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april

PARKINSON'S AWARENESS MONTH

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Expert Briefing: Research Update – Working to Halt PD

Register: Parkinson.org/ExpertBriefings

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Moving Day Charleston

Sign up: MovingDayCharleston.org

Moving Day Knoxville

Sign Up: MovingDayKnoxville.org

Moving Day San Jose

Sign Up: MovingDaySanJose.org

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Moving Day Kansas City

Sign Up: MovingDayKansasCity.org

Moving Day Tampa Bay

Sign Up: MovingDayTampaBay.org

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Moving Day Columbus

Sign Up: MovingDayColumbus.org

may

8

Expert Briefing: Trouble with Zzz's: Sleep Challenges with Parkinson's

Register: Parkinson.org/ExpertBriefings

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Moving Day DC

Sign up: MovingDayDC.org

Moving Day Salt Lake City **NEW**

Sign Up: MovingDaySaltLakeCity.org

Moving Day San Francisco

Sign Up: MovingDaySanFrancisco.org

Moving Day Twin Cities

Sign Up: MovingDayTwinCities.org

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Moving Day Finger Lakes NY

Sign Up: MovingDayFingerLakesNY.org

Moving Day Southeastern PA

Sign Up: MovingDaySoutheasternPA.org

june

1

Moving Day Albuquerque

Sign Up: MovingDayAlbuquerque.org

Moving Day Baltimore

Sign up: MovingDayBaltimore.org

Moving Day Cleveland

Sign up: MovingDayCleveland.org

Moving Day Portland, ME **NEW**

Sign Up: MovingDayPortlandME.org

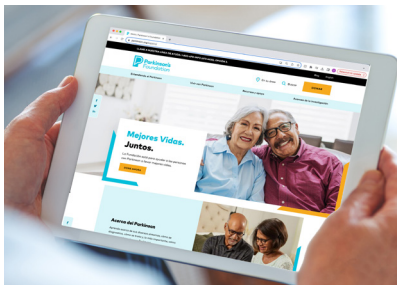
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Moving Day Omaha

Sign Up: MovingDayOmaha.org

View all upcoming events at Parkinson.org/Events.

Explore Our Resources in Spanish






Explore our new articles created for the Spanish-speaking PD community.

Visit Parkinson.org/Espanol.

Run as a Parkinson's Champion

Make life better for people with Parkinson's as a Parkinson's Champion! Explore upcoming events:

-  **September 29:** HOKA Chicago Half Marathon & 5K
-  **October 6:** Medtronic Twin Cities Marathon Weekend (10-miler, Marathon)
-  **November 24:** Philadelphia Marathon (8K, Half, Marathon, Multi-Challenges)

Find your next race at Run4PD.org.



JOHN LEHR, PRESIDENT & CEO

A Note From Our CEO

Parkinson's disease (PD) awareness month occurs every April. But at the Parkinson's Foundation, Parkinson's awareness is a year-round commitment. For us, it is about **bringing attention to a life-changing disease that is on the rise**. It is about educating people on the myriad of symptoms that impact daily life. It is about helping people recognize the early signs that can lead to an earlier diagnosis. And it is about connecting people to information and resources that can change how they live with this disease.

The Parkinson's Foundation is committed to translating awareness into action. We are excited to announce that our pioneering genetics study, PD GENERation, which provides genetic testing and counseling to people with PD, is expanding throughout the United States and into Central and South America. Read more on page 4 to discover what this expansion means for the greater PD community.

In this special awareness month issue, we invite you to meet Cindy (page 9) and let her story inspire you as it does all of us at the Foundation. Find out how we are working to expand inclusion in clinical trials for everyone living with PD through tailored events (page 10). And check out our #ABCsofPD awareness month campaign and find out which of those keywords resonates with your PD experience. Dive in on page 8 and learn more and at [Parkinson.org/Awareness](https://www.parkinson.org/Awareness).

Helpful Parkinson's Resources

Take a few minutes this month to try new tools that can help you and your loved one with Parkinson's navigate this disease:

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 sign up for local events. [Parkinson.org/YourArea](https://www.parkinson.org/YourArea)
3. **PD Library** — From videos and articles to podcast episodes, deep dive into the symptoms and topics that matter most to you. [Parkinson.org/PDLibrary](https://www.parkinson.org/PDLibrary)
4. **PD Health @ Home Events** — Register for new, weekly online events and explore our on-demand at-home exercise classes. [Parkinson.org/PDHealth](https://www.parkinson.org/PDHealth)
5. **Parkinson.org** — Explore every stage, symptom and the latest research findings. [Parkinson.org](https://www.parkinson.org)

Explore all our Parkinson's resources at [Parkinson.org/Resources](https://www.parkinson.org/Resources).



PD GENERation Study Announces Global Expansion

Through its Global Parkinson's Genetics Program (GP2), Aligning Science Across Parkinson's (ASAP) has awarded the Parkinson's Foundation a grant that will significantly expand its landmark international genetics study, *PD GENERation: Mapping the Future of Parkinson's Disease*. The study provides genetic testing and genetic counseling to people with Parkinson's disease (PD).

ASAP's funding will allow the Foundation to accelerate the study's impact by focusing on those who have been historically underrepresented in research. Through the study expansion, the Foundation will drive wide-scale recruitment, reaching a larger and more diverse community in the U.S., Canada, and beyond. PD GENERation is available in English and Spanish and will expand to Latin America.

Understanding the genetics of PD among diverse populations allows researchers to compare people with PD. Every case of PD is unique, so understanding the genetics that people with PD have in common across populations could reveal key disease biology, with the potential to lead to new treatments.

"Genetic research offers one of the most promising pathways toward new therapies for PD," said Roy Alcalay, MD, MS, Tel Aviv Medical

Center, Israel, and the Department of Neurology, Columbia University Irving Medical Center, and lead principal investigator for PD GENERation. "It is critical that our research includes data from a diverse body of participants because no two people with PD are identical. Data is power, and by providing genetic data to study participants, PD GENERation empowers the community to be involved in additional research toward a cure. The collaboration between the Parkinson's Foundation, ASAP, and GP2 will benefit all people who live with the disease."

To maximize the efficiency of sample and data sharing with researchers, the Foundation will also move to whole-genome sequencing. This will allow researchers the fullest opportunity to investigate the genetic underpinnings of PD. In hopes of accelerating PD research, the



"I want people with Parkinson's to know that participating in PD GENERation is free, private, doesn't involve any medications and is a way of contributing to a finding a cure someday. When you get your genetic testing results, you can review them and ask questions with a health professional."

- **Richard Huckabee**

Living with Parkinson's since 2013, PD GENERation participant, Parkinson's Foundation Research Advocate

Foundation will share research data with the Accelerating Medicines Partnership® Parkinson's Disease portal.

ASAP's GP2 program aims to improve understanding of the genetic architecture of PD by integrating ancestrally diverse populations to address a large gap in scientists' knowledge about the disease. Led by Dr. Andrew B. Singleton and Dr. Cornelis Blauwendraat, of the NIH's National Institute on Aging, the program's partnership with the Parkinson's Foundation will further increase the racial and ethnic diversity of global PD genetic data.

"What sets PD GENERation apart from traditional genetic research studies is that participants receive their test results. This generous grant from ASAP will allow us to have not only a significant impact on PD research but also the thousands of participants receiving insight from their genetic testing."

- James Beck, PhD
Parkinson's Foundation Chief Scientific Officer

PD GENERation

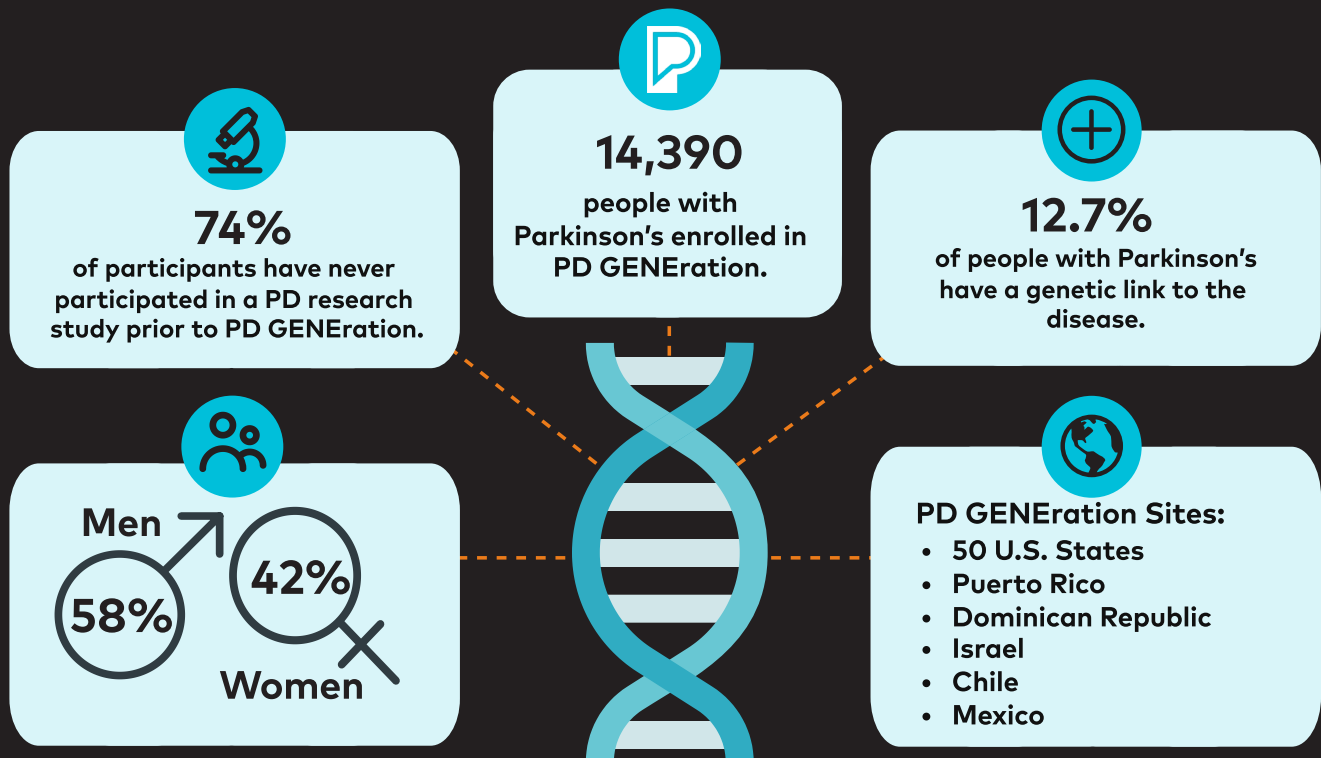
MAPPING THE FUTURE OF PARKINSON'S DISEASE

Launched in 2019, PD GENERation tests for mutations among select, clinically relevant genes to improve PD care by accelerating research to advance treatments. The study aims to make genetic testing accessible to every person with PD, helping people with the disease and their physicians identify whether they qualify for enrollment in clinical trials, and advancing research. Through PD GENERation, the Foundation works to increase participation in research across all racial and ethnic groups.

PD GENERation will continue to return genetic results to all participants through a genetic counselor, building a critical bridge between people with PD and clinicians to accelerate research collectively.

To enroll and learn more about PD GENERation, visit Parkinson.org/PDGENERation.

PD GENERation By the Numbers



How to Communicate Top 5 Parkinson's Care Needs During a Hospital Visit



People with Parkinson's disease (PD) are at a higher risk of hospitalization and face many challenges while in the hospital. However, careful preparation and clear communication can help minimize complications and recovery time.

Use these Parkinson's Care Needs from the new Parkinson's Foundation Hospital Safety Guide to communicate PD needs during a hospital visit:

1. I need my hospital chart to include my exact medications and match my at-home schedule.

Hospital staff often follow standardized medication schedules to ensure timely administration for most patients, but this doesn't prioritize the complex medication routines that people with Parkinson's follow. Make sure the hospital records your exact medication times rather than the number of times per day you take them. Otherwise, the hospital will follow their schedule instead of yours.

What to do: Ask to verbally review your hospital medication list and schedule with your hospital care team, confirming medications align with your at-home schedule. You can request a printout and compare it to your Medication Form.

2. I need to take my Parkinson's medications within 15 minutes of my usual schedule.

Many hospitals allow nurses to give medications up to an hour before or after the scheduled time. Delayed or missed PD medications can lead to falls, difficulty participating in rehabilitation and being less prepared to go home once discharged.

What to do: Remind nurses when it is almost time for your medications. Describe your symptoms and how they are affected when you do not receive medication on time.

3. I need to avoid medications that make my Parkinson's worse. These can include those that block dopamine, sedatives and certain pain medications.

Lack of dopamine in the brain is the primary cause of PD movement symptoms. If a person with PD takes a dopamine-blocking medication, symptoms can worsen and result in harmful side effects. A hospital care team may prescribe these medications to treat nausea, confusion and psychosis (hallucinations and delusions) without realizing they can worsen Parkinson's symptoms.

What to do: Share the list of harmful medications on the Parkinson's Care Summary form (available at [Parkinson.org/HospitalSafetyGuide](https://www.parkinson.org/HospitalSafetyGuide)) and ask for a safe alternative.

4. I need to move my body as safely and regularly as possible, ideally three times a day.

For people with PD, regular movement — often coupled with physical and occupational therapy — is important for controlling PD symptoms, preventing falls and minimizing complications. The hospital care team may limit movement to keep you safe, especially if you have low blood pressure or other issues that put you at risk of falling.

What to do: Ask for physical or occupational therapy if you need help moving safely. Talk to your care team about continuing daily activities, such as dressing, walking to the bathroom, sitting in a chair for meals and taking short walks.

5. I need to be screened for swallowing changes to safely maintain my medication routine and minimize my risk of aspiration pneumonia and weight loss.

Difficulty swallowing, called dysphagia, is common for people with Parkinson's. Minor swallowing issues can worsen and create severe complications during a hospital stay. Staff may order "NPO" (nothing

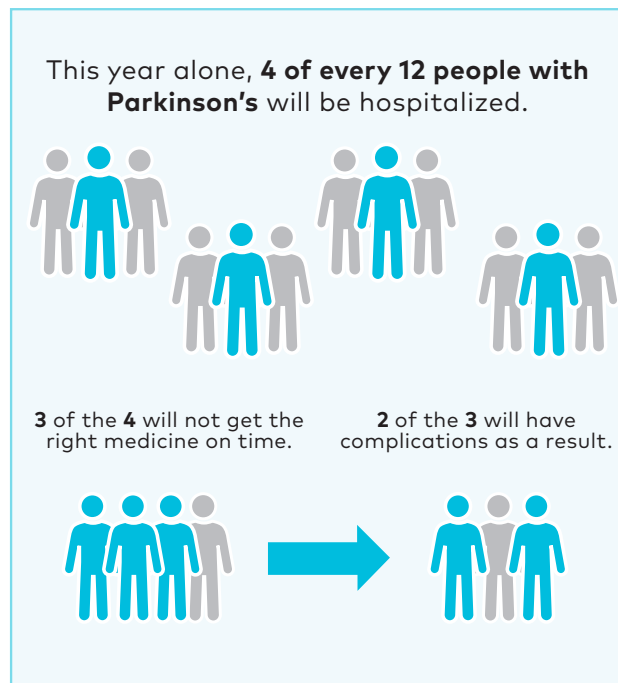
by mouth) with the goal of preventing severe swallowing-related complications. This usually includes stopping PD medications, along with food and liquids, which can make swallowing issues worse.

What to do: Ask the nurse about ways to continue Parkinson's medications safely.

Committed to Improving Hospital Safety

The Parkinson's Foundation just launched an updated Hospital Safety Guide. The Foundation is committed to leading the national effort to improve hospital care and drive systemic change for people with PD.

In 2023, we began the Parkinson's Foundation Hospital Care Learning Collaborative, a bi-monthly meeting of hospital leaders and healthcare professionals who are committed to improving hospital care for people with Parkinson's in their institutions. This one-year program allows members — representing 20 healthcare systems across North America — to collaborate, share data, troubleshoot problems and explore the successful innovations that lead to improving PD care.



Read and order your Hospital Safety Guide at [Parkinson.org/HospitalSafety](https://www.parkinson.org/HospitalSafety).

Preparing for A Hospital Stay Checklist

A hospital stay — whether planned or unplanned — can be especially challenging for people living with Parkinson's. Follow these tips to help you prepare for a hospital stay.

- Choose a hospital care partner** to accompany you in the hospital. This person should be someone you trust and can help ensure your medication schedule is being followed.
- When scheduling a procedure**, request an early morning appointment when medications are working best to minimize medication schedule interruptions.
- Set up a Medical ID** on your smart phone. Follow our step-by-step instructions at [Parkinson.org/HospitalSafety](https://www.parkinson.org/HospitalSafety).
- Print PD-related health forms** that can help you advocate for your best care — from a medical alert card, medication routine form, my personal care details. Download these forms for free at [Parkinson.org/HospitalSafety](https://www.parkinson.org/HospitalSafety).
- Prepare a hospital "go bag"** with these items:
 - Parkinson's Foundation Hospital Safety Guide
 - Completed Medication Form and signed Doctor's Letter
 - Current medications in labeled pharmacy bottles (2+ day supply)
 - Completed Advance Directives
 - DBS remote, if applicable

Explore hospitalization and all Parkinson's resources at [Parkinson.org/Resources](https://www.parkinson.org/Resources).

All You Need to Know About Parkinson's Disease – From A to Z

ABCs of PD
DEFG
HIJKL
RSTUVWXY

This Parkinson's Awareness Month, we partnered with Mitsubishi Tanabe Pharma America to help people understand the complexity of Parkinson's disease (PD) and recognize its symptoms.

A	Anxiety	Parkinson's symptoms not related to movement are often more troublesome and disabling than movement symptoms. These symptoms can include anxiety, depression, vertigo and more.
B	Balance	More than half of people with Parkinson's will experience a fall in the next year. There are many tips and ways to prevent falls.
C	Care Partner	Like Parkinson's, there are several stages of the care partner journey. Explore free articles, tools and courses designed for you.
D	Diagnosis	Finding out you have Parkinson's can be a lengthy process. A diagnosis is made through a combination of in-office tests and diagnostic tools.
E	Early Signs	From small handwriting and loss of smell and trouble sleeping, know the 10 early signs of Parkinson's.
F	Fitness	People with PD who exercise for 2.5 hours per week experience a slowed decline in quality of life. Find the exercise that works for you.
G	Genetics	12.7% of participants in our study have a genetic tie to PD. PD GENERation is a study that provides genetic testing and counseling to people with PD, at no cost.
H	Hospital Safety	People with Parkinson's are at a higher risk of hospitalization and longer hospital stays.
I	Incidence	Know how to prepare and advocate for yourself with our Hospital Safety Guide. Nearly 90,000 people in the U.S. will be diagnosed with Parkinson's this year.
J	Job	"How long will I be able to work with Parkinson's?" This question is especially important to people with young-onset PD.
K	Knowledge	Find the information you need now – from tools that help you work alongside your care team to resources that empower you.
L	Lewy body dementia	Robin Williams brought awareness to the prevalent disease known as Lewy Body Dementia, a progressive brain disorder where cognitive decline is an early symptom.
M	Medication	There is no one-size-fits all treatment for Parkinson's. Treatments and medications should be tailored to symptoms.
N	Neurologist	Neurologists (and specialized neurologists called movement disorders specialists) diagnose and treat Parkinson's.
O	Occupational Therapy	Rehabilitation therapies – occupational, physical and speech therapies – can slow disease progression, address symptoms and enhance mental health.
P	Parkinsonism	Parkinsonism is the collection of signs and movement symptoms associated with several conditions – including Parkinson's disease.



Mitsubishi Tanabe Pharma America

Read all the ABCs of PD and find more information on every word at [Parkinson.org/Awareness](https://www.parkinson.org/Awareness).

Cindy Won't Let Parkinson's Slow her Down

Cindy Finestone does it all. The on-the-go, soon-to-be first-time grandmother serves on community boards, cooks a mean Sunday feast, goes to the gym six days a week, and fundraises for causes she believes in. And she does it all fighting Parkinson's disease (PD).

Cindy was diagnosed with Parkinson's 10 years ago. By now, she's heard enough misdiagnosis stories to consider herself "one of the lucky ones." A year after ruling out carpal tunnel, she noticed a tremor in her hand. "A lot of times people put things off and don't address health problems right away, making it worse, so I got it checked out," Cindy said.

Cindy thought it was unusual that her doctor was standing at the exam room door waiting for her. She later found out he was observing her gait. "I left with a Parkinson's diagnosis, an Azilect® prescription and a referral for a movement disorders specialist."

Soon after, Cindy began experiencing severe cervical dystonia (sustained and repetitive muscle spasms or cramps). The pain caused her to look up and impacted her daily life. Her doctor started Cindy on Botox injections in her neck. "Parkinson's caused the muscles in my neck to atrophy, so I started exercising like I never had before to strengthen my body," she said. Fast forward to 10 years later, exercise is part of Cindy's routine. Rock Steady Boxing classes changed everything.

"Exercise is not just about physical health, but mental health. I believe that the more you push yourself when exercising, the better your movements will be every day. If I don't go to the gym, I feel like something is not right."
- Cindy

Between her treatments and her Rock Steady Boxing instructor having her do entire classes holding a tennis ball under her neck, Cindy's dystonia dramatically improved. She felt better and was ready to get involved in the PD community.



Cindy and family

Cindy found Moving Day Rochester, and attended by herself for years until her son's teacher was diagnosed with Parkinson's, and asked his mom if she had heard of Moving Day. "He couldn't believe I was going alone and insisted on helping me fundraise." Cindy went into planning mode, she created jewelry and T-shirts to



Cindy at Moving Day Rochester

raise funds, along with her first Facebook account and page — and raised \$5,000 in four weeks.

"Being involved in the Parkinson's Foundation makes me feel like I'm doing something that's helping. Everything I do is somehow related to the Foundation. I attend a women's PD support group with 60 members, that I found through the Foundation. I call the Helpline for referrals. I visit Parkinson.org every time I feel a new symptom coming."

In 2023, Cindy joined the Parkinson's Foundation People with Parkinson's Advisory Council, a group of dedicated people in the PD community who advise and collaborate with the organization.

While Cindy notices that Parkinson's has slowed her down, especially in the morning, she doesn't let it stop her from living life. "I play mahjong, do pottery and knitting classes. I love cooking and spending time in my craft room, but volunteering is what keeps me busy, it keeps me aware."

Explore the many ways to get involved with the Parkinson's Foundation at [Parkinson.org/GetInvolved](https://www.parkinson.org/GetInvolved).



Parkinson's Research Training Aims to Advance Health Equity

As researchers develop Parkinson's disease (PD) treatments, there is a critical need to engage with the Parkinson's community during the research process. Populations of focus — including Black and African Americans, hispanics/latinos, women and others — are underrepresented in, and historically excluded from, research. Engaging these communities in the design of clinical trials allows for greater representation in research. The Parkinson's Foundation is committed to making research inclusive and creating a systemic change in the PD research space.

On September 13, 2023, the Parkinson's Foundation hosted a new, tailored version of its Learning Institute, which trains people with Parkinson's and care partners in research and advocacy to work alongside scientists and government agencies in the drug development process.

Held in Atlanta, GA, in collaboration with Morehouse School of Medicine, the training sought to engage the Black and African American Parkinson's community (people with Parkinson's, care partners, neurologists and professionals). During the training, participants found a community, learned how to confidently work alongside researchers and use their voice to advocate for changes in research.

Training participants received exclusive insight into the

Foundation's global genetics initiative, PD GENERation: Mapping the Future of Parkinson's, and the opportunity to enroll and receive on-site genetic testing as part of the study. Before the training, 29% of attendees had reported participating in a research study. By the end of the Learning Institute, 100% of participants with PD had completed their first PD research study, PD GENERation.

"Interacting with other African Americans with Parkinson's, neurologists that look like me and sharing our daily challenges was empowering. Becoming a Parkinson's Foundation Research Advocate has provided me with a new village of support, and I feel empowered to fight this disease every day." - Vanessa Russell Palmer, a person with Parkinson's and Learning Institute attendee.

No Topic Off-Limits

Black and African Americans experience health disparities when navigating Parkinson's — and are more likely to be diagnosed later in the disease stage than white people. Knowing this, the event featured roundtable discussions, with every table assigned a PD expert, neurologist or Foundation staff member to lead a PD topic.

The training directly addressed medical mistrust and historical mistreatment. "Understanding past mistakes is crucial to preventing their recurrence. Discussing the root causes of medical mistrust is necessary for acknowledgment and progress, fostering a path towards informed and empowered healthcare decisions," said Reversa Joseph, MD, movement disorders specialist.

Next, the Parkinson's Foundation is working to tailor more trainings and local educational events to populations of focus. The goal is to help people with PD and their families live better with Parkinson's.

Read the full version of this story and the latest PD articles at [Parkinson.org/Blog](https://www.parkinson.org/Blog).



A Family Foundation Committed to Raising Awareness

Over the past several years, Cindy and Scott Heider have helped three family members navigate a Parkinson's disease (PD) diagnosis. As avid philanthropists, becoming supporters of the Parkinson's Foundation felt like a natural fit as they set out to learn more about the disease to aid those in their family with PD and help raise awareness.

"I don't think people really understand the progression of Parkinson's disease and how it affects so many aspects of a person's life, as well as the people around them," Cindy said.

One thing Cindy has noticed firsthand is how PD symptoms and progression are unique to each person who has it. While one of her family members battles movement symptoms, another fights both movement and non-movement symptoms.

After connecting with the Foundation and learning more, Cindy and Scott decided to make a generous gift through the Heider Family Foundation and have become valued supporters and advocates.

"We decided to support the Foundation because we think it is important for more people to know about Parkinson's," she said. "As the population ages, more and more people are getting diagnosed with this disease, and we know from experience how important it is to learn more about it. We also believe in supporting research initiatives like PD GENERation, which is a great avenue to get more people with Parkinson's involved in research. The more people you can engage, the more accurate your results are, and the faster research can progress."

With your support, we can help people live better with PD. Contact Kate Nelson, Associate Vice President of Individual Giving at KNelson@parkinson.org.



Elizabeth Goldberg is the top Parkinson's Foundation 2024 Miami Marathon runner, raising \$12,000. "After watching my father get diagnosed with Parkinson's 15 years ago, I recognize the urgent need to find a cure or slow the progression of the disease so people living with PD can continue to enjoy a quality of life they once knew."



As a person living with Parkinson's, Edward understands the need for more PD research and awareness. Taking inspiration from his journey with PD, he raised more than \$2,000 through hosting an art show in Jupiter, FL, featuring his photography collection at the New Studio for the Visual Arts 3rd Annual Master Artists Showcase.

Become a Parkinson's Champion today at [Parkinson.org/Champions](https://parkinson.org/Champions).



LEAVE A MEANINGFUL LEGACY

Join our Legacy Society and create a lasting impact when you include us as a beneficiary in your will. We have partnered with Giving Docs to offer you FREE tools to write your will. Visit GivingDocs.com/Parkinson to get started.

If you would like to discuss the best way to leave a gift, please email us at Legacy@Parkinson.org.

GIVE ONLINE TODAY



PD GENERation: Mapping the Future of Parkinson's Disease

Help us change the
course of Parkinson's



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

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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.



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