Calendar of Events

A Note From the CEO

FEATURE
Parkinson's Foundation Expands Expert Care Network

Ask the Doctor

TIPS & TOOLS
Tips for Activities of Daily Living: Hiring In-Home Care

Caregiver Summit Preview: Intimacy and Parkinson's

How Hector and Mary Fight Parkinson’s Together

Parkinson’s Foundation Hosts First-Ever Volunteer Summit

Your Planned Giving Questions Answered
At every Parkinson’s Foundation event I attend — from Moving Day events to Parkinson’s disease (PD) symposiums — there is one group of people who remain unsung heroes: caregivers and care partners. Throughout every stage of Parkinson’s, they offer strength and support to their loved ones living with Parkinson’s. The Parkinson’s Foundation is here for caregivers — whether you care for someone who is recently diagnosed or are adapting to new challenges as the disease progresses, a strong support network is essential for your well-being and the well-being of the person you are caring for.

In this issue, dedicated to these unsung heroes like Hector (page 9), we invite caregivers to join us for the Caregiver Summit | Cumbre Para Cuidadores, from home or a satellite location, on December 1. Sign up today at Parkinson.org/Summit.

As we close out 2018, I am excited to announce the expansion of our prestigious Center of Excellence network. We also hosted our first-ever Volunteer Leadership Summit where we celebrated dedicated volunteers, many of them caregivers, for helping us fulfill our mission in local communities across the country (page 10).

Finally, we’re excited to announce an expanded community grants program for local Parkinson’s education and outreach programs that address unmet needs. Learn more at Parkinson.org/CommunityGrants.

A Note From the CEO
Parkinson’s disease (PD) diagnosis is life changing — not just for those diagnosed, but for families, too. Living well requires coordinated care. Too often, a person will receive a Parkinson’s disease diagnosis, but for families, too. Living well requires access to expert care, so they can navigate the unknown alone.

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The Parkinson’s Foundation is changing the status quo, raising the standard of Parkinson’s care around the world and ensuring more people with Parkinson’s have access to expert care through every stage of the disease. The Foundation has designated 45 medical centers as “Centers of Excellence,” including 31 centers in the U.S., altogether delivering expert care to more than 145,000 people with PD.

A Parkinson’s Foundation Center of Excellence is a medical center with a specialized comprehensive care team that includes:

- neurologists with movement disorders or PD specialization
- registered nurse, nurse practitioner or physician’s assistant
- social workers, psychologists, psychiatrists or other therapists
- physical therapist
- occupational therapist
- speech-language pathologist

“Today, only 10 percent of people living with Parkinson’s receive the best care from health professionals who specialize in this complex disease,” said John Lehr, Parkinson’s Foundation president and chief executive officer. “Our Centers of Excellence play a critical role in helping the Parkinson’s Foundation reach our goal to ensure the other 90 percent have access to expert care, so they can live better lives.”

This year, the Parkinson’s Foundation added three new Centers of Excellence to its global network: Cleveland Clinic; Medical University of South Carolina; and University of Iowa Hospitals and Clinics. The expansion of the Parkinson’s Foundation Center of Excellence network was made possible by the support of Stephen Bittel, chairman and founder of Terranova.

The Parkinson’s Foundation Center of Excellence status is the most respected and sought-after designation in the movement disorders field, with each center required to meet rigorous research, professional education and patient care criteria. These requirements mean health professionals and people with Parkinson’s alike know that when a center boasts the designation, the quality of care offered is first-rate.

In fact, the Parkinson’s Foundation brings the Center of Excellence network together for an annual conference to share unique treatment ideas and best-care practices. Here, center leaders collaborate, share tried-and-true Parkinson’s treatment successes and present PD-related research findings.

Going Above and Beyond

The Center of Excellence network advances critical research to improve the lives of people with Parkinson’s. Twenty-three centers participate in the Parkinson’s Foundation Parkinson’s Outcomes Project, the largest-ever clinical study of PD. The study tracks more than 12,000 participants living with PD over time to identify which treatments and therapies provide the best outcomes.

The Parkinson’s Foundation also requires centers to help the local underserved PD community, who cannot easily access expert Parkinson’s care. Several centers offer modern treatment options like telemedicine, where people with PD can speak with their specialist from home. Other centers bring care to patients, traveling across the state to train health care providers in Parkinson’s care, allowing patients who live in rural areas to visit the center for an annual appointment, then regularly visit a center-trained local provider. Some centers even offer in-home visits for homebound patients.

Despite the rigor of attaining the Foundation’s Center of Excellence designation, medical centers strive for it. That’s because each center stands as a beacon of regional, long-term hope for people with Parkinson’s.

Expert care means tackling every angle of Parkinson’s. Centers of Excellence do this by providing people with PD, and their caregivers, with a community of support.

To find a Parkinson’s Foundation Center of Excellence near you, visit Parkinson.org/Search or call 1-800-4PD-INFO (473-4636).
I am retired, in my late 60s, and am the primary caregiver for my husband, who has been living with Parkinson's disease (PD) for almost a decade. Lately, I find myself frequently feeling overwhelmed and unable to keep up with my own needs. What should I do?

Caregiver stress and caregiver fatigue occur in most cases. You should take immediate action when you find you are ignoring your own needs, feel isolated, experience anxiety, resentment, demoralization or depression. Up to 70 percent of caregivers are significantly stressed. Half meet the criteria for clinical depression. These symptoms can interfere with day-to-day activities.

Try to alleviate caregiver strain by recruiting friends and family or hiring a paid caregiver to help with care. We try to work with caregivers to identify stress triggers. A referral to a counseling psychologist or licensed clinical social worker usually helps with stress management.

Additionally, some caregivers may require treatment with depression therapy and antidepressants as well as other psychiatric treatments. Remember that you need with depression therapy and antidepressants as well as treatment with medications optimized, see a physical and occupational therapist and use assistive devices (canes, walkers, wheelchairs, etc.). A physical therapist can safely teach your father how to get up from a fall.

Having a plan in case a fall happens is a good idea. An emergency call button or other alarm-based system can be useful. Identifying a nearby friend, relative or neighbor as a first responder is a good precautionary step. Falls often occur in areas (like the kitchen) where the turning radius is narrow.

In the event of a fall:
• Don’t panic.
• Make sure there are no injuries.
• Keep the person comfortable. Avoid further injury by assessing the situation before immediately moving the person.
• If necessary, call a friend, family member or 911 for help getting the person up.
• If there is an injury, immediately see a doctor.

My father has Parkinson’s. We’re concerned his balance issues will lead to a fall. Are there any precautions we can take? What do we do if he falls?

The most important approach is to prevent falling. We recommend that people with Parkinson’s have their medications optimized, see a physical and occupational therapist and use assistive devices (canes, walkers, wheelchairs, etc.). A physical therapist can safely teach your father how to get up from a fall.

Some of our patients use web-based telemedicine services (e.g., Alexa with video) to regularly check in with family members. Set a designated call date and time every week to talk to your mother — not only to see how she’s doing, but to socialize.

Visit as much as possible as nothing replaces in-person care. Ask her for a contact list of her doctors, specialists, pharmacist and neighbors to be used in case of emergency. Also, keep a copy of her financial and legal documents including detailed advanced directives handy.

You may want to consider hiring a geriatric care manager in your mother’s area, who can help arrange financial, legal and medical services, as well as in-home care providers and transportation. Make sure to interview and vet candidates in-person.

For more information on caregiving, call the Parkinson’s Foundation Helpline at 1-800-4PD-INFO (473-4636).

The “Ask the Doctor” Forum is not intended to replace, and should not be relied upon as professional or medical advice. Always consult your doctor for medical issues. The Parkinson’s Foundation assumes no liability for any Forum content. The Foundation does not endorse or recommend any Forum information.

While hiring in-home care can ease duties for caregivers, it comes with its own challenges. It is important to find someone you are comfortable with and who can perform the tasks you need. Here are the ABCs of deciding between hiring through an agency or privately:

• Administration. Hiring privately involves screening applicants, background checks, verifying work eligibility, doing payroll including filing forms and paying taxes, supervising, evaluating and, if necessary, firing the worker.

• Backup. If the worker becomes ill or has a family emergency, who will provide service? Agencies can usually provide another worker relatively quickly.

• Bonding. This is an insurance policy that protects both the employee and the employer against financial loss. Agencies usually bond their employees. Ask your insurance agent if you should bond your privately hired worker.

• Cost. Hiring privately usually costs less than hiring through an agency.

• Consistency. An agency may not be able to provide the same person every time. You may end up having to train several workers.

For more information on how to find outside help visit Parkinson.org/OutsideHelp.
Addressing concerns early can foster emotional well-being. "Start with a frank discussion about feelings, concerns and what feels possible for each person," Dr. Silver said.

Discovering new ways to connect and communicate frees people from expectations and can lead to a deeper intimacy. A professional counselor or therapist can help improve communication. It’s important to discuss feelings of depression, concerns regarding changes in sexual performance or difficulties with current relationships with your doctor, counselor or social worker.

"Intimacy creates a sense of balance for an individual. It can also foster emotional calm, boost connection, and help improve quality of life," Dr. Silver said.

Remember, PD medications can also affect sexual function or create hypersexuality or impulsive control issues; discuss those issues with a healthcare professional, who can adjust medications or offer other options.

Register to listen live to Dr. Silver’s Caregiver Summit presentation along with sessions on “Communication & Coping Strategies” and "Collaborative Caregiving in Action.” Multiple sessions will be hosted in English and Spanish.

Register for the 2018 Caregiver Summit at Parkinson.org/Summit.

Join us 2018 Caregiver Summit December 1

Focusing on Collaborative Care, the Caregiver Summit | Cumbre Para Cuidadores is a free event for caregivers for someone living with Parkinson’s, featuring bilingual sessions.

Register today!
Select a way to participate:
1. Join us in Phoenix, AZ.
2. Watch from your smart device.
3. Attend a live-stream event at a satellite location:
   - Bay Area, CA
   - Orange County, CA
   - San Diego, CA
   - Jacksonville, FL
   - St. Petersburg, FL
   - Tampa, FL
   - Kansas City, KS
   - Manhattan, KS
   - Minneapolis, MN
   - Rochester, NY
   - Syracuse, NY
   - Fargo, ND
   - Columbus, OH
   - Milwaukee, WI

Made possible by Presenting Sponsor ACADIA Pharmaceuticals, Inc.

Learn more at Parkinson.org/Summit.

Not many couples who have been married for 41 years, with four children, seven grandchildren, a dog named Lola, and a Parkinson’s disease (PD) diagnosis, would consider themselves still in their honeymoon stage, but Hector and Mary do.

"Throughout my entire career, every time I traveled for work, Mary took care of everything," said Hector Padilla about his wife, Mary Padilla. "I always appreciated that someone so beautiful, talented and smart, devoted all her efforts to make me happy."

In 2015, Mary was diagnosed with Parkinson’s. Hector was familiar with the disease, as his uncle lived with it. "When Mary was diagnosed I was scared," he said. "She went from being a life-long multi-tasker and a powerful woman, to doubting herself."

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Hector knew it was his chance to take care of Mary. "When she needs me I cannot say no," he said.

Together, they began learning how to manage Parkinson’s. Their first step was to seek the best Parkinson’s care, so Mary began treatment at Memorial Regional Hospital, a Parkinson’s Foundation Center of Excellence. In three years, Hector has never missed an appointment. "I ask questions, describe new symptoms and talk through everything, even though Mary doesn’t always want me to," Hector said.

From day one, the couple complemented their care with Parkinson’s Foundation resources, such as Parkinson.org, to read about symptoms, research and the latest treatment approaches.

"We fight this together," Hector said. "We started exercising hard, eating better, learning more about Parkinson’s and trying to deal with it objectively."

Mary attends PD boxing classes at Memorial Regional Hospital, a Parkinson’s Foundation community grant recipient. Hector also attends, standing in the back of the room, mimicking Mary’s hook-uppercut boxing combinations. "When we go to the gym, I coach her. I’m here for encouragement, which is important for anyone fighting a disease," he said.

Hector helps Mary in all facets of life. “I’ll cook, clean, and bathe her — always helping as much as I can,” he said. “I also don’t baby her. I want her to give all she has and fight as hard as she can to see if we can stabilize this disease.”

Hector’s caregiver advice is simple: “If you care or love someone, you’ll do whatever it takes to support them. I feel great doing things for my wife. She’s the love of my life. How can I walk away from that?”

For information tailored to caregivers visit Parkinson.org/Caregivers.

Hector’s unending love and source of strength in my life is what has allowed me to fight,” Mary said.

“My journey with Parkinson’s is manageable because of his constant support and encouragement to make me feel normal again.”

It’s through classes like boxing that Mary and Hector built their PD community. They were so moved by the sense of togetherness and hope at Moving Day Broward, A Walk for Parkinson’s, that they also attended Moving Day Miami — always attending together to raise awareness and funds to support the Parkinson’s Foundation mission.

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For information tailored to caregivers visit Parkinson.org/Caregivers.
Parkinson’s Foundation Hosts First-Ever Volunteer Summit

“I want to deal with my Parkinson’s disease (PD) and help others deal with theirs. Parkinson’s made me realize we have one life to live and I need to spend time with those most important to me while gaining new experiences,” said Brian Grant, retired NBA player, person living with PD, and keynote speaker at the first-ever Parkinson’s Foundation Volunteer Leadership Summit.

On September 6 and 7, the Parkinson’s Foundation brought together more than 150 of its top volunteers in Irvine, CA — research advocates, fundraisers, People with Parkinson’s Advisory Council members and community leaders — to help further the Foundation’s mission to make life better for people with Parkinson’s.

“The summit was an incredible opportunity for volunteer leaders around the country to come together and share best practices. Every attendee left excited about the Foundation and equipped with new ways to make an even bigger impact in their own PD communities,” said Jim Morgan, summit steering committee member and community leader.

The Parkinson’s Foundation thanks Adamas Pharmaceuticals and the Jeffery Donnelly Trust for their support of the Volunteer Summit. The Parkinson’s Foundation will soon begin hosting monthly volunteer webinars around the country.

To learn more about volunteer opportunities, email Volunteer@Parkinson.org.

Brian Grant speaks at Volunteer Summit.

What is a planned gift?
A planned gift is a donation promised to be given at a future date. These gifts are most often made through a will or trust and allow us to continue our work advancing Parkinson’s care and research.

What is the Parkinson’s Foundation Legacy Society?
The Legacy Society consists of honored supporters who plan to leave a gift to the Foundation in a will, trust, life income gift, retirement plan or another way. Our generous donors leave lasting legacies for future generations.

Can I join the Legacy Society?
Anyone can become a member and no estate gift is too small. Please send us your Letter of Intent for Estate Gifts, which documents your gift and helps ensure your donation is used how you envision.

Which type of planned gift should I make?
We are here to walk you through the process and personalize your planned gift. We’ll help you find out how to give and which gift option provides your best tax and income benefits. These can include gifts of life insurance policies, property, stock gifts and others.

What if I already included the Parkinson’s Foundation in my estate plan?
Please let us know. We want to thank you for your generosity and enroll you as our newest Legacy Society member.

To learn more about planned giving opportunities, visit Parkinson.org/PlannedGiving.

SUPPORT THE FIGHT AGAINST PARKINSON’S DISEASE

We love our monthly donors! Monthly donors are crucial to our work. Your regular contributions provide the reliable funding we need to help the Parkinson’s community, allowing us to conduct groundbreaking research and offer even more free resources.

Join this incredible group at Parkinson.org/Monthly
We have expanded our Helpline hours!
Call our free Helpline at 1-800-4PD-INFO (473-4636) Monday through Friday from 9 a.m. to 8 p.m. ET to get your Parkinson’s questions answered in English or Spanish.