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Parkinson Report



Parkinson's
Foundation



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april

PARKINSON'S AWARENESS MONTH

- 8** Expert Briefing: Inside the Science: Parkinson's Research Today
Register:
Parkinson.org/ExpertBriefings
- 11** Moving Day San Antonio
Moving Day South Alabama
- 17** Disney Springtime Surprise Weekend
- 18** Moving Day Piedmont Triad
Moving Day Las Vegas
- 25** Moving Day Ventura County
Moving Day Shreveport
Moving Day Knoxville
Eugene Marathon Weekend
- 26** Moving Day Kansas City
Moving Day Columbus
Big Sur Marathon



Moving Day Ventura County

may

- 2** Moving Day DC
Moving Day Huntsville, AL
Moving Day Salt Lake City
Moving Day San Jose
Moving Day Santa Fe
Moving Day Twin Cities
- 9** Moving Day Tampa Bay
- 13** Expert Briefing: Artificial Intelligence & Parkinson's
Register:
Parkinson.org/ExpertBriefings
- 16** Moving Day Albuquerque
Moving Day Charleston
Moving Day Finger Lakes, NY
Moving Day Lexington
Moving Day Milwaukee
Moving Day New Hampshire
Moving Day Orange County
Moving Day San Francisco
Moving Day Southeastern PA
Moving Day Westchester County, NY
- 17** Lifetime Chicago Spring Half Marathon
Denver Colfax Marathon Weekend
- 24** Cape Town Marathon
World Parkinson Congress
- 30** Moving Day Sacramento

june

- 6** Moving Day Baltimore
Moving Day Cleveland
Moving Day Portland, ME
- 7** Moving Day Omaha
- 21** Grandma's Marathon (MN)

Shop with Purpose

Shop our official merch designed to raise awareness and bring visibility to Parkinson's.



Parkinson.org/Buy

SAVE THE DATE

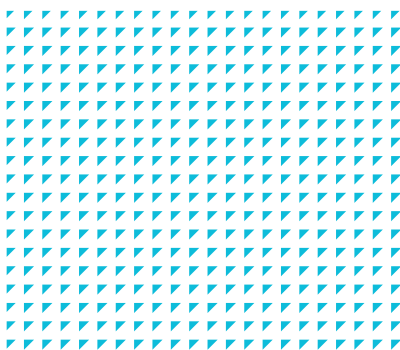


Visit WPC2026.org

View all upcoming events at Parkinson.org/Events.



JOHN LEHR, PRESIDENT & CEO



A Note From Our CEO

This special awareness issue of the *Parkinson Report* is one of my personal favorites. From cover to cover, it reflects our commitment to helping people live better with Parkinson’s disease (PD). It also serves as a powerful introduction to Parkinson’s Awareness Month, highlighting essential topics everyone should understand about this complex disease.

Inside, we address the most common PD questions and how to find real answers. Meet Robert “Bob” Baittie, whose humor and perspective on living with PD will inspire you. Plus, learn how we are advancing Parkinson’s policy and advocacy priorities at the federal and state levels to improve care and advance research.

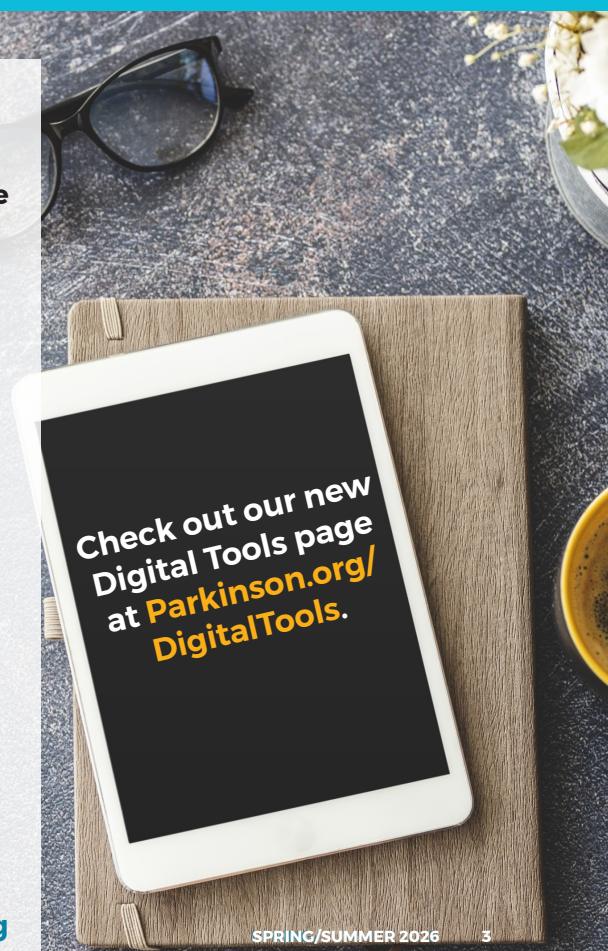
We also dive into two issues important to our community: the burden of stigma in Parkinson’s; and the need to connect more people to clinical trials through our new and exciting PD Trial Navigator program.

Your support drives everything we do. Whether you join us at a Moving Day walk or share one of our webpages, you help strengthen our mission. This April, explore our awareness campaign and see how you can help connect more people to information that makes a difference. Learn more at Parkinson.org/Awareness.

5 Go-To Parkinson’s Tools

Take advantage of our free tools that can help you and your loved one navigate Parkinson’s. Start here:

- 1. Helpline** – Get answers to your PD questions and referrals to local healthcare professionals and wellness programs. Contact 1-800-4PD-INFO (1-800-473-4636) or Helpline@Parkinson.org
- 2. Local Chapter** – Build connections in your community. Find your Parkinson’s Foundation chapter to attend local events. Parkinson.org/YourArea
- 3. Learning Lab** – Learn about the latest PD information from experts. Each free course shares tips for daily living and resources. Parkinson.org/LearningLab
- 4. PD Health @ Home Events** – Register for new, weekly online events and explore our on-demand at-home exercise classes. Parkinson.org/PDHealth
- 5. Parkinson.org** – Ask PAM, our new AI-powered chat tool to find customized answers to your PD questions. Parkinson.org



One Diagnosis. One Million Questions.

Find Real Answers at the Parkinson's Foundation.

Q Parkinson.org/Awareness x

One diagnosis. One million questions. From the moment you hear the words Parkinson's disease (PD) – and every stage that follows – you and your family will likely have a million questions about symptoms, medications, daily living and what's next.

When Parkinson's gets real, the Parkinson's Foundation is here to help you find real answers. We offer trusted, accessible support through our Helpline, website, social media and enhanced web tools. This Parkinson's Awareness Month, we're helping people find answers to Parkinson's questions. Here are some of the top questions people have about Parkinson's:

What are the early signs of Parkinson's?

Early signs of Parkinson's can be subtle. While movement symptoms like tremors, stiffness and trouble with balance are the most noticeable, early signs also include a change in handwriting, loss of smell, trouble sleeping and vertigo. For a full list visit [Parkinson.org/Signs](https://www.parkinson.org/signs).

What do you do after noticing early signs?

No one symptom means you have Parkinson's. If you have several symptoms, consider seeing your primary doctor, then asking for a referral to a neurologist, or ideally, a movement disorders specialist (a specialized neurologist).

How is Parkinson's diagnosed?

Parkinson's is diagnosed based on observation – a doctor assesses medical history, current symptoms and a physical exam. No single lab or test confirms a diagnosis, though certain tests can help rule out other conditions.

What causes Parkinson's?

Scientists believe a combination of genetic and environmental factors are the cause of Parkinson's. Genetics contribute to 10–15% of PD cases, with specific gene mutations linked to the disease.

How do you manage Parkinson's symptoms?

Treatment often includes medications specific to your needs. The medication Levodopa is the most effective treatment for movement symptoms as it converts to dopamine in the brain. Treatments also include things that you do yourself, such as exercise, physical therapy or speech therapy.

Is there a cure for Parkinson's?

While there is no cure for Parkinson's, treatments can effectively manage symptoms. Medication, exercise and rehabilitative therapies help maintain mobility, balance and mental health. The Parkinson's Foundation also funds research to advance better treatments and move us closer to a cure.

Can you live a long life with Parkinson's?

Yes. Parkinson's symptoms and rate of progression are unique for every person living with the disease. Navigating PD involves building a care team with specialists who can address symptoms as they occur, building a support network and staying active.

How can I find more answers?

- Visit [Parkinson.org](https://www.parkinson.org) to ask our new AI-powered chat tool, PAM, your toughest questions anytime.
- Call our Helpline at **1-800-4PD-INFO (1-800-473-4636)** for local referrals, personalized support, and more.



Get more answers and help us raise Parkinson's awareness at [Parkinson.org/Awareness](https://www.parkinson.org/Awareness).

How Mindfulness and Humor Shaped Bob's Parkinson's Journey

After living with Parkinson's disease (PD) for 14 years, Robert "Bob" Baittie finds hope in talking to people living with PD. He offers advice and experience for anyone new to Parkinson's and emphasizes the importance of perspective and mindfulness.

Bob began using Parkinson's Foundation resources when a series of kidney stones landed him in the hospital, and he relied on the Hospital Safety Guide to advocate for his care. "Some of the nursing staff had no clue as to the importance of PD medication and wanted to take my medication away. I used the Hospital Safety Guide to get medication management under control and have been connected to the Parkinson's Foundation ever since," said Bob.

Bob soon found Moving Day Chicago, where his team, Martini Shakers, injected humor into living with PD, and gave Bob a new avenue to build his support team. "I was hesitant to share my diagnosis with my friends, but it was my friends and business associates who supported me through Moving Day. We ended up hosting fun martini parties and raising \$60,000 through our team, but what was most amazing was how people showed up and continued to spur my fight."

Bob credits his positive mindset, rooted in mindfulness and his support team, with shaping his Parkinson's experience.

"I love to talk to people when they were first diagnosed because it's so important to talk about mindset. Their mindset is going to change how they deal with Parkinson's. The first opportunity to start healing from PD is at diagnosis. Being involved socially, being in support groups, all of it works hand in hand. I don't think one works without the other."

- Bob, Parkinson's Advocate

"Early on it seems like a lot of people with Parkinson's isolate themselves and that's something they don't need to do especially when the Parkinson's Foundation is there to support them," Bob said. The Parkinson's

Foundation Helpline connects people with Parkinson's to local resources such as exercise classes, support groups, events and referrals to PD specialists, such as movement disorders specialists and physical therapists.

For Bob, and most of the one million Americans living with Parkinson's, his questions about living with PD have evolved over time. At diagnosis he sought answers from his neurologist – *did he need medications? Are there other treatments?* But over time, his questions morphed through his experiences – *what exercises made him feel better? How can he connect to more people with PD? How can he reach more people and get involved with the Parkinson's Foundation?*

Parkinson's has made Bob not only more mindful, but adaptable. "I joke and say that Parkinson's would not define me, but the joke's on me. I've written a book, given a Ted Talk, volunteered and speak about Parkinson's all the time. Parkinson's has become my identity, and I'm thankful for that."

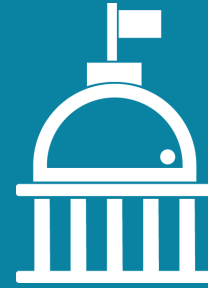


Look for Bob in our new PSA aiming to help people find real answers to their Parkinson's questions. [Parkinson.org/PSA](https://www.parkinson.org/PSA).

This Parkinson's Awareness Month, Bob is helping the Parkinson's Foundation raise awareness. Read his full story at [Parkinson.org/MyPDStory](https://www.parkinson.org/MyPDStory).



5 Policy Priorities That Matter to the Parkinson's Community Right Now



For the first time, the Parkinson's Foundation is building a dedicated policy department to help make life better for people with Parkinson's disease (PD) by improving care and advancing research toward a cure.

Parkinson's is the fastest-growing neurodegenerative disease, with 90,000 new people diagnosed each year. Yet there is no cure and too many people experience delayed diagnoses and uneven access

to quality care. Through federal and state policy and advocacy efforts, the Parkinson's Foundation is working to address these longstanding issues.

Parkinson's Policy Areas



Research: We are closer than ever to developing treatments that could slow or stop PD, not just manage symptoms. However, federal support for research has not kept pace with the rise of Parkinson's. Our policy goal is to help deliver new and better therapies to people with Parkinson's as quickly as possible.



Care & Prevention: As PD prevalence increases, access to quality care is becoming further out of reach. Shortages of healthcare professionals can mean long travel distances, while coverage and costs can be unpredictable and quality varies. We also know that exposure to chemicals like paraquat and trichloroethylene (TCE) have been tied to PD, yet exposure to these chemicals continues across the U.S. We are advancing policies that improve quality of life, transforming the future of care and working toward a world where fewer people develop PD.



Education: We are advancing policy changes to improve education about PD, empowering people to make informed decisions about their health and ensuring healthcare providers have access to the latest training. People living with PD, families, healthcare professionals and the public deserve high-quality, accessible information that is tailored to their needs.

1. Implement and Protect the National Parkinson's Project

The National Parkinson's Project is the first dedicated federal initiative that supports PD research, prevention and care – and our advocacy

work is essential to its success. The Parkinson's Foundation is working to help protect the project and build momentum as the government moves forward with implementing this initiative.

2. Secure Consistent Funding for PD Research

To keep moving forward, we must increase and sustain research support across federal agencies. Agencies like the National Institutes for Health (NIH) need the resources to keep supporting new Parkinson's treatments and care breakthroughs, including identifying people accurately earlier in their disease.

The Parkinson's Foundation is working to increase federal investments in Parkinson's research, including a goal of \$600 million a year in NIH-funded research. We are also advocating for state government investments in Parkinson's research that complement and build on federal research funding.

“These are challenging times in policy circles, but there's a real opportunity to reimagine what's possible when it comes to improving Parkinson's care and research through policy. There are many ways for people with Parkinson's, and the people who care about them, to get involved. Policymakers need to hear directly from you as they consider policy changes, and we're working to help people engage with policymakers, year-round.”

- Andi Lipstein Fristedt, Parkinson's Foundation Chief Strategy and Policy Officer

3. Improve Access to Timely, Affordable and Quality Parkinson's Care

We support policies that help people with Parkinson's access timely, quality care wherever they live, including making it easier to diagnose, treat and provide ongoing PD care. That includes stabilizing and expanding telehealth coverage to ensure continuity of care for people with Parkinson's and certainty for providers.

We also work to ensure the strongest possible public health programs, to ensure that we are moving toward better treatments and a cure for Parkinson's.

4. Address Environmental Health Threats Linked to Parkinson's

Chemicals like paraquat and trichloroethylene have been tied to Parkinson's. Policy changes can make a big difference. Paraquat is banned in more



Andi Lipstein Fristedt at the Policy Forum

than 70 countries, including China, even though they still sell it to the U.S. We have the power to change this by working with the Environmental Protection Agency (EPA), which could end paraquat use now, and engaging with state governments on the use of paraquat in their states.

5. Education: Access to PD Information

Knowledge is power — especially when it comes to PD prevention and early diagnosis. This is why we are advancing policy changes to improve education for people living with PD and healthcare providers. People living with PD, families, healthcare professionals and the public deserve high-quality, accessible information that is tailored to their needs.

We are also helping people share their stories and experiences with lawmakers, because stories make this disease tangible and make policy changes stronger. People with Parkinson's are at the center of everything we do.

Learn more about our policy efforts and sign up for our advocacy email updates at [Parkinson.org/Policy](https://www.parkinson.org/Policy).

3 Ways to Take Action for Parkinson's

Visit our Advocacy Center at [Policy.Parkinson.org](https://www.policy.parkinson.org) to:

1. **Join our Advocacy Network.** Sign up to receive advocacy updates and take part in our policy efforts.
2. **Help ban paraquat.** Use our Advocacy Center to contact your members of Congress and urge them to push for the ban of paraquat.
3. **Keep the National Plan to End Parkinson's Moving.** Write to your congress members to keep this project moving forward.

The Kensington: Leading the Way in Compassionate Parkinson's Care



At The Kensington in White Plains, NY, compassionate Parkinson's disease (PD) care is put into practice through training and personalization. As a Parkinson's Foundation Community Partner, team members at senior living communities and home care agencies receive expert-led education on how Parkinson's affects movement and mood, equipping them with practical strategies to improve daily care. In this article, Associate Executive Director Joanne Hubbard shares how The Kensington delivers person-centered PD support.

How prevalent is Parkinson's disease at The Kensington?

Joanne: It fluctuates but about 15 to 30% of our residents are living with Parkinson's. In New York, there's a special license for assisted living communities called an enhanced license that allows residents to age in place. We have that license, which enables people to remain in our community as their condition progresses. Parkinson's care is more than managing symptoms, we aim to preserve dignity, purpose, voice and quality of life at every stage.

Why did you become a Parkinson's Foundation Community Partner?

Joanne: Community Partners training equips our team to do more than share information – it builds a shared understanding that allows residents, families and team members to navigate Parkinson's together. Through this partnership, we can support more people with Parkinson's and give our teams and residents the tools they need to succeed.



How does staff provide specialized Parkinson's care?

Joanne: One way we provide PD care is to be intentional with time – slowing down, allowing medication to take effect, giving residents extra time during “off” periods and communicating clearly. When you see these strategies making a difference, it reinforces that PD training truly works.

How do you train staff to provide better Parkinson's care?

Joanne: We use the Community Partners Portal for self-paced lessons, but we also watch courses together. New team members receive a full day of Parkinson's training. One thing that resonates with our team is the Community Partner Experiential Toolkit. Every team member tries the heavyweight shoes with Velcro that get stuck when trying to walk, so you can't take that first step. They can imagine what a freezing of gait episode feels like and apply that feeling when helping a resident.

How does The Kensington deliver Parkinson's medication on time?

Joanne: Many of our residents with Parkinson's require up to eight medication passes a day. After becoming a Community Partner, we created an additional nursing position to administer PD medication. Today, our residents with Parkinson's get their PD medications within a 15-minute window.

What advice would you give someone considering community living?

Joanne: When looking at potential senior living communities, always ask questions such as:

1. How are PD medications managed? Who manages them? What is the window of time they'll get medications?
2. What kind of specialized PD programs do you offer?
3. What training in Parkinson's care do they have? Look for the Parkinson's Foundation Community Partners badge.

Thank you to Acadia Pharmaceuticals and the Edmond J. Safra Foundation for their support of Community Partners in Parkinson's Care.



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Learn more about the Community Partners in Parkinson's Care program and find a community partner near you at Parkinson.org/CommunityPartners.

The Hidden Burden of Parkinson's: Understanding and Overcoming Stigma



In our latest *NeuroTalk*, Sneha Mantri, MD, Chief Medical Officer of the Parkinson's Foundation, highlights the stigma that can accompany living with Parkinson's disease (PD).

What is stigma?

Stigma is when a person or group is judged or treated unfairly because of a negative belief or stereotype about them. Stigma is associated with stereotypes, prejudice, discrimination and exclusion. Experiencing stigma can significantly impact the lives of people living with Parkinson's and care partners.

What does stigma look like for people with Parkinson's?

Stigma around Parkinson's often begins with misunderstanding. Stereotypes ignore the reality that people of all backgrounds – men and women – live with PD. Visible symptoms like tremors, freezing of gait or speech issues can be misread as intoxication or aging, rather than signs of a complex neurological condition. These reactions can be hurtful and isolating.

Many people with Parkinson's internalize stigma, leading to delaying treatment, hiding symptoms or their diagnosis out of embarrassment or shame. In the workplace, stigma can fuel fear of being seen as less capable. It can also show up as fear of becoming a burden to loved ones. Acknowledging these experiences is a critical step toward breaking down stigma.

"As a movement disorders specialist, I talk to patients about stigma. Research shows that practicing narrative medicine – using a patient's story to guide care – helps their care team address the issues that matter most to them. This approach can strengthen independence and reduce stigma."



Dr. Mantri, Parkinson's Foundation Chief Medical Officer

Research Findings Surrounding PD and Stigma

- Stigma worsens quality of life for people with Parkinson's. It contributes to social anxiety, isolation, hesitation to seek medical care, loneliness and emotional distress.
- Stigma shapes the PD experience. Misconceptions and bias lead to people with Parkinson's being stereotyped, devalued or even avoided. This,

and worsening symptoms over time, can lead to self-stigma, impacting self-esteem and depression.

- For healthcare professionals, understanding stigma's impact can help them respond with greater empathy and more proactive care strategies.

Ways to Combat Stigma.

One of the most powerful ways to reduce stigma is through education and staying connected. The Parkinson's Foundation works to share information about Parkinson's to help spread awareness and knowledge, breaking down the misconceptions that fuel stigma.

Personal stories (like those at [Parkinson.org/MyPDStory](https://www.parkinson.org/MyPDStory)), humanize Parkinson's and highlight resilience. While community engagement – through events like Moving Day, support groups or exercise classes – helps people feel less alone and build connection. Everyone can play a role in reducing stigma by knowing the signs of Parkinson's, volunteering or sharing information to raise awareness.

Watch Dr. Sneha's latest NeuroTalk at [Parkinson.org/NeuroTalk](https://www.parkinson.org/NeuroTalk).



PD Trial Navigator Matches People to Clinical Trial Opportunities

Knowing whether you have a genetic link to Parkinson's disease (PD) can provide actionable insights to help you navigate your care. For example, those with the *LRRK2* variant are statistically more likely to experience a slower disease progression and milder symptoms of depression. Understanding your genetic tie to PD can also open the door to participating in new clinical trials designed around specific genetic mutations.

To help close this gap, the Parkinson's Foundation launched *PD Trial Navigator*, a program connecting *PD GENERation*: Powered by the Parkinson's Foundation participants who know their genetic results with relevant clinical trials. Through education and one-on-one guidance, navigators help people understand their options and make informed decisions.

Building on *PD GENERation* – which has provided free genetic testing and counseling to more than 30,000 people with Parkinson's – the program expands access to research opportunities linked to participants' genetic results.

How does it work?

- 1 People with a confirmed Parkinson's diagnosis enroll in *PD GENERation* at [Parkinson.org/PDGENERation](https://parkinson.org/PDGENERation).
- 2 Participants receive their genetic test results along with genetic

counseling, at no cost.

- 3 Those with a PD-related genetic variant may enroll in *PD Trial Navigator*, where the Parkinson's Foundation helps connect them to clinical trials.

"Through *PD GENERation*, we learned that more people than expected carry Parkinson's-related genetic variants," said James Beck, PhD, Parkinson's Foundation Chief Scientific Officer. "This underscores the need for the widespread genetic testing that *PD GENERation* offers and opens the door to gene-targeted therapies. *PD Trial Navigator* moves us closer to leveraging large, diverse genetic registries to advance new Parkinson's treatments."

Genetic-focused clinical trials are testing next-generation PD therapies aimed at specific gene mutations. Despite their potential, these studies face funding challenges and difficulty finding eligible participants. Through *PD*

Trial Navigator, the Parkinson's Foundation actively engages and guides *PD GENERation* participants who meet trial criteria – helping more people turn their genetic insights into meaningful research participation and accelerate progress toward breakthrough discoveries.

"With the knowledge derived from *PD GENERation*, I can now target my efforts on research that focuses on my specific genetic mutation. I am excited that my participation in this program, which was motivated by a desire to learn more about my own diagnosis, may now enable me to help others by participating in and accelerating research that focuses on this shared genetic abnormality," said Daniel Rothschild, a *PD GENERation* participant.

PD GENERation

POWERED BY THE PARKINSON'S FOUNDATION

Explore active clinical trials at [Parkinson.org/JoinAStudy](https://parkinson.org/JoinAStudy). To learn more about *PD Trial Navigator* email PDNavigator@parkinson.org.

John and Jill Find Community and Hope by Joining the Parkinson's Revolution



"The Parkinson's Foundation has opened up a new world for John and changed his vision of what it is to have Parkinson's and what it means to be part of a community," said Jill, John Nicholson's wife.

After utilizing several Foundation resources to better understand PD and how to live well with it, Jill found Parkinson's Revolution, the Foundation's indoor cycling fundraiser. Both Jill and John felt it was a great way to get more involved and connect with more people in the Parkinson's community.

"I've ridden a bike for years, indoors and outdoors, and used to do a lot of fundraising rides for different causes," said John. "I always enjoyed the rides, but now I finally had a chance to do one for me. It was a natural fit to be able to ride the bike and raise money for Parkinson's at the same time." Jill immediately joined and began fundraising as well, sharing their story on social media and asking family and friends for support.

She was moved by the response. Together, they completed the ride and became the top fundraisers for Parkinson's Revolution 2025, generously matching the amount they raised. "It is stunning that every six minutes someone is diagnosed with Parkinson's," said Jill. "It's vital to get the word out and explain the urgency of Parkinson's. The Parkinson's Foundation is a great steward of the funds they receive. Every dollar spent goes to great use and will benefit quality of life for people with Parkinson's and hopefully lead to a cure."

With your support, we can help people live better with PD. Visit Parkinson.org/Donate or contact Kathryn Sheppard, Associate Vice President of Individual Giving at KSheppard@parkinson.org.



Todd Carolonza tackled the TCS NYC Marathon as a Parkinson's Champion in honor of his Grandy, Mary Jane, who lived with Parkinson's. He raised an incredible \$16,731, and is already training and fundraising for his next race as a Parkinson's Champion, the Sydney Marathon!



The Egg Bowl Run, a nearly 100-mile relay led by Mississippi State University and Ole Miss Army ROTC cadets, raised more than \$5,000 for the Parkinson's Foundation. Since 2013, cadets have carried the official Egg Bowl game ball from the campus to stadium – this year they ran in honor of their PD community.

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



LEAVE A MEANINGFUL LEGACY THROUGH YOUR ESTATE

GIVE ONLINE TODAY

Join the Parkinson's Foundation Legacy Society when you designate us as a beneficiary in your estate plans. You can make a difference in people's lives and create a meaningful legacy. Simply designate a percentage of your estate via your will or trust.

Learn more at Parkinson.org/PlannedGiving or email us at Legacy@parkinson.org.



PD GENERation: Powered by the Parkinson's Foundation

Help us change the
course of Parkinson's



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Get your PD questions answered.
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English / Español

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PD GENERation

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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.



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