healthy bacteria. That’s why it is important to take probiotics with antibiotics, either in a supplement or by eating probiotic-rich foods such as yogurt. This can help prevent the disruption of gut bacteria. While it’s important to treat infection aggressively, if your mother is on a prolonged course of antibiotics or experiences a worsening of symptoms, talk to her doctor about temporarily adjusting medications.

Q Most of what I’ve read explains REM (rapid-eye movement) behavior disorder (RBD) as something that happens after age 50. Do many younger Parkinson’s patients report this, or is it rare in 30-somethings?

A People with Young-onset Parkinson’s disease generally experience a better quality of sleep with fewer incidences of nightmares and sleep problems than those who are over 50. Even so, younger patients develop sleep disorders, which should be taken seriously because too little sleep can exacerbate PD symptoms. In general, RBD is common in people with PD. The condition causes people to act out their dreams during the REM phase of sleep, moving their legs and arms, shouting and even hitting or punching while sleeping. For safety reasons, it’s important to address RBD with your doctor, regardless of age. A sleep study is the key to getting properly evaluated and treated. The sedative clonazepam may be
prescribed to treat the condition. Overall, disturbed sleep patterns tend to worsen as PD progresses.

**Q** My 87-year-old father who has Parkinson’s is terribly constipated, to the point it has become debilitating. Do Parkinson’s medications cause this? Do you have any advice for this problem?

**A** Severe constipation is a very common, uncomfortable problem for people with PD. It’s caused by the disease itself in both the brain and gut systems. Even though the condition is under recognized and under treated in most people with PD, we have found that many practical therapies, especially when used in combination, are very helpful for combating constipation.

Here are some suggestions to help your father: the first thing he can do is to make sure he gets as much regular exercise as possible. For example, if he can walk or climb stairs, he should do so daily. This will help move food through the bowel. Be sure to check with his doctor before increasing his physical activity. Also, drinking six to eight glasses of water a day, which softens the stool, tends to alleviate constipation. Next, work on gradually increasing his fiber intake. Whole-grain breads and cereals, fruits and vegetables are the best fiber-rich sources. The American Dietetic recommends at least 30 grams of dietary fiber daily for those who have constipation. He might also try a fiber supplement like Metamucil or Citrucel. Below is an at-home recipe we give patients for constipation. He can prepare the natural recipe in advance and take it when convenient:

- 1 cup unprocessed wheat bran
- ½ cup applesauce
- ½ cup prune juice

Mix these ingredients together and refrigerate. Take one to two tablespoons daily for one week. Replace the mixture each week. If needed, increase by one tablespoon each week. Stool frequency and gas may increase the first few weeks, but will usually adjust after one month. To supplement fiber intake, sprinkle wheat bran on food.

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**Tips for Daily Living – Managing Depression**

Like Parkinson’s, depression affects each person differently. No one treatment works for everyone, but through trial and error people can find the regimen that works for them. While antidepressants are often effective, they should be used as part of a comprehensive treatment approach that combines counseling, exercise and social support.

Try some of these options to avoid and treat depression:

- **Weekly check-ins.** Ask family and friends to stop by or call every week.
- **Increase your Vitamin D.** Two to three times a week, go for a walk or read in the sun. Take your sunscreen.
- **Talk to your doctor.** A new prescription or adjustment to your dosage may help.
- **Continue your exercise routine.** Fight the natural tendency to exercise less when feeling down. Exercise improves your mood.
- **Do something different.** Try a new coffee shop or park. Attend a new support group or exercise class.
- **Open all the blinds.** Allow in as much natural light into your home as possible.
- **Try one non-conventional treatment each month.** You might respond positively to: light therapy, music therapy, meditation, massage therapy, acupuncture or aromatherapy.

To talk to a Parkinson’s specialist about depression or other PD symptoms call our Helpline at 1-800-4PD-INFO (473-4636).
This month try something new. According to Mayo Clinic, trying new things boosts confidence and self-esteem, while reducing boredom and loneliness. Call our Helpline, watch a new video, order a free book or attend a new exercise class. Take the quiz to see what resource might help make your life a little easier. Share the quiz with others.

Call our Helpline at 1-800-4PD-INFO (473-4636) to order free educational materials.
As the nation’s population continues to age and more and more people are diagnosed with Parkinson’s disease (PD), the need for community-based programs will increase. The Edmond J. Safra National Parkinson’s Wellness Initiative is already anticipating this need.

The initiative follows a medical-community partnership model, which makes it unique among Parkinson’s fitness programs. Parkinson’s Foundation Center of Excellence healthcare professionals train staff at Jewish Community Centers (JCCs) on PD, so they are best able to meet participants’ needs — inside and outside the fitness center. In turn, JCCs use their expertise in establishing inclusive wellness programming to deliver high-quality, Parkinson’s-specific classes and events in a community-based setting.

One program partner, the Tampa JCC & Federation, recently unveiled a $30 million, 110,000-square-foot facility in south Tampa, complete with an indoor track, rooms for fitness classes and two outdoor swimming pools. The Tampa Parkinson’s program officially launched in early 2016 at their north Tampa campus, in partnership with the University of South Florida (USF) Health’s Byrd Parkinson’s Disease and Movement Disorders Center, a Center of Excellence.

“The new Bryan Glazer Family JCC is in an area that has many seniors living with Parkinson’s,” said Jennifer Goldberg, Tampa JCC executive director of education and special projects.

This new site allows us to reach further into the community, bringing these essential services even closer to those who need them most, Jennifer said.

Between the north and south Tampa JCC campuses, people with PD and caregivers can now participate in five Parkinson’s-specific classes each week, including NIA (neuromuscular integrative action), which blends dance, stretching and martial arts to improves balance, posture and mood. Participants can also attend water aerobics, which helps keep joints fluid and muscles toned. The physical benefits derived from these classes can be crucial for people with PD.

Research has proven that physical activity is a key factor in maintaining a sense of wellbeing and improving mobility. In addition, the Parkinson’s Outcomes Project, the largest-ever clinical study of Parkinson’s, showed that regular exercise can slow the progression of PD.

When the new Tampa JCC location opened, the USF Center of Excellence team offered an in-service day for JCC members and fitness instructors that covered Parkinson’s basics. USF staff reviewed PD symptoms that can manifest during an exercise class and how to help manage them.

“Working together with the JCC and being a source of Parkinson’s education has allowed us to really improve the overall fitness awareness for the instructors. But more importantly, it’s been amazing for my team and the JCC staff to see patients improve as a direct result of attending exercise classes tailored to improving their balance and strength,” said Leigh Donharl, research director at the USF Byrd Parkinson’s Disease and Movement Disorders Center.

The Center of Excellence sees these results first-hand. “One of our patients raves about the JCC’s Tai Chi class,” Leigh said. “He told us his friends noticed a huge improvement in his overall walking, stability and balance. His neurology exam recently confirmed his friends were right.”

In addition to Tampa, the Edmond J. Safra National Parkinson’s Wellness Initiative is offered in the greater Boston, Chicago, New York and Washington, D.C., areas. Everyone is welcome to attend classes, regardless of religious affiliation. Parkinson’s exercise classes and care partner support groups are offered weekly. JCC membership is not required.

The program is funded through the generous support of The Edmond J. Safra Philanthropic Foundation.

For more information visit: www.parkinson.org/wellness.
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<td><strong>4/5:</strong> Celebrate Spring New York, NY</td>
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*Visit our event calendar at [www.parkinson.org/events](http://www.parkinson.org/events).*
As an estate planning and elder law expert, Brian Perlin, PA, knows the importance of establishing long-term care and an estate plan. “The idea behind estate planning is to preserve as much as you can by proper planning, while also making sure you get government benefits, especially if living with Parkinson’s,” said Brian.

Brian would like to share fundamental tips he has learned from his 30-year plus career to help people with Parkinson’s and their families:

- Plan ahead. Do not wait for a new health crisis to start planning.
- A trust may help ensure that you qualify for Medicaid eligibility and government benefits, while securing your assets.
- An estate plan may help you avoid probate, ensuring assets go exactly where you want.
- Including charitable gifts in your estate plan may provide income tax deductions.

Helping thousands of clients establish their estate plans has shown Brian that preparedness is essential. “Planning ahead allows you to make sure that your assets go to whom you want, when you want, at the least possible cost,” Brian said.

Our free planning guide can help you get started. Legacy Society members are a select group of donors who have recognized the Foundation in their wills, trusts, estates and other planned gifts. The generosity of Legacy Society members along with their forethought will help thousands of people with Parkinson’s live better lives in the years to come.

Creating a plan to provide for your family and support the Parkinson’s cause is easy with our step-by-step guide. To request our FREE planning guide, please contact Amy Mauser, Planned Giving Officer, at amauser@parkinson.org or 305-537-9928.

To learn more about estate planning visit www.parkinson.org/plannedgiving.

Team Hope™ for Parkinson’s Endurance Events

- April 30, 2017 – Big Sur International Marathon
- October 8, 2017 – Bank of America Chicago Marathon
- October 22, 2017 – Marine Corps Marathon
- November 5, 2017 – TCS New York City Marathon

For more information, please contact Sara Teeter at teamhope@parkinson.org or 305-537-9951.