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**FEBRUARY**
9
Expert Briefing Webinar: Motor Symptoms Co-Management: Occupational Therapy and Neurology
Register: Parkinson.org/ExpertBriefings

Virtual events are open to all and available online. For a full list of events and upcoming spring Moving Day walks visit Parkinson.org/Events.

**MARCH**
9
Expert Briefing Webinar: Exploring Non-Motor Symptoms: Neuropathy, Fatigue, GI Issues
Register: Parkinson.org/ExpertBriefings

**APRIL**
20
Expert Briefing Webinar: Mental Well-being and Memory
Register: Parkinson.org/ExpertBriefings

Stay up to date on COVID-19 and Parkinson’s at Parkinson.org/COVID19.

Top 5 Virtual Care Partner Resources

Parkinson’s disease (PD) is often life-altering for caregivers, but you are never alone. We are here for you with these top virtual caregiver resources and more:

1. **Helpline.** Our PD specialists answer all your PD care partner questions and provide referrals to healthcare professionals. → Call 1-800-4PD-INFO (473-4636) or email Helpline@Parkinson.org.

2. **Care Partner Articles.** From tackling a new diagnosis to caring for someone with advanced PD, our articles can help you at every stage. → Check out Parkinson.org/Caregiving.

3. **Podcast.** Listen to experts discuss the latest in PD research and treatments in every episode. → Listen at Parkinson.org/Podcast.

4. **Parkinson’s Today Blog.** Every week, our blog features a new article — from the latest PD research studies to articles written for care partners. → Stay up to date at Parkinson.org/Blog.

5. **Aware in Care Kit.** Care partners can download and print components from our free hospitalization kit to organize a loved one’s medical needs in the event of a planned or unplanned hospital stay. → Visit Parkinson.org/AwareInCare.

Visit Parkinson.org/CaregiversMonth for more resources.
A Note From Our CEO

Every November, we recognize National Family Caregivers Month, and the hundreds of thousands of care partners in the Parkinson’s community. This year, given COVID-19, it is especially important to honor care partners. Care partners are resourceful and flexible, and those skills are even more in demand now because of COVID-19. Care partners also must do everything in their power to stay healthy at home, and ensure they monitor their own physical and mental health.

This issue is dedicated to the wonderful care partners in the Parkinson’s community. Learn about the upcoming supportive care program we will soon launch across our U.S. Centers of Excellence (page 4) and how we are tracking the emotional and financial cost of caregiving in the world’s largest clinical study of Parkinson’s disease (page 7).

The Parkinson’s community is resilient and strong! We will get through this pandemic together and look forward to better days ahead. As we do, read about one remarkable care partner, Parkinson’s Advisory Council member Kelly Weinschreider. She has early onset Parkinson’s and helps her father navigate the disease as well. “Just to see him not have to go through the things that I went through has made it worth it,” Kelly said. Read Kelly’s story on page 8.
U.S. Centers of Excellence Network to Launch Modern Supportive Care Program

The Parkinson’s Foundation and the University of Rochester, a Parkinson’s Foundation Center of Excellence, are working together to launch a groundbreaking initiative to make palliative care a standard part of care across all U.S. Centers of Excellence. Parkinson’s Foundation Centers of Excellence are designated medical centers with a specialized team that practices the best Parkinson’s disease (PD) care, treatments and research.

“It’s exciting because Centers of Excellence are international leaders in Parkinson’s care and set the standard for the field,” said Benzi M. Kluger, MD, MS, project lead. “If successful, in the next three years, team-based palliative care will be a new standard at centers, a new option for everyone who seeks treatment at centers and a new skillset for the healthcare professionals who train at these centers.”

The project, titled Implementing Team-based Outpatient Palliative Care in Parkinson’s Foundation Centers of Excellence, received a Patient-Centered Outcomes Research Institute (PCORI) award. The award will fund the creation of a new program that will launch customized palliative care training across all 33 U.S. centers.

“The Parkinson’s Foundation is excited to create an innovative care program that can not only modify how we treat Parkinson’s through providing an extra level of support to patients and care partners, but how we utilize a front-line telemedicine approach to train PD professionals,” said Nicole Yarab, RN, Parkinson’s Foundation vice president of clinical affairs and secondary lead on the project.

Why A Palliative Care Program?
Palliative care is not the same as hospice care. Palliative care can include hospice — end-of-life palliative care — but also provides support for patients and families from the time of diagnosis. Dr. Kluger, a neuropalliative care (the combination of neurology and palliative care) expert, uses the term “supportive care” to avoid misconceptions around palliative care.

“Proactive supportive care helps people plan for the future; we’re not waiting for care partners to burn out or a patient crisis,” Dr. Kluger said. “A care team provides an extra layer of support for the many medical, emotional and social challenges of this serious illness.”

Palliative care helps people live as well as possible for as long as possible, while assessing care partner needs. In a previous study, Dr. Kluger showed that palliative care for people with Parkinson’s:
• Improves quality of life for the person with PD and caregiver.
• Improves detection and management of non-motor symptoms.
• Addresses known gaps in PD care including caregiver support and advance care planning.
• Can be delivered by teams without formal fellowship training if they receive appropriate guidance.

Palliative Care Training
“Palliative care has been shown to
work for people with Parkinson’s, which is why we are excited to make this a standard practice throughout our Centers of Excellence, while providing virtual training to all our center teams,” said Nicole.

Every U.S. center will receive 10 hours of individualized training sessions designed to create and launch a palliative care program that utilizes each team’s strengths, staff and PD care model. “This is one of the largest implementation models of palliative care ever conducted,” Dr. Kluger said.

COVID-19 quickly shifted the program’s original in-person design to a virtual platform.

Thanks to PCORI’s “COVID-19-Related Project Enhancement” award, the Parkinson’s Foundation is developing the online training for each center and will address COVID-19 topics and telehealth within the supportive care model. After training, each center will receive ongoing coaching to adjust and optimize each palliative care program once in practice.

The Parkinson’s Foundation and Dr. Kluger will launch the new palliative care training program this fall, ultimately reaching approximately 650 Center of Excellence healthcare professionals — including neurologists and clinicians. Soon, every person with Parkinson’s who receives treatment at a U.S. Center of Excellence and their care partners will have a new level of supportive care designed to make life better.

The phrases palliative care or hospice can make anyone feel unsettled and anxious. However, knowing what these terms mean and how they can help a person with Parkinson’s disease (PD) and a care partner can bring calmness and often an extra layer of support.

Visit Parkinson.org/Library for more fact sheets and educational resources.
Between telehealth and in-person appointments, medication alarms, meal preparation and more, many care partners do not often have the time to attend a weekly class or group. What if care partners had access to programs made for them, located where their loved one receives treatment?

Parkinson’s Foundation Centers of Excellence are designated medical centers, each with a specialized team that treats people with Parkinson’s disease (PD). While centers acknowledge the unique needs and tireless efforts of care partners, some go beyond and some also provide specially designed care partner programs.

With two locations in Minnesota, the Struther Parkinson’s Center treats approximately 1,800 people with Parkinson’s. Up to 90 percent have a care partner who can access the center’s classes, conferences, support groups and respite through its day program.

Located in Phoenix, AZ, the Muhammad Ali Parkinson Center (MAPC) in Barrow Neurological Institute delivers expert care to more than 2,300 people with PD, along with unique care partner classes and support. “We’ve often been described — as many centers probably are — as a lifeline for patients and caregivers,” said Darolyn O’Donnell, MS, CTRS, recreation therapy coordinator at MAPC. “We love to see our caregivers involved and we know they need help, so we want to support and help them along the way.”

The center’s popular online six-week “Caring for You, Caring for Me” class is led by MAPC’s Joanne Ruelas, LMSW, social worker and educator, and designed by The Rosalynn Carter Institute for Caregiving. Courses explore self-care, stress reduction, communication, problem-solving, resource building and more.

The center’s acclaimed Hispanic Outreach Program for PD connects MAPC with more than 800 people in the nearby community — while reaching 16 countries through virtual conferences. For 13 years, MAPC program coordinator Claudia Martinez, MD, has familiarized herself with the local Hispanic community, helping customize center programs. “Many times, we mistakenly think that providing services in Spanish will be enough, but if you don’t understand the culture there are a lot of barriers that will come into play,” Dr. Martinez said.

“The Parkinson’s Foundation Centers of Excellence Network is constantly evolving and so do each center’s local programs. It is inspiring to see how centers help their local underserved PD communities, while addressing the wide-ranging needs of care partners,” said Kristin Wallock, OTD, Parkinson’s Foundation director of clinical affairs.

One of Struthers’ most popular care partner programs is its 12-part “Caregiver Skills-Building Class,” where various healthcare professionals teach critical, hands-on care skills like how to address hallucinations and incontinence. “We thought we taught people absolutely everything to find out they didn’t know the basics,” said Rose Wichmann, PT, director of Struthers Parkinson’s Programs. These classes deliver practical,
actionable caregiving steps without taking time away from valuable support groups.

Struthers support groups are designed to help care partners through all stages of PD and other movement disorders. Advance planning quarterly classes cover health care directives, estate and financial planning and more. “It’s going to help guide families if decisions need to be made,” Rose said.

Before COVID-19, both centers hosted unique annual events in recognition of National Family Caregivers Month. Struthers hosted an annual complimentary caregiver luncheon, while MAPC hosted a luncheon and workshop in English, as well as a picnic to celebrate extended family who, in the Hispanic community, often help care for a loved one with PD.

In August 2020, the Foundation launched its new Centers of Excellence Community Outreach Resource Education grants to support community-based education and outreach programs that address unmet needs in the PD community.

The newest care partner program in the Center of Excellence network is the University of Pennsylvania’s “Close Contact for Couples with Parkinson’s” workshop, a Parkinson’s Foundation grantee. Designed for couples, the program will foster intimacy and communication that may have been lost while managing with PD.

Find your nearest Parkinson’s Foundation Center of Excellence at Parkinson.org/Search.

Parkinson’s Outcomes Project Explores Emotional and Financial Cost of Caregiving

The Parkinson’s Outcomes Project is the largest clinical study of Parkinson’s disease (PD) in the world. In addition to tracking 13,130 people with PD, the study also clinically measures care partner burden using the Modified Caregiver Strain Index (MCSI) across 21 Parkinson’s Foundation Centers of Excellence, with 8,275 care partners enrolled in the study. Among these care partners, 78% experience care partner strain with the biggest sources of strain being time (37%) and social constraints (31%).

In a new study, Nabila Dahodwala, MD, from the University of Pennsylvania, a Center of Excellence, examined the emotional and financial cost of caregiving. The study surveyed 660 people with Parkinson’s and care partners who were enrolled in the Parkinson’s Outcome Project across 15 U.S. Centers of Excellence.

Dr. Dahodwala found that caregivers experienced higher rates of caregiver strain and symptoms of depression as Parkinson’s disease progressed in their loved one. Additionally, the annual cost of caregiving became increasingly unaffordable as the disease progressed.

660 Care partners surveyed, all enrolled in Parkinson’s Outcomes Project.

Annual Cost
The cost of caregiving increased from $12,500 a year in the early stages to $35,000 for advanced PD.

Time Each Week
Increased from 33 hours a week in early stages to 93 hours per week for advanced PD.

Care Partner Gender
- Female (72%)
- Male (28%)

Care Partner Relation
- Spouse (92%)
- Parent (1%)
- Child (4%)
- Other (2%)

Read more about navigating caregiving-life balance at Parkinson.org/CaringForYou.
The Life of a Parkinson’s Advocate: Living With and Helping My Father With Parkinson’s

Before Tom Arnold was diagnosed with Parkinson’s disease (PD) in 2015, his daughter and part-time care partner Kelly Weinschreider already knew he was living with the movement disorder. He’d lost his sense of smell, experienced problems sleeping and eventually, developed a tremor. Though they waited until Tom’s symptoms impacted his quality of life to see a neurologist, Kelly was certain it was Parkinson’s because she was diagnosed with it at 29.

Kelly, who lives with her husband in Chicago, IL, continued working until 2012, eventually making the difficult decision to step back from her role due to PD progression and medication side effects. “I’m very much a people person,” Kelly said. “I felt like my purpose was gone.” She soon found it again, this time playing an active role at the Parkinson’s Foundation. “I threw everything I had at it and really found that it came back to me in a great way.”

Now beginning her second year on the Parkinson’s Advisory Council (formerly PPAC), Kelly helps align Foundation priorities with the needs of the community. “It’s not just a title and we’re not just patients or caregivers, we actually have influence in the organization, which is wonderful,” Kelly said.

She’s given her time to many Foundation initiatives, including Moving Day, A Walk for Parkinson’s, and Research Advocates, who are trained to assist researchers with studies and clinical trials. She also helped establish the groundbreaking Women in PD initiative, addressing the needs of women living with PD who are often overlooked when it comes to Parkinson’s research, symptoms management and more.

“I’ve been part of various studies, I approve grants — I’ve really tried to be a part of everything the Foundation has offered me,” Kelly said. She also utilizes what she has learned along the way, honored to be able to help her father discover team-based PD care and to ease her mother’s care partner responsibilities.

“Just to see him not have to go through the things that I went through has made it worth it.
- Kelly

Kelly helps her father live with Parkinson’s, from experience. When Kelly noticed a sudden cognitive change, she immediately knew who to call — the symptom was linked to a PD medication he soon stopped taking. She helps him find specialists and helped her mother order his medication in pre-sorted packets. “There are things I can do to help them that they wouldn’t know to do,” Kelly said.

Kelly’s unique perspective gives her a rare insight serving on the Parkinson’s Advisory Council and helps bring attention to available resources for the PD community. “I want to bring awareness to what’s out there and what opportunities are available to make people’s lives easier,” Kelly said.

At this part of her life, Kelly is relieved to be a part of something again. “The Foundation has been wonderful — they reach out when they need help, they have guided us in such a great direction with Women in PD — everybody has such a passion for what they’re doing,” she said.

Get engaged with the Parkinson’s Foundation. Learn more at Parkinson.org/GetInvolved.
Experts Answer Top Care Partner Mental Health Questions

Though essential to well-being, optimal mental health can be difficult to maintain for those living or caring for a loved one with Parkinson’s disease (PD).

Care partners worldwide asked mental health questions during the popular session “Your Questions: Mental Health” at the Parkinson’s Foundation 2020 Care Partner Summit | Cumbre Para Cuidadores. Panelists included Linda Pituch, Helpline Senior PD Information Specialist; Travis Turner, PhD, Assistant Professor and Director of the Neuropsychology Division, Medical University of South Carolina; and Caryn Balaban, MPH, care partner.

**Q:** What mental health issues are part of Parkinson’s?

Dopamine level changes in the brain in PD can influence mood changes. Depression, apathy, anxiety and mood swings are common. Anger and irritability are too, whether as symptoms, medication side effects or even frustration arising from feeling a loss of control.

Uncover what’s behind mood changes to begin addressing them. Is your loved one sleeping well? Are they socializing? Active, attuned listening (repeating back what you think your loved one is saying) can de-escalate frustrations and ease mood changes.

**Q:** How can you alleviate PD mental health issues?

Exercise improves everyone’s mental health and is one of the best ways to combat Parkinson’s symptoms, including apathy. Whether you live with PD or care for someone who does, choose an exercise you enjoy and do it regularly.

Social engagement, in a PD support or exercise group and volunteering, can be as important as exercise to improve apathy, depression and other mood changes. During the COVID-19 pandemic, take advantage of virtual meeting apps, text or call friends and family, or check out a PD Health @ Home event at Parkinson.org/PDHealth.

**Q:** How can I encourage my loved one to be more social?

Physical and cognitive changes that accompany Parkinson’s can frustrate those who live with PD. Remind them people are less concerned with us than we are with ourselves. Friends and family often quickly adapt to changes in one’s communication or abilities.

Psychotherapy or counseling can help people process change, but affordability can be an obstacle. Some Medicare plans cover a set amount of individual psychotherapy sessions per year. Cognitive behavioral therapy can also help. It teaches people to create new behaviors and thinking patterns.

**Q:** What is the best way to manage my own mental health as a care partner?

Caring for your own mental health as a care partner is vital. Take regular caregiving breaks and seek help professionally or from a trusted friend. As COVID-19 keeps us social distancing, visit PDConversations.org — the online Parkinson’s Foundation support network for care partners and those living with PD — to discover more ways to engage, decompress and stay social.

Watch 2020 Care Partner Summit sessions at Parkinson.org/Summit.
12 Ways to Stay Active and Engaged From Home

Many people with Parkinson’s disease (PD) and care partners have spent most of 2020 at home, trying to stay safe and healthy. Social isolation and repetitive days can easily lead to care partner burnout, worsening PD symptoms due to emotional stress, anxiety and less exercise for both. Use this article as a checklist to try new ways to engage online and stay physically and mentally active.

Engage Online
The Parkinson’s Foundation has developed and launched new PD-related online programs and events:

1. **PD Health @ Home** hosts new weekly online events designed for care partners and people with PD. Learn relaxation techniques and hear from experts at Parkinson.org/PDHealth.

2. **Expert Briefings** educational webinars launched its new season addressing critical PD topics. Register for all upcoming webinars and participate at Parkinson.org/ExpertBriefings.

3. **Connect with us on social media**. We love when you comment on our Facebook, Instagram and Twitter. Visit Parkinson.org/Social.

4. **Virtually volunteer**. Complete our volunteer interest form at Parkinson.org/Volunteer.

Keep Moving
Exercise can help people with Parkinson’s manage their symptoms but staying indoors adds a new challenge. Plan to move every day — from a quick walk to trying new online exercise videos.

5. It is never too late to begin physical, occupational or speech therapy to help with PD symptoms. Many therapists currently offer telehealth sessions; speak to your care team.

6. **Try PD Health @ Home’s Fitness Friday** series. Follow our 12-minute physical therapist-led videos at Parkinson.org/FitnessFriday.

7. **Go on a daily walk**. Remember to wear your mask and stay six feet apart from others. Walking helps maintain leg strength and strong, healthy bones.

8. **Ask your loved one to help with household tasks**, no matter how small.

Thinking and Memory Exercises
Parkinson’s can impact thinking skills. Exercise your brain to avoid the additional inactivity and social isolation of staying home. Mental stimulation can help with depression and anxiety.

9. **Find a local support group** or wellness program that meets virtually. Call our Helpline at 1-800-4PD-INFO (473-4636) to find one nearby.

10. **Keep meaningful objects** in clear view, like photographs and mementos, to inspire and share memories.

11. **Listen to our podcast**; every episode features a PD expert and discusses the latest PD topics, treatments and research. Visit Parkinson.org/Podcast.

12. **Schedule a weekly call** or FaceTime session with a family member or friend to stimulate the day. Reach out to new people every week.

Find and register for free upcoming virtual events at Parkinson.org/Events.
Super Bowl Champion Kansas City Chiefs player Daniel Sorensen and his family began noticing gradual physical changes in his dad, Kory, who was diagnosed with Parkinson’s disease (PD). The family was stunned.

“This was the most amazing man in the world to us — so strong, always active and a coach to me and my five siblings growing up,” Daniel said. Suddenly, Kory seemed to age 10 years in three months and had trouble moving. The family began looking for help.

“My mom called the Parkinson’s Foundation Helpline, where she found kind words, vital resources and much-needed reassurance that helped us prepare for this disease,” Daniel said. “In a way, this time in our lives was a gift. When we otherwise may have gone about our busy lives, instead we came together every chance we could. I called him every day on my drive home from my Chiefs practices. Dad always wanted to hear how my game went.”

The Sorensens battled Parkinson’s as a family. Kory’s symptoms progressed and a few years after his diagnosis, the “heart and soul of the family” passed away.

Today, the mission of the Parkinson’s Foundation remains personal to Daniel. “Those living with Parkinson’s and the loved ones caring for them need all the help we can get in navigating daily life with this disease. My family and I are committed to the Parkinson’s Foundation and ultimately finding a cure. We are fortunate enough to make a $100,000 donation and hope this will inspire our greater community to support their work.”

“I hope this gift motivates others to give to the Parkinson’s Foundation,” Daniel said. “It means so much to honor my father’s legacy, and I’m proud to have a role in raising awareness and funds for this disease. After all, Parkinson’s doesn’t stop. And as a supporter of the Parkinson’s Foundation, neither will I.”

Learn how a major gift can impact the Parkinson’s community and critical research. Contact Katherine Griswold, Vice President of Individual Giving, at KGriswold@Parkinson.org to learn more.
Let us answer your Parkinson’s questions!

Call our free Helpline at 1-800-4PD-INFO (473-4636) Monday through Friday from 9 a.m. to 8 p.m. ET to speak to a Helpline specialist in English or Spanish.

Join the Conversation.
PDCConversations.org

- Join the conversation in one of our eight discussion groups.
- Find a community with others who share your interests.
- Check out the top five trending topics.

We’re here for you.

1.800.4PD.INFO
Helpline@Parkinson.org

Comments or Questions? Contact us.
Contact@Parkinson.org
Toll-Free: 1-800-4PD-INFO (473-4636)
Parkinson.org

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