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Parkinson's
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2023 Events

FEBRUARY

25 Parkinson's Revolution
Sign Up: Parkinson.org/Revolution



View all upcoming events at
Parkinson.org/Events.

MARCH

8 Expert Briefing: Parkinson's and Medications: What's New
Register: Parkinson.org/ExpertBriefings

19 United Airlines NYC Half Marathon
Sign Up: Parkinson.org/NYCHalfMarathon

30 Big Sur International Marathon
Sign Up: Parkinson.org/BigSurMarathon

APRIL

12 Expert Briefing: A Balancing Act: Freezing and Fall Prevention in Parkinson's
Register: Parkinson.org/ExpertBriefings

15 Moving Day San Jose
Register: MovingDaySanJose.org

28 Eugene Marathon Weekend
Sign Up:
Parkinson.org/EugeneMarathon

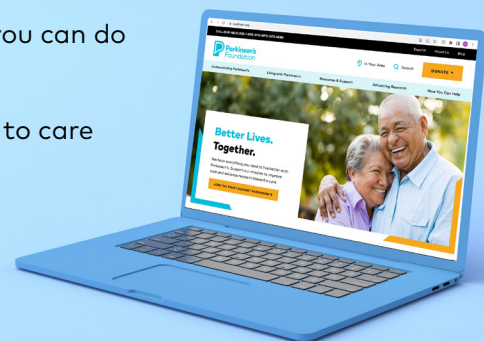
29 Moving Day Westchester County, NY
Register:
MovingDayWestchesterNY.org

30 Moving Day Palm Beach
Register: MovingDayPalmBeach.org

How to Find Support for Care Partners

November is National Family Caregivers Month. This year, the Parkinson's Foundation and Kyowa Kirin are joining together to highlight the resources designed to help Parkinson's disease (PD) care partners and their loved ones. Here are six ways care partners can find support:

- 1. Contact our Helpline.** Find answers to your PD care partner questions and references to local healthcare professionals and wellness programs. Call **1-800-4PD-INFO (473-4636)** or email Helpline@Parkinson.org.
- 2. Connect with your Parkinson's Foundation Chapter.** Getting involved with your local chapter can help you build connections in your community. Find a chapter near you at Parkinson.org/YourArea.
- 3. Take a free online care partner course.** Our Care Partner Program offers self-paced online courses that feature conversations with care partners and lessons from health professionals. Register at Parkinson.org/CarePartnerProgram.
- 4. Make plans.** Register for weekly virtual events (including exercise classes you can do together) at Parkinson.org/PDHealth.
- 5. Explore our new website.** Our all-new website features articles dedicated to care partners. Visit Parkinson.org/Caregivers.
- 6. Visit us** as we highlight care partner resources throughout November at Parkinson.org/CaregiversMonth.



Update From Our People with Parkinson's Advisory Council Chair



LISA CONE
PERSON LIVING WITH PARKINSON'S

The only way the Parkinson's Foundation can help people with Parkinson's disease (PD) is through the participation of the people who live with this disease. Advocates, like me, who openly share their successes and challenges provide a window into first-hand insights. By sharing, we have an opportunity to improve the lives of others.

With one million people living with PD in the U.S., and rising, there is greater urgency to the work of the Foundation, and to provide more access to care. The Foundation's Global Care Network is an invaluable resource to thousands (learn more on page 6).

This November is National Family Caregivers Month. This issue is dedicated to care partners – to those who partner with us in our effort to live our best lives. Often a care partner will experience something about us in a way we can't see ourselves, so we need to make sure their voice is treated equal to ours. We also need to encourage our partners to care for themselves too.

This November, join us and engage with our **#CareGiversCan** campaign. All month long we will highlight resources and the many ways caregivers can do anything, and we invite you all to work alongside us.

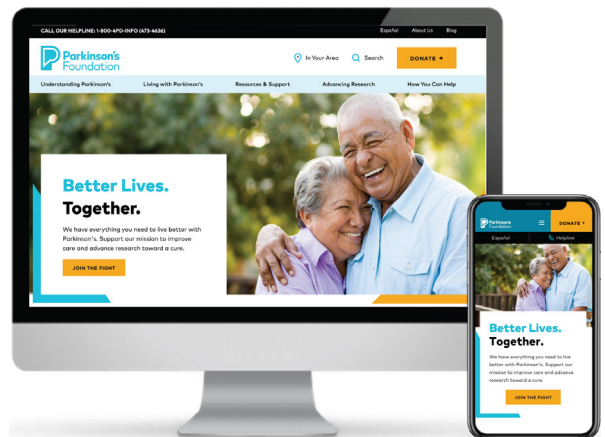
Lisa Cone
People with Parkinson's Advisory Council Chair

Help us invest an additional \$30 million to accelerate Parkinson's research, improve care and increase access to quality-of-life programs.

**REACH
FURTHER**

Learn more at Parkinson.org/Reach.

Check out our new look at **Parkinson.org**



Featuring new articles and the latest information to help you live better with Parkinson's.

Our Essential Guide to Identifying Care Partner Needs



Since Parkinson's disease (PD) is unpredictable and progresses differently for everyone, being the care partner to a loved one with this disease can often leave you feeling out of control and worrying about many possible futures.

We identified the needs of care partners to help you feel more in control through this process. As you read this, know that the goal is not to address every need, all at once. Use this as a guide that can help you identify where you should start, and who in your life can help you address each need.

1. Learn About Parkinson's

Equipping yourself with information can help you manage and prepare for this disease as a care partner. It can be helpful to learn about PD in categories — early-stage, symptoms, treatments. Explore our PD Library at [Parkinson.org/Library](https://www.parkinson.org/Library) for in-depth information.

2. Master Your Time

For most, caregiving is time-intensive. You may find yourself always working towards using your time effectively so that you can make time for yourself and your loved one — and that's OK. Try these tips:

- Get organized. Make daily and weekly lists of things to do. Aim for manageable and realistic tasks.
- Prioritize. Do the most important or difficult things first. Forget unnecessary tasks and delegate tasks that don't have to be done by you (like yardwork).
- Balance flexibility and routine. Routines will help you and your loved one maintain a manageable day-to-day flow. However, remember that some things are beyond your control.

3. Prioritize Self-Care, Health and Respite

If you do not stop to take care of yourself, you will not be adequately prepared to take care of your loved one with PD.

- Schedule breaks. Resting is necessary and productive. Build it into your schedule and protect it.
- Tend to your own health. Exercise leads to better sleep, decreased tension and depression

and increased energy. Staying hydrated, eating well, and keeping your own medical appointments are all essential.

- Recognize when you are stressed. Only you can set your limits and stick to them. Bring in outside help (family or paid worker) so that you can take a break.



Know the Signs of Depression

- An estimated 20 to 60% of care partners experience depression. Symptoms can include sleeplessness, loss of appetite and feelings of hopelessness, among others. If you think you may be depressed, find a supportive mental health professional. In most cases, depression can be treated. **Learn more at [Parkinson.org/Depression](https://www.parkinson.org/Depression).**

4. Build Your Support Team

It may sometimes feel like you are alone, which is why it is important to establish a support team early on. A support team can consist of health professionals, friends, family and other loved ones who can help prevent isolation and provide help when you need it.

No one person is ever able to meet all an individual's needs. Begin adding outside resources to your caregiving early on. This makes adding other care sources easier as the disease progresses.

5. Work on Your Relationship

Work to maintain your relationship outside of the caregiving role. Communicating about Parkinson's throughout your journey is a critical aspect of living well with the disease, that can also be compromised if your loved one experiences speech or voice issues.

Good communication takes intention and adaptation. Allow time to have conversations about each of your PD experiences; share your fears, feelings and needs. Express love and appreciation as well as concerns. Try to find new activities that allow you to enjoy each other outside of PD-related tasks.

6. Review Medical, Financial and Care Decisions

Just as there is no one-size-fits-all PD treatment, there is no single best approach to making decisions surrounding financial planning, medical preferences and long-term care. Bring up these topics early and often so you are on the same page. For more information on PD-specific legal and medical planning, visit [Parkinson.org/LivingWithParkinsons](https://www.parkinson.org/LivingWithParkinsons).

7. Utilize Parkinson's Resources

For many care partners, the hardest part of getting help is finding the help you need. The good news is, that there are many types of organizations and diverse resources, services, information and support. Know that your first call can always be to the Parkinson's Foundation Helpline at **1-800-4PD-INFO (1-800-473-4636)**. We can provide up-to-date PD information, referrals to healthcare professionals, community resources and more.



Explore the all-new [Parkinson.org/Caregivers](https://www.parkinson.org/Caregivers) for in-depth articles and resources designed for care partners.

Activities of Daily Living: For Care Partners

As Parkinson's disease (PD) progresses, daily activities can become more challenging. Care partners are essential in helping their loved ones adjust to these changes, however it is important to know your limits and protect your own health — and back — as you offer support.



STANDING AND SITTING

- Find a chair with sturdy arm rests and a stable base. Low seating and upholstery such as velvet can make it more difficult to move.
- Check that your loved one's feet are placed firmly underneath before standing.
- Use cues like "nose over toes" to set a goal for leaning forward and transitioning to a standing position.
- Avoid pulling arms or legs.



WALKING

- People with PD often take small steps, which are more unstable. Remind them to take big, long steps.
- Focus on only walking — avoid distractions or doing another task at the same time.
- Remove tripping hazards around the home — such as area rugs.



FREEZING

- "Freezing" episodes are often described as feeling like your feet are glued to floor. Freezing is a significant cause of falls. There are ways to help a loved one through these episodes.
- Avoid tight turns. Instruct your loved one to make wider turns as freezing often happens while turning around in close quarters.
- Count aloud or play music to help during a freezing episode.

Explore more care partner tips for activities of daily living at [Parkinson.org/CaregivingTipsforDailyLiving](https://www.parkinson.org/CaregivingTipsforDailyLiving).

Global Care Network Expansion Extends Access to Parkinson's Care

The Parkinson's Foundation is growing its Global Care Network in response to the needs of the one million Americans currently living with Parkinson's disease (PD). The Foundation recently designated 10 new Global Care Network medical centers in the U.S., all of which aim to provide people with PD access to high-quality care when and where they need it.

Though Parkinson's is the world's fastest-growing neurological disease, comprehensive care is not widespread. Nearly 40 percent of people with PD do not receive care from a doctor with advanced movement disorders training.

"Ensuring everyone with Parkinson's disease can access the care, tools and support they need to live well is the driving force of our mission," said John L. Lehr, Parkinson's Foundation President and CEO. "Every center in the Global Care Network is a leader in Parkinson's care and helps bring forward new treatments and practices that improve outcomes for people with Parkinson's."



Dartmouth Hitchcock Medical Center team, a newly designated Parkinson's Foundation Center of Excellence.

What is the Global Care Network? The Parkinson's Foundation Global Care Network expands access to high-quality care for people with PD and enables health professionals to advance and share their knowledge. These designated centers offer specialized, team-

based Parkinson's care. Center teams include movement disorder specialists, physical and occupational therapists, mental health professionals and others who stay current on the latest PD medications and therapies.

THE 4 NEW CENTERS OF EXCELLENCE

- **Cleveland Clinic Las Vegas**, Las Vegas, NV
- **Dartmouth Hitchcock Medical Center**, Lebanon, NH
- **The University of Utah**, Salt Lake City, UT
- **Virginia Commonwealth University**, Richmond, VA

Centers of Excellence

These 51 medical centers located around the world offer care teams who provide the latest treatments and are on the forefront of conducting cutting-edge Parkinson's research. Each center must meet rigorous care, research, professional training, community education and outreach standards.

Comprehensive Care Centers

The newly established Parkinson's Foundation Comprehensive Care Center designation recognizes medical facilities with specialized, multidisciplinary teams providing evidence-based PD care. Participation in clinical research is not mandatory, but these centers

must meet all other rigorous qualifications.

"Following a rigorous process to receive this designation, we are thrilled to be the first-ever Comprehensive Care Center in the Gulf Coast region. We are proud to join this larger network of high-quality sites that actively make a difference in communities by providing comprehensive care to people with Parkinson's disease."

- Dr. David J. Houghton,
Medical Director of Ochsner
Neuroscience Institute

Each of these six new centers reach locations previously underserved in wide-ranging Parkinson's care, including first-ever Michigan, Hawaii, Louisiana, Connecticut and Arkansas locations.

THE 6 NEW COMPREHENSIVE CARE CENTERS

- **Spectrum Health**, Grand Rapids, MI
- **Queens Medical Center**, Honolulu, HI
- **Ochsner Neuroscience Institute**, New Orleans, LA
- **Hartford HealthCare**, Hartford, CT
- **University of Tennessee Medical Center**, Knoxville, TN
- **University of Arkansas Medical Sciences**, Little Rock, AR

Visit [Parkinson.org/GlobalCareNetwork](https://www.parkinson.org/GlobalCareNetwork) for a full list of all Global Care Network centers.

DO'S and DON'TS of Caregiving from Afar

People who live far away may wonder how they can help their loved one with Parkinson's disease (PD) in a meaningful way. Living out of town does not mean you are not involved or do not care. There are limitations when caregiving from afar, but you can still help in many ways.



DO'S



Learn about Parkinson's. You will be better able to provide support if you have a basic understanding of the disease. Get stated at [Parkinson.org/PDLibrary](https://www.parkinson.org/PDLibrary).

Be well-versed in your loved one's needs. Learn about his or her general health and keep a list of doctors and neighbors along with contact information. Also keep financial and legal documents easily accessible.

Let the primary care partner know you are there for them. Keep an open line of communication.

Even during tough times, many people do not want to bother their adult children or relatives.

Call every week. Set a designated day and time and make the call faithfully. Try to use video during calls so you can see each other.

Talk finances. Inquire tactfully but clearly. People rarely ask for

financial help. If possible, offer to buy groceries online, a weekly meal, medical products, help with household utility bills or home-related services.

Send a caregiver gift. This can be something simple from a hand-written card or flowers to a self-care appointment, like a massage. Small acts of kindness can mean a lot for a caregiver going through a trying week.

Visit. Budget funds for regular trips to check on your family and plan ahead with the primary caregiver so you can provide them with respite.

- Remember you are there to provide a listening ear and a helping hand.
- Offer to take over key responsibilities during your visit so the primary caregiver can take time for themselves and catch up on appointments.

Don't give up offering to help.

There are many ways you can offer support. If in doubt, directly ask how you can be of the most help.

Never assume that "no news is good news." Have a set time to call and check-in.

Do not underestimate the severity of day-to-day Parkinson's symptoms, as well as the level of caregiver burden of advanced PD.

Don't forget that thinking and memory changes are part of PD, and difficult to handle. They are

often more taxing than physical symptoms for the care partner and person with PD.

If you visit, don't add to the caregiver's stress level. If staying in the same home, help, take on daily chores and provide respite.

Try not to allow worries and family dynamics to get in the way of doing what's best for your loved ones. Remember that Parkinson's and caregiver responsibilities progress over time and easily escalate to caregiver burnout. Help when you can.

DON'TS



Learn more about caregiving from afar at [Parkinson.org/CareFromAfar](https://www.parkinson.org/CareFromAfar).

Tips for Daily Living: Helping A Loved One with Parkinson's and Dementia



Dementia is when someone experiences problems in memory and thinking that are advanced and interfere with daily activities and quality of life. While not everyone with Parkinson's disease (PD) will develop dementia, some do.

In most cases, dementia also severely impacts the care partner. Significant cognitive decline in the person with PD is frequently associated with caregiver stress, strain and burnout.

Tips for Daily Living

- ☆ **Consider causes behind disruptive behavior.** Can your loved one be hungry, thirsty, tired, in pain, frustrated, lonely or bored?
- ☆ **Create a routine.** Plan for meals, and visitors, for the same time every day. Many people with PD feel more comfortable with a clear, structured schedule.
- ☆ **Simplify décor.** Reducing excessive stimuli may help reduce distraction or confusion and can help minimize memory, visual-perceptual or orientation difficulties.
- ☆ **Watch out for sensitivity to medications.** Many antipsychotic medications that are commonly prescribed for Alzheimer's are contraindicated (when a drug can be harmful) in PD. Be vocal about avoiding these medications, especially in a hospital setting. Learn more at [Parkinson.org/AwareInCare](https://www.parkinson.org/AwareInCare).
- ☆ **Find community resources before you need them.** Explore resources in your community early on, such as the Area Agency on Aging and services like home health aides and long-term care facilities.
- ☆ **Schedule time for yourself.** Dementia not only impacts the person with Parkinson's but leads to greater care partner stress. To best care for your loved one, remember to prioritize self-care.

Tips for Communicating

- PD-related mood and movement symptoms can impact communication — dementia can further these difficulties.
- ☆ **Speak slowly and at eye level.** Communicate in simple sentences.
 - ☆ **Limit distractions.** Turn off the TV or radio before asking a question.
 - ☆ **Try using humor to diffuse a stressful situation.** A well-placed laugh can make everyone feel better. However, avoid using negative humor or sarcasm, which can be misunderstood.
 - ☆ **Keep calm.** Avoid speaking sharply or raising your voice. People with dementia may respond with impatience or even aggression if they can't find the right words to express what they mean. Try asking if they can explain in a different way.
 - ☆ **Demonstrate your care and affection.** Maintaining physical contact throughout the stages of dementia is important.
 - ☆ **Resist the urge to argue or correct.** If your loved one says something that is not true, try to find ways around the situation, instead of contradicting them.

Remember, there is no single definition of "advanced" Parkinson's. Suggestions and tips for helping your loved one manage advanced PD should always be modified to best suit both of your needs.

Learn more about advanced Parkinson's at [Parkinson.org/AdvancedPD](https://www.parkinson.org/AdvancedPD).

A Couple's Shared Passion for Parkinson's Advocacy

Navigating the new normal — whether moving to another state, welcoming their first grandchild or living with Parkinson's disease (PD) — is becoming a matter of course for Radhika Iyer, JD, MSW, diagnosed with PD in 2015, and her husband and care partner, Dharma Iyer, PhD, an environmental chemical engineer. Married 36 years, they are as committed to each other as they are to advocating for the PD community and debunking disease-related myths.

The couple moved from New York to North Carolina following Radhika's diagnosis, nearer to adult children and a movement disorder neurologist at University of North Carolina and Duke Health Movement Disorders Center, a Parkinson's Foundation Center of Excellence. They settled in a community for active people 55 and older — a perfect fit for the pair who spent the last two summers hiking 200 miles across New York state.

“

“Once you recognize that Parkinson's is a new normal, then you decide how you're going to manage it.”

- Dharma

“We knew it was important to keep activity going,” Dharma said. We know once we stop, Parkinson's symptoms can progress very fast.



Radhika and Dharma Iyer participated in our photo shoot, where we highlighted those bravely navigating this disease.

The idea is to balance medication with activity — both physical and mental.”

While learning how to live with Parkinson's, they also realized they had to work to dispel disease-related stigma, or misunderstandings. “Culturally, in many Eastern/Asian countries, there's always a sense that past karma may have precipitated this disease,” Dharma said. “This is not karma. You're not paying a price for a past life.”

Recognizing there are genetic, environmental and other factors behind diseases is important, he added. “We really want to encourage Indian individuals who have this disease to advocate for themselves and for others,” Dharma said.

Radhika's advocacy began soon after her diagnosis. She served as a local chapter board member followed by a three-year advisory term on the Foundation's People with Parkinson's Advisory Council —

volunteer advisors who help shape Foundation programming and priorities.

The couple has forged strong ties within the PD community and feel a sense of duty to share what they have learned. “When I was first diagnosed and I started finding out about my disease, I was getting emotional,” Radhika said. “We need mentorships.” She hopes to someday see people who have long lived with PD provide guidance to those newly diagnosed.

As for Dharma, adapting to the role as a care partner has come naturally. “This disease can affect anybody, either one of us, husband or wife, we have to be there for each other,” Dharma said. “You start creating trade-offs; what can I do, what can we do together. Every five to 10 years brings a new stage of life. In our case, Parkinson's happens to be the new normal and you face that.”

Looking for more inspiration? Read Dharma and Radhika's full story and explore more stories at [Parkinson.org/MyPDStory](https://www.parkinson.org/MyPDStory).

Explore the Parkinson's-Friendly Adaptive Cottage

From mobility challenges to falls to vision changes, Parkinson's disease (PD) symptoms often impact daily life. What if there was a house that already accounted for adaptive living, built to lower the risk of PD-related injuries and keep you aging in place?

Southern Living built its first-ever Adaptive Cottage, an innovative new house plan designed to accommodate people who have mobility challenges. Scott Rider, a passionate Parkinson's advocate, made the home a reality. He undertook the project and worked alongside a land company, builder, architect and interior designer who all know the first-hand need for adaptive living from personal experiences.

between conventional design and a fully Americans with Disabilities Act-compliant house. The single-story house plan combines thoughtful home elements with accessible features such as:

- Wider hallways with pocket doors throughout, which do not get in the way.
- Zero entry showers.
- Purposeful kitchen design that includes a removable cabinet beneath the sink for roll-in wheelchair access.
- A back bedroom that can transition from a guest room to a private caregiver suite, with outdoor access.
- Custom closet with hooks and a pull-down rack at wheelchair height to simplify grabbing clothing.



Guest Bedroom. Photos provided by Southern Living.

otherwise be possible," said Scott. "My hope is that this project will increase awareness of Parkinson's disease as well as much needed funds that will help lead to a cure."

The Southern Living House Plan for the Adaptive Cottage is available now, with a portion of the proceeds of all sales going to the Parkinson's Foundation.

"This project is sure to impact lives for the better and bring much-needed awareness to the daily challenges of living with Parkinson's, as well as those with mobility issues who wish to age in place with independence," said John Lehr, President and CEO of the Parkinson's Foundation.

Learn more about adaptive living and view our Home Safety Tour Checklist at [Parkinson.org/HomeSafety](https://www.parkinson.org/HomeSafety).



Photos provided by Southern Living.
Credit: Laury W. Glenn
Styling: Kathryn Lott

"As a person living with Parkinson's, the Southern Living Adaptive Cottage represents what I believe individuals living with Parkinson's disease need: independence and collaboration."

- Scott

Located in the Habersham community in Beaufort, SC, the Adaptive Cottage bridges the gap

"The unique design and finishes make it possible for a person who has physical limitations to live more independently than would



Kitchen. Photos provided by Southern Living.



Reaching Further to End PD

The cure for Parkinson's disease (PD) begins with research. Marlene Perdan and her husband Bill, who was diagnosed with PD at 51, are generous supporters of breakthrough Parkinson's Foundation research and active community members. Bill's father also lived with PD, as does another family member of the couple.

"Supporting the Parkinson's Foundation, we feel like we can reach the most people, and the most diverse groups of people," Marlene said.

Bill participated in the nationwide *PD GENERation: Mapping the Future of Parkinson's Disease* initiative, which tests for Parkinson's-related genes and offers genetic counseling. He also served on the board of the Foundation's Great Lakes Chapter (formerly known as the Ohio Chapter). The couple helped bring Moving Day to Cleveland to raise

PD awareness and support, and Marlene serves on the Care Partner Summit Committee.

"The Parkinson's Foundation opens up so many channels to get involved," Bill said. That involvement has helped remind the Perdans in difficult times that they aren't alone. It's a message they want to share with others.

"Being involved with the Foundation connected us to a lot of people going through the same type of journey but also empowers you — this is something you can do to make a difference," Marlene said. "We really want to help promote a cure."

Help us fund research that advances Parkinson's treatments and drives us towards a cure. Contact Kate Nelson, Associate Vice President of Major Giving, at knelson@parkinson.org to learn more.

Parkinson's Revolution rider Jess Frank not only volunteered at her local 2022 Revolution event in Hoboken, NJ, she recruited 10 riders and shared her story during the opening ceremony. Jess rode in honor of her dad Rick who lived with Parkinson's.

To volunteer or register for Parkinson's Revolution, taking place February 25, 2023, visit Parkinson.org/Revolution.



Seventeen-year-old Kaden Lewis ran a summer fundraiser in honor of his "Uncky" Andrew who is living with Parkinson's. With the support of his mom, Johanna, he designed and sold T-shirts in his community, raising an amazing \$28,000 while spreading awareness and hope!

Become a Parkinson's Champion at Parkinson.org/Champions.

HELP FIGHT PARKINSON'S ALL YEAR LONG

Become a Parkinson's Hero. Join the special group of donors who make monthly gifts to the Parkinson's Foundation. Your regular monthly support will provide critical funds we can rely on to fuel the fight against Parkinson's year-round.

Commit today at Parkinson.org/Hero.

GIVE ONLINE TODAY



PD GENERation: Mapping the Future of Parkinson's Disease

Help us change the
course of Parkinson's

PD GENERation
MAPPING THE FUTURE OF PARKINSON'S DISEASE

Enroll now:
Parkinson.org/PDGENERation

We're here for you.

1.800.4PD.INFO

Helpline@Parkinson.org

Let us answer your Parkinson's questions!

Call our free Helpline at 1-800-4PD-INFO (473-4636) for current disease information, health questions and referrals to local health professionals and resources — in English and Spanish.



HELPLINE

1-800-4PD-INFO (473-4636)

Get your PD questions answered.

Mon-Fri, 9 a.m. – 7 p.m. ET

English / Español

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Comments or Questions? Contact us.

contact@parkinson.org

Toll-Free: 1-800-4PD-INFO (473-4636)

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