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2025 Events

april

PARKINSON'S AWARENESS MONTH

- **1-30** Golf Parkinson's (National)

 Parkinson.org/GolfPD
- Moving Day Palm Beach
- 9 Expert Briefing webinar: The Latest Advances in PD Research and Treatment
- Moving Day South Alabama
 (Mobile)
- 21 Boston Marathon Run4PD.org
- 26 Moving Day Baton Rouge
 Moving Day Charleston
 Moving Day Columbus
 Moving Day Knoxville
 Moving Day Lexington
 Moving Day San Francisco
 Moving Day Ventura County
- Big Sur Marathon Weekend (Monterey, CA) *Run4PD.org*

Eugene Marathon Weekend, OR - *Run4PD.org*

may

- Moving Day DC
 Moving Day Finger Lakes NY
 (Ithaca)
 Moving Day Huntsville, AL
 (NEW)
 Moving Day Kansas City
 Moving Day Las Vegas
 Moving Day Piedmont Triad
 (formerly Winston-Salem)
 Moving Day Sacramento
 Moving Day Salt Lake City
 Moving Day Santa Fe
 Moving Day Tampa Bay
 Moving Day Twin Cities
- 14 Expert Briefing: Managing Nighttime Interruptions in Parkinson's
- Moving Day Albuquerque
 Moving Day Milwaukee
 Moving Day New Hampshire
 Moving Day San Jose
 Moving Day Southeastern PA
 Moving Day Westchester
 County, NY
- 31 Moving Day Orange County

june

- Moving Day Baltimore Moving Day Portland, ME
- 8 Moving Day Cleveland Moving Day Omaha



View all upcoming events at Parkinson.org/Events.

Explore Our Resources in Spanish



Explore articles and tools in Spanish.

Visit Parkinson.org/Espanol.

SAVE THE DATE



Visit worldpdcoalition.org.



JOHN LEHR, PRESIDENT & CEO

A Note From Our CEO

Parkinson's Awareness Month is about the one million people in the U.S. living with Parkinson's disease (PD), and the 90,000 individuals who will be diagnosed in 2025. This April, we will also reach those who are living in the unknown — managing early symptoms or scheduling their loved one's first neurologist appointment. At the Parkinson's Foundation, we believe knowledge is power, and that through education and community support we can improve lives, and through research we can develop new and better therapies, and ultimately a cure.

In this special awareness issue, we highlight the stories of two people navigating Parkinson's every day. Kathy serves on our advisory council and is helping us amplify PD awareness by sharing her story. Rex shares his genetic testing experience in our global research study, PD GENEration.

Your support fuels our mission. Whether you participate in a Moving Day event, engage with our resources or share this newsletter, you help make life better for people with Parkinson's. This April, learn more about our awareness campaign and find out how you can help us connect more people to information that can change their lives. Learn more at **Parkinson.org/Awareness**.

5 Go-To Parkinson's Tools

Are you taking advantage of our free tools that can help you and your loved one navigate Parkinson's? Start with these:

- 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
- Local Chapter Build connections in your community. Find your Parkinson's Foundation chapter to sign up for local events. Parkinson.org/YourArea
- 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** Explore every stage, symptom and the latest research findings. **Parkinson.org**



SPRING/SUMMER 2025



Hi! I'm PAM:

Your Guide To:
Parkinson's
Awareness
Month



Meet PAM, your guide to Parkinson's Awareness Month.

This April, PAM will help us raise Parkinson's disease (PD) awareness by addressing the key issues that surround PD. Here are the top three topics everyone should know about PD:

#1: 10 Early Signs of Parkinson's

It can be hard to tell if you or a loved one has PD. With early detection, treatment and expert care, many people live long, productive lives with Parkinson's. These are 10 early signs of Parkinson's:

- · Tremors, often in the hands or fingers
- · Small handwriting
- · Loss of smell
- · Trouble sleeping
- Trouble moving or walking, including stiffness and balance problems
- Constipation
- · A soft or low voice
- Facial Masking: a reduction of facial expressions
- · Dizziness or fainting
- Stooping or hunching over

No single one of these signs means that you should worry, but if you have more than one sign, consider making an appointment with your doctor.

#2: PD Symptoms & Managing Them

Parkinson's symptoms vary widely from person to person. While there are common symptoms associated with PD, everyone's experience is unique.

Symptoms of Parkinson's fall into two main categories: movement and non-movement.

Common movement-related symptoms include tremors, balance issues and slowness of movement.

Common non-movement symptoms include anxiety, depression, fatigue, loss of smell and sleep disorders.

These are only a few examples of symptoms someone with PD may experience. Finding the right combination of medications, complementary therapies, exercise, support systems and strategies for maintaining independence can help those with Parkinson's lead a fulfilling life.

#3: The Latest in PD Research

The only path to a cure is through accelerating research. While there's still a lot we don't know about this disease, we are working to close the gaps in PD knowledge. Through funding innovative researchers worldwide who look at many aspects of PD, to offering research studies for people with Parkinson's, the Parkinson's Foundation is committed to advancing our understanding of PD and accelerating progress.

Did you know the global genetics study PD GENEration offers genetic testing and counseling at no cost to people with Parkinson's? The Parkinson's Foundation study is leading the way to empower participants with more information about their disease and help them find new clinical trials that look for people with specific PD-related genetic mutations.

Learn more about these topics and find out how you can help us spread Parkinson's awareness at Parkinson.org/Awareness.



One Woman's Mission to Advocate for the Parkinson's Community

"My commitment to raising Parkinson's disease (PD) awareness is not just because I have the disease; it's because of the growing number of people living with PD. We have to get this on people's radar," said Kathleen (Kathy) Blake, MD, MPH, a retired physician who serves as vice chair of the Parkinson's Foundation People with Parkinson's Advisory Council. One way she helps raise PD awareness is by telling her story.

Like many people, Kathy's diagnosis was delayed. She experienced symptoms five years before receiving a diagnosis, attributing the pain and reduced swinging of her left arm to arthritis and aging. A physical therapist referred her to the movement disorders specialist who diagnosed Kathy seven years ago. Kathy's first question to her neurologist was, "How sure are you that it's Parkinson's?"

Physical therapy and exercise changed everything. "If I exercise today, I will feel better tomorrow," Kathy said. "Another benefit of exercise has been the chance to meet so many other people who are dealing with Parkinson's and their caregivers, a huge boost for my spirits and my husband's."

Eventually, Kathy found her way to the Parkinson's Foundation. She joined the Foundation's genetics study, PD GENEration: Mapping the Future of Parkinson's, becoming one of the more than 20,500 study participants who receive a genetic test and counseling at no cost, to learn their genetic tie to PD. Today, she recommends Parkinson.org as her go-to resource for anyone new to Parkinson's. "The website is full of information, not just for the person living with Parkinson's, but also for their families, scientists and physicians. You don't have to consume and incorporate all of it right away. You have time," Kathy said.

Kathy's advice for people who have been living with PD for many years, like herself, is to be adaptable. "Expect that how you take care of yourself will change over time. When that happens, don't assume there isn't something new that can help you, because increasingly, there is."

Kathy's medical background gives her a unique point of view for helping people with PD communicate with their care team.

"As a doctor, when you stand up and prepare to leave the exam room, that's often when your patient asks their most important question. To overcome this, write down your top three concerns before your appointment, whatever keeps you up at night, because they are what needs to be addressed."

- Kathy

Volunteering has opened a new world to Kathy. "I applied to serve on the advisory council because I was told, 'The Foundation staff and leadership really wants to hear from you; they listen and improve their programs based on what you say.' I thought, I can help; maybe five or 10 years from now I won't have the capacity. This is what I care about, and I'm doing it now," Kathy said.



This Awareness Month, Kathy is helping the Parkinson's Foundation raise PD awareness. Read her full story at Parkinson.org/MyPDStory.



"Even though my grandmother and aunt had Parkinson's disease (PD), and I had the textbook early signs, I was flabbergasted at my own early-onset Parkinson's diagnosis."

- Rex Polkinghorne, who was diagnosed at 42

After his initial diagnosis, Rex found a great doctor whose treatment is heavier on exercise than medication. Rex retired to focus on his health and family — but also, to spread the word that there is life after diagnosis. Rex's PD experiences and introduction to the Parkinson's Foundation led him the global genetics study that offers genetic testing and counseling at no cost to people with Parkinson's called PD GENEration: Mapping the Future of Parkinsons' Disease.

Earlier this year, we accompanied Rex to his PD GENEration genetic testing session and asked him questions along the way.

Can you summarize your PD GENEration genetic testing experience?

Rex: It was really seamless. The process took little to no time. With a regular blood draw you have to keep your arm still, and they stick this needle in you. You feel anticipation, you feel it going in, and then you feel it in you for the longest time. As someone who doesn't like needles, this test was easy and painless.

Did you have any surprising feelings after the test, being closer to knowing your genetic tie to Parkinson's?

Rex: Yes, actually. If you look at my mother, her husband, son, sister, mother — we all have Parkinson's. I'm interested in promoting research about this disease, but I also want that proof that genetics was the problem.

What are you planning to do with your genetic information?

Rex: In the event that I have children, it would be good to know what to look out for regarding Parkinson's and genetics. Additionally, genetic results could be tied to what else might be coming up for me. Things I might be able to prepare for, like cognitive issues. I don't subscribe to the idea that it will automatically happen, but I want to know, and I want to be ready.

Is it important to you to participate in Parkinson's research?

Rex: I want to do my part. I don't want to be a victim. I want to help. I want to use this diagnosis to further research, further a cure. I would love to see a cure, and I'll do my part for that. Participating in this is easy compared to what the Parkinson's Foundation is doing.

Like all PD GENEration participants, Rex will receive his genetic test results within a few weeks of testing. He will set up a virtual counseling session, at no cost, to talk through his results and find out what they mean with a genetic counselor.

To enroll and learn more about PD GENEration, visit Parkinson.org/PDGENEration.



Genetics Research in Motion:

What PD GENEration Has Taught Us So Far

PD GENEration has already transformed how we understand Parkinson's disease. By offering genetic testing and counseling to people with PD at no cost, the study has helped thousands uncover their genetic links to the disease.

2024 Milestones

In 2024, the Foundation expanded PD GENEration geographically and biologically. Genetic diversity is essential for large-scale studies like PD GENEration that are helping to unlock the genetic secrets of PD. Therefore, having genetic data from people who can trace their origins from across the world creates a strong foundation for research breakthroughs — and helps us find new treatments faster. In just months, the Foundation began providing valuable genetic testing and counseling to new populations in Latin America, broadening our understanding of the disease. Today, PD GENEration is offered in 10 countries and growing.

Accessibility is a key to the PD GENEration study, allowing people to participate either in person at a medical center or through an at-home test. This ensures that anyone interested can take part. In March 2024, accessibility remained a priority as the study upgraded its genetic testing backbone to be able to share more data with researchers — and faster, too.

Today, PD GENEration participants still receive the results from the core genetic testing panel of the seven PD-related genes and now have the option of adding

21 genes with a potential PD connection. They can also choose a new option for testing 10 CDC Tier 1 genes related to other diseases like hereditary cancer and heart disease.

What Comes Next

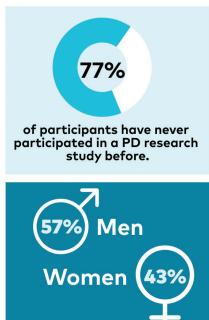
"In the coming years, PD GENEration will continue to play a crucial role in advancing Parkinson's research," said James Beck, PhD, Parkinson's Foundation Chief Scientific Officer. "With a growing database of genetic insights, researchers around the world can utilize PD GENEration data to accelerate our understanding of PD genetics and, in turn, the development of targeted treatments tailored to genetic profiles, moving us closer to new therapies for PD."

The future of PD GENEration is focused on expansion, deeper analysis and impact. The study is now available at more locations than ever and is actively working closely with researchers and partners to fill clinical trials.

Visit Parkinson.org/JoinAStudy to learn more and participate in relevant studies.

PD GENEration MAPPING THE FUTURE OF PARKINSON'S DISEASE 20,500+ People with Parkinson's have received genetic testing and counseling at no cost through PD GENEration ~13% of participants have a genetic form

of Parkinson's





Advocacy in Action: Empowering Local Black and African American Parkinson's Communities



Black and African American people living with Parkinson's disease (PD) often face significant health disparities that limit their access to care. To bridge this gap, the Parkinson's Foundation launched Parkinson's Journey in Color: Advancing Research and Care in Your Community — events tailored to meet the unique needs and experiences of local Black and African American PD communities. Each event offered in-person genetic testing at no cost through the Foundation's landmark genetics study, PD GENEration: Mapping the Future of Parkinson's Disease.

Parkinson's Journey in Color was designed by Parkinson's Foundation staff and research advocates, who helped guide every aspect of these events — from shaping topics to selecting locations. Advocates also identified and worked with community partners to promote and participate in the events, ensuring the programs resonated with local audiences.



Tailored Programming to Address Community Needs

Three Parkinson's Journey in Color events took place in 2024, including:

- Atlanta, GA: Held alongside Morehouse School of Medicine and Emory Brain Health Center, 55 people attended this event with 10 completing PD GENEration testing onsite.
- Charlotte, NC: This event hosted 51 attendees and was held at The Park Church,

- a recommendation by a research advocate. Attendees shared their clinical research experiences and met local healthcare professionals experienced in PD.
- Chicago, IL: Held at the University of Illinois Chicago, 45 participants met movement disorders specialists from Northwestern University and Rush University (both Parkinson's Foundation Centers of Excellence), among other Chicago medical centers.

"Each of our journeys are quite colorful. In Charlotte, one of our church leaders shared with me, 'who knew so many African American people have a PD diagnosis?' I shared that there are even more. That's what this advocacy is all about," said Lisa Fletcher, a care partner and a Parkinson's Foundation research advocate who helped design the event series.

Building a Stronger Future Together

Through designing new initiatives that reach more populations of focus, the Parkinson's Foundation aims to build stronger connections within local communities, address disparities in care and empower through providing accessible resources.

"Parkinson's Journey in
Color is a testament to the
power of community-driven
solutions and advocacy.
Through centering the
voices of Black and African
American individuals living
with Parkinson's, we are
fostering a more inclusive and
equitable approach to care,
research and support."

Evelyn Stevens,
 Parkinson's Foundation
 senior director of
 community engagement



Find ways to get involved with the Parkinson's community that works for you at Parkinson.org/GetInvolved.



What People with Parkinson's Want Health Professionals to Know

Many people with Parkinson's disease (PD) feel their doctors do not fully understand the many challenges that can accompany this disease. From unpredictable symptoms to the emotional toll that parallels progression, they have valuable insights to share. In this article, we highlight what our social media community wishes healthcare providers knew — offering a deeper understanding that can lead to more compassionate and personalized care.

"I wish they understood there are a lot of nonmotor symptoms — hypotension, constipation, mood disorders, cognitive issues, etc. These need to be considered and monitored during regular appointments as well as those with their movement disorders specialists."

- Deanna

While non-movement symptoms are invisible, they are common and many people with Parkinson's find them more troublesome and disabling than movement symptoms.

"This disease is very complex, not just a movement disorder. It affects your brain, your confidence, your sense of self, and there are day-to-day changes."

- Michele

Working on your mental health is key to living with Parkinson's. A mental health counselor or support group can help you feel safe and validated while helping you navigate PD.

"They should combine medical care with social worker care. Don't tell someone their life is about to radically change but offer nowhere to start or available services."

- Lee

Ask your doctor to help you build a care team that can help you manage symptoms and improve overall quality of life. Medical centers that are part of our Global Care Network provide interdisciplinary teams that provide wide-ranging PD care. Learn more at Parkinson.org/GlobalCareNetwork.

"Refer early for speech and swallowing changes!"
- Julia

Addressing Parkinson's symptoms early, such as speech and swallowing changes, is extremely important. Without intervention, swallowing difficulties can be especially dangerous.

"They need to know the importance of taking medication at the right time when in the hospital. It was a nightmare trying to ensure that my mother got her medications on time."

- Roisin

People with PD face a higher risk of hospitalization and encounter unique challenges during a hospital stay. Our Hospital Safety Guide (Parkinson.org/HospitalSafetyGuide) is designed to help people with PD and their care partners advocate for high-quality care in the hospital.

"We are all very different, and whatever they learned in a book or heard from their last patient may not apply to me. Everything we tell our doctors pales in comparison to what we go through most days. We aren't liars or exaggerating; we need a little relief."

- Esther

All people with PD deserve to receive proper care. Our PD stories allow people to share their stories and advocate for themselves and their community. Find inspiration in PD stories or share your own at Parkinson.org/MyPDStory.



As Parkinson's disease (PD) progresses, people with PD may experience freezing of gait or "freezing" episodes. Freezing of gait is the temporary, involuntary inability to move. Not all people with PD experience freezing episodes, but those who do have a greater risk of falling. Usually, freezing only lasts a few seconds, but it is one of the more frustrating and dangerous symptoms of PD. You may not always be able to prevent a freezing episode, but recognizing when this PD symptom may happen can minimize injury.

5 Tips for Overcoming a Freezing Episode

- Shift the weight of your body from one leg to another.
 Then exaggerate a large shift to one side while you step with the other foot.
- 2. March then swing your leg high and parallel to the ground with knees locked.
- 3. Imagine a line to step over or focus on a target on the floor to step on.
- 4. Turn on music and step in time with the rhythm. If you can't turn on music during an episode, try humming or counting.
- 5. Turn by walking half a circle or square instead of by a pivot turn.

Facts About Freezing

- During a freezing episode, a person often feels like their feet are stuck to the ground.
- Freezing may also affect other parts of the body or speech.
- Freezing may occur when the person with PD is due for the next dose of dopaminergic medications. This is called "off" freezing — usually, freezing episodes lessen after taking the medicine.
- The exact cause of freezing is unknown.

What can trigger a freezing episode?

Freezing can occur at any time, but freezing episodes tend to happen more often when a person with Parkinson's is in transition. Freezing most often occurs when a person is walking through a doorway, turning a corner, turning around, or stepping from one type of surface to another. Experiencing stressful situations or multitasking while walking can also lead to a freezing episode.

Freezing and Falls

About 38% of people living with Parkinson's fall each year. PD-related falls are often related to a freezing episode. Not everyone living with PD will experience freezing episodes, but those who do are at a much higher risk of falling. Freezing creates a danger of falling because the beginning and end of a freezing episode are unpredictable. The unpredictability of freezing, along with efforts by well-meaning companions to force the person with PD to move, may cause loss of balance and falls.

Talk to your doctor if you experience frequent freezing episodes.

Adjusting your PD treatment may be helpful. You may also ask about seeing a physical and/or occupational therapist trained in Parkinson's, who can teach you techniques that reduce the risk of falling.

Learn more about freezing episodes and other activities of daily living at Parkinson.org/Freezing.





Building community has been a critical part of Jo Zimmerman's journey with Parkinson's. Knowing there were five people in her church who were living with PD, she decided to start a support group after her diagnosis 14 years ago. Later, she worked with her local Parkinson's Foundation chapter and other women with Parkinson's in Rochester to form a Women and PD support group.

"I've got my community here. I've built it. It's been an interesting journey,"
Jo said. Jo utilizes Parkinson's
Foundation resources to help people who are new to PD and those in the support groups she runs. "The Parkinson's Foundation has been a good springboard for me and others to learn more about the disease," she said. "The detailed information on anxiety, depression, nutrition, exercise and many other topics are so helpful for people with Parkinson's or even for people who think they might have it."

Jo has also been an enthusiastic supporter of the Foundation's

education programs and Moving Day, A Walk for Parkinson's. She is proud to support the Foundation's research initiatives as well. She encourages others to build their PD community and advocate for themselves.

"I tell everyone in the groups I run that they cannot hide in the shadows,"
Jo said. "We need to advocate for ourselves, others in our community, continued quality research and resources that help us live better with PD. You know yourself better than anyone else — if something is bothering you, make sure your doctor knows it. If they don't listen, find somebody else. It took me a while to find people that really listen. Organizations like the Parkinson's Foundation can help you with that."

Your donation can help people with Parkinson's today. To donate, contact Kathryn Sheppard, Associate Vice President of Individual Giving at KSheppard@parkinson.org.



awareness.



Inspired by his father's PD journey, Scott Rofstad took action to make a difference. Hosting the Golf Fore Parkinson's tournament in Chicago, IL, he raised more than \$70,000 for the Parkinson's Foundation, bringing together friends, family and community — including participants from Wintrust Commercial Banking, the Chicago White Sox, Medinah Country Club and more.

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



LEAVE A MEANINGFUL LEGACY THROUGH YOUR ESTATE

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.

GIVE ONLINE TODAY



PD GENEration: Mapping the Future of Parkinson's

Help us change the course of Parkinson's

Disease



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MAPPING THE FUTURE OF PARKINSON'S DISEASE

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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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