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**Parkinson's
Foundation**

2024 Events

january

- 11-14** DISNEYLAND HALF MARATHON WEEKEND
Register: Parkinson.org/Run4PD
- 28** LIFE TIME MIAMI MARATHON
Register: Parkinson.org/Run4PD

february

- 24** PARKINSON'S REVOLUTION
Sign Up: Parkinson.org/Revolution

march

- 13** EXPERT BRIEFING: PARKINSON'S RESEARCH: WHAT'S NEW?
Register: Parkinson.org/ExpertBriefings
- 16** MOVING DAY THE VILLAGES, FL
Sign Up: MovingDayTheVillagesFL.org
- 16-17** LOS ANGELES MARATHON
Sign Up: Parkinson.org/Run4PD
- 17** UNITED AIRLINES NYC HALF MARATHON
Register: Parkinson.org/Run4PD

april

- 1-30** PARKINSON'S AWARENESS MONTH
60 MILE CHAMPIONS CHALLENGE
Register: Parkinson.org/Champions
- 7** MOVING DAY PALM BEACH, FL
Sign Up: MovingDayPalmBeach.org
- 10** EXPERT BRIEFING: UNDERSTANDING PAIN IN PARKINSON'S
Register: Parkinson.org/ExpertBriefings
- 13** MOVING DAY SOUTH ALABAMA
Sign Up: MovingDaySouthAlabama.org
- 20** MOVING DAY CHARLESTON, SC
Sign Up: MovingDayCharleston.org
- 20** MOVING DAY SAN JOSE, CA
Sign Up: MovingDaySanJose.org
- 27** MOVING DAY TAMPA BAY, FL
Sign Up: MovingDayTampaBay.org
- 27-28** EUGENE MARATHON WEEKEND
Sign Up: Parkinson.org/Run4PD
- 28** BIG SUR INTERNATIONAL MARATHON WEEKEND
Sign Up: Parkinson.org/Run4PD

View all upcoming events at Parkinson.org/Events.

Helpful Parkinson's Resources

In honor of National Family Caregivers Month, we are sharing resources that can help care partners and their loved ones with Parkinson's disease (PD) live better lives:

- 1. Helpline** — Get answers to your PD care partner 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 educational programs and events. Parkinson.org/YourArea
- 3. Virtual Care Partner Courses** — Visit our Learning Lab for self-paced Care Partner Program online courses that feature care partners and health professionals. Parkinson.org/CarePartnerProgram
- 4. PD Library** — From fact sheets and podcast episodes to videos and articles, deep dive into the symptoms and topics that matter most to you. Parkinson.org/PDLibrary
- 5. PD Health @ Home Events** — Register for new, weekly online events (including exercise classes you can do together). Parkinson.org/Events

Explore all our Parkinson's resources at Parkinson.org/Resources.





Update From Our People With Parkinson's Advisory Council Chair

Living with young-onset Parkinson's disease (YOPD) while raising three kids with my wife has offered a few unique challenges and a superabundance of blessings. Along the way, I have come to understand that we were not made to sit on the bench. We were created to actively engage in this life, making an impact in our own small but significant way.

My volunteering experiences ultimately led me to serve as the new chair of the Parkinson's Advisory Council. Not only do I have the privilege of working alongside people with Parkinson's and care partners, but I am also grateful to help make life better for people with Parkinson's.

MARK KELM

This issue aims to empower the PD community. Resources and information are key to helping people with PD and care partners navigate this disease through every stage (see page 4). Research is how we will find a cure — explore the latest studies from two Parkinson's Foundation research grantees (page 9).

This November is National Family Caregivers Month. We dedicate this issue to care partners — to those who stand alongside us for every ebb and flow. This month, visit Parkinson.org/CaregiversMonth to help us make an impact.

MARK KELM

People with Parkinson's Advisory Council Chair

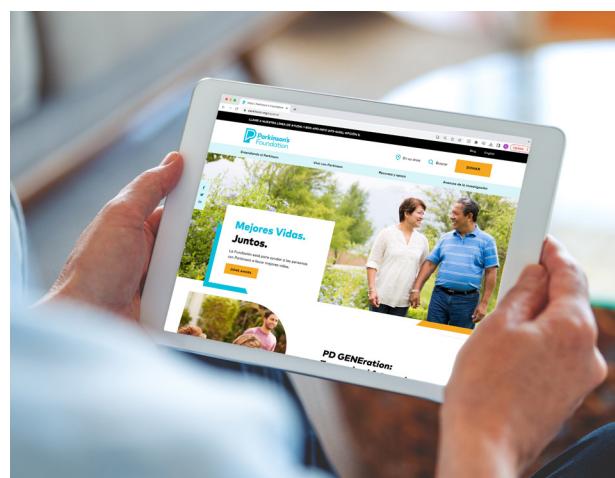
Help us invest an additional **\$30 MILLION** to accelerate Parkinson's research, improve care and increase access to quality-of-life programs.

**REACH
FURTHER**

Learn more at
Parkinson.org/Reach.



New Spanish Pages
Visit Parkinson.org/Espanol.



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

Caregiver Tips for Navigating the 5 Stages of Parkinson's

Parkinson's disease (PD) progresses over time, as does the role of a care partner. In this article, we explain the stages of the PD care partner journey and practical tips that aim to help along the way.

Early in the Journey: Stages 1 & 2

While your loved one's Parkinson's diagnosis probably changed your life overnight, the role of care partner is a role and an identity that you grow into. Early on, try to:

- **Build your knowledge base.**

Learn about PD so you can participate in healthcare discussions, make informed decisions and provide support. Find the resources you need at Parkinson.org/PDLibrary.

- **Find support in your area.**

In addition to having an environment to ask questions and share experiences, support groups can lead to friendships. Contact our Helpline at 1-800-4PD-INFO (1-800-473-4636) to find one near you.

- **Get on the same page.** Talk to your loved one about how you want to navigate this, together. How and when will you tell friends and family? Start openly discussing financial and career planning.

What should I expect as the disease progresses? Mental health-wise, changes to how the person feels, thinks and reasons can be more frustrating than movement symptoms, for both you and the person with PD. Anxiety, apathy and depression are common mood symptoms that are often treatable.

Exercise is medicine for people with Parkinson's and care partners. Research shows that people who begin regular exercise early in the disease experience a slower decline in quality of life. Exercise, physical and occupational therapy can help with movement and non-movement symptoms of PD. Devote time and energy to exercising.

Mid-Stage: Stages 3 & 4

Adaptability sums up this stage of Parkinson's. Symptoms advance, and as a care partner you will learn when to assist and when to allow the person more time to complete a task. When it comes to activities of daily living, try to:

- Seek a referral to an occupational therapist early on for personalized recommendations.
- Relocate frequently used items in the kitchen, bedroom and



bathroom to a place where they can be readily accessed.

- Simplify hygiene tasks with electric toothbrushes and shavers.
- Make mealtimes easier with assistive technology and devices like weighted utensils.

Caring for the Caregiver

Regular breaks from caregiving are an essential part of finding balance. Take an hour daily, an afternoon weekly or a day monthly — whatever you can manage. Remember that your loved one is only doing as well as you are.

Read more at

Parkinson.org/CaregiverSelfCare.

Anticipate that medications may not be as effective as they once were. This can lead to:

- Motor fluctuations (known as "on-off" fluctuations): changes in the ability to move, often related to when medications kick in or start to wear off.
- Dyskinesia: involuntary, erratic, writhing movements of the face, arms, legs or trunk.

Bring these symptoms up to the care team, who can recommend medication adjustments and treatment options.

Stages of Parkinson's & Resources That Can Help

People with Parkinson's and care partners rarely adjust to living with PD at the same rate. You might need to adjust household and lifestyle responsibilities, which can be a hard transition. Try leaning on your PD community and support system.

Advanced Parkinson's: Stage 5

There is no single definition of "advanced" Parkinson's. In general, when a person with Parkinson's is no longer physically independent, the disease is considered advanced. Tips for navigating this stage include:

- Try to stick to a daily routine. Your loved one will usually function better if he or she knows what is going to happen each day.
- Try to make time with your loved one that is not focused on caregiving tasks.
- Schedule time to rest within the daily routine.

Thinking and memory changes often occur in this stage, including slowed thought processes, forgetfulness, confusion and compulsive behaviors. Try to acknowledge and adapt to these changes, even though they can be frustrating and frightening. Report new or sudden changes to the care team and try these tips:

- Use the same cues each time to provide instructions. Teach these cues to anyone who provides care.
- Try using humor to diffuse a stressful situation, but avoid using negative humor or sarcastic remarks, which may be misinterpreted.

As you and your loved one navigate Parkinson's, it is paramount to have open conversations with one another and your care team as you find the methods and routines that work best for you both.

Explore [Parkinson.org/Caregivers](#) for in-depth articles and resources designed for care partners.

STAGE 1

In this initial stage, symptoms are often mild. Tremor and other movement symptoms occur on one side of the body. Non-movement symptoms are present and can include anxiety and trouble sleeping. [Learn more about building a care team at Parkinson.org/FindingCare.](#)

STAGE 2

Symptoms begin to worsen. Tremor, rigidity and other symptoms affect both sides of the body. Walking problems may be apparent. Daily tasks may take longer to complete. [Get connected and find local resources at Parkinson.org/YourArea.](#)

STAGE 3

In this stage, most people are independent but daily activities can become more difficult. Movement symptoms worsen, including loss of balance, making falls more common. Find an occupational therapist who can help optimize daily living. [Call our Helpline at 1-800-4PD-INFO \(1-800-473-4636\).](#)

STAGE 4

At this point, symptoms are fully developed and disabling. It is still possible to walk and stand without assistance, but using a cane or walker may be necessary. Significant help may be needed for activities of daily living. [Read about home safety at Parkinson.org/HomeSafety.](#)

STAGE 5

In the most advanced and debilitating stage, around-the-clock care is usually required. [Read in-depth articles at Parkinson.org/AdvancedPD.](#)

Learn more at [Parkinson.org/Stages.](#)

New Study Shows Only 9% of People with Parkinson's See A Movement Disorders Specialist

Regularly seeing a neurologist can improve the lives of thousands of people with Parkinson's disease (PD) each year. However, access to expert Parkinson's care is not always easily available. A recent Parkinson's Foundation-funded study found that only 9% of Medicare beneficiaries with PD received care from a movement disorders specialist (expertly trained neurologists who treat PD).

The study identifies critical gaps in care for people with Parkinson's in the U.S. Those with the greatest disparities in care are women, people of color (those who identify as Asian, Black, Hispanic and Native American) and residents of rural areas. Using Medicare data from 2019, the study represents 90% of people living with Parkinson's in the U.S.

Study Findings

- 50% of people with PD receive care for the disease from general neurologists.
- 29% receive PD care from primary care providers.
- Although depression affects 53% of people with PD receiving Medicare, only 2% receive treatment from a mental health professional.
- Medicare recipients with PD are not likely to access supplemental therapies — physical and occupational therapy, speech-language therapy and mental health services.

The Urgency of Connecting People to Expert Care

Every year, 90,000 people in the U.S. are newly diagnosed with PD. Receiving an accurate PD diagnosis can be half the battle, while the other half is finding quality PD care. Those who engage with healthcare professionals trained in PD in the early stages of the disease report better outcomes and quality of life.

Only...

10%
of Men

8%
of Women

7%
of Rural Residents

Have Access to a Movement Disorders Specialist for Parkinson's Care



"Our findings underscore that Parkinson's specialists are not the care providers for most people with PD — it is the general neurologist and other clinicians. This key information helps the Parkinson's Foundation design and launch new programs rooted in best-practice care to reach all professionals who treat people with PD."

JAMES BECK, PhD

Senior study author and Parkinson's Foundation chief scientific officer.

The economic burden of Parkinson's to individuals, families and the U.S. government is nearly \$52 billion every year. Not only is expert care critical to living better with Parkinson's, receiving care early on can reduce the economic burden of Parkinson's drastically on a personal and nation-wide basis.

The number of people with PD will continue to increase substantially in the next 20 years due to the aging population. That is why the Parkinson's Foundation is determined to educate healthcare professionals, so that **people with Parkinson's will receive a diagnosis earlier, treatment sooner and better care.**

Find expert care near you at Parkinson.org/YourArea.

Only 9% of People with Parkinson's Disease Receive Care from Movement Disorders Specialists

9%



Currently, there are 660 Movement Disorders Specialists in the United States.

Only 6 are practicing in rural areas.



Global Care Network Adds 8 New Parkinson's Care Centers

The number of people living with Parkinson's disease (PD) in the U.S. is expected to rise to 1.2 million by 2030. A central priority of the Parkinson's Foundation is to ensure that all people with PD have access to expert PD care when and where they need it, which can improve overall health and quality of life. The Parkinson's Foundation is doing just that through designating eight new Global Care Network medical centers in the U.S. and Japan.

"The Stanford Movement Disorders Center is deeply honored to be designated a Parkinson's Foundation Center of Excellence," said Kathleen L. Poston, MD, MS, Edward F. and Irene Thiele Pimley Professor in Neurology and Chief of Movement Disorders for Stanford University. "Through patient care, education and research, our providers and staff embrace the Foundation's mission to make life better for people with Parkinson's disease."

To become part of the Global Care Network, Centers of Excellence and Comprehensive Care Centers must demonstrate exemplary PD care, with Centers of Excellence leading the PD field in advancing clinical research. These medical centers excel in utilizing a specialized, multidisciplinary team-based approach to treating Parkinson's and also provide community outreach.

The 4 new Centers of Excellence include:

- University of Michigan Health, Ann Arbor, MI
- University of California, Davis Health Center for Movement Disorders & Neurorestoration, Sacramento, CA
- Stanford Movement Disorders Center, Palo Alto, CA
- Juntendo University Hospital, Tokyo, Japan

Among the eight new centers, these are the first-ever designations in Wisconsin and Washington, as well as in Japan.

Visit Parkinson.org/CareNetwork for a full list of all Global Care Network centers.

The 4 new Comprehensive Care Centers include:

- Ohio State University Wexner Medical Center, Center for Parkinson's Disease and Other Movement Disorders, Columbus, OH
- University of Texas Health Science Center, San Antonio, TX
- Froedtert & The Medical College of Wisconsin Neuroscience Institute, Milwaukee, WI
- Swedish Movement Disorders Clinic, Seattle, WA

Science News: Study Finds Promise in Treating Parkinson's-Related Constipation

While the most well-known Parkinson's disease (PD) symptoms are movement-related — tremor, slow movement, trouble walking — many people with Parkinson's find non-movement symptoms — sleep disturbance, depression and constipation — more troublesome and disabling. More than 60% of people with Parkinson's experience constipation, and for most of those people it can be chronic, severe and unresponsive to standard treatments.

The muffled connection between the brain and the gut in Parkinson's has been studied for decades, and a protein called alpha-synuclein is thought to be the root cause. In Parkinson's, alpha-synuclein accumulates abnormally in the nervous system and impacts the production of dopamine, the chemical that helps us move and feel good. Additionally, alpha-synuclein clumps within the nerves of the gastrointestinal (GI) tract have been linked to a decrease in the strength and coordination of the bowels and can lead to constipation.

A new clinical trial shows a possible treatment for constipation in people with Parkinson's. A drug called ENT-01 (Enterin) acts on nerve cells in the GI tract and prevents the protein from clumping. An earlier study found that ENT-01 is not absorbed into the body, suggesting it acts only in the gut.

Study Results

The phase 2b clinical trial enrolled

150 people with Parkinson's and constipation and found that:

- People with PD and constipation who received ENT-01 had a significant increase in the number of daily bowel movements and had better stool consistency as well as ease of stool passage.
- There were no serious adverse effects of ENT-01. The most common side effects were nausea (experienced by 33% of participants) and diarrhea (experienced by 20% of participants).



In its clinical trial, the new drug ENT-01 is shown to help people

with Parkinson's who experience constipation. The drug will undergo the next phases in clinical trials (phase 3 and 4), which will also examine the safety and effectiveness of long-term use before it can become widely available.

Can this drug also help with cognitive issues?

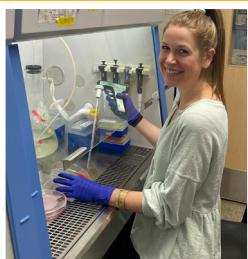
A small number of participants in this study who experience psychosis saw improvements in their cognitive symptoms. However, this study was not designed to examine these symptoms, so the Parkinson's Virtual Biotech is designing one that is. This new project will assess the potential of ENT-01 and how it may impact people with Parkinson's who experience memory problems.

Through our drug discovery initiative with the Parkinson's UK, Parkinson's Virtual Biotech, we are fast-tracking the development of new treatments that can treat, and ultimately cure, Parkinson's. ENT-01 is one of these new treatments.

Learn more about this drug and new medications underway through Parkinson's Virtual Biotech at Parkinson.org/VirtualBiotech.

Researchers Pursuing the Next Parkinson's Breakthrough

There is still a lot we do not know about Parkinson's disease (PD), which is why the Parkinson's Foundation funds researchers who are working to understand the root of the disease to lead us to a cure. This year, the Parkinson's Foundation funded \$2.8 million in research grants. Meet two researchers whose work gives us hope for a future without PD.



Sarah Talley, PhD

Loyola University of Chicago, Parkinson's Foundation Postdoctoral Fellowship for Basic Scientists

Untangling the Connections Between Inflammation, Aging and Parkinson's

Inflammation is the body's natural response to dealing with a threat, such as an injury or disease. However, as we age it becomes more difficult for the body to recover after a threat has passed. This results in a consistent age-related inflammation known as "inflammaging" that is thought to weaken cells and tissues, including the brain. Many have hypothesized that inflammaging plays a role in the development and progression of PD.

Sarah Talley, PhD, seeks to understand how inflammaging may worsen the spread of alpha-synuclein clumps in the brain (the hallmark protein associated with PD). The key to Dr. Talley's new study is a genetically modified mouse line, in which key cell types in the brain light up when experiencing inflammation. This light can be measured using a high-powered microscope, allowing Dr. Talley to quantify inflammation in different brain cell types over time.

Dr. Talley will inject alpha-synuclein tangles into the brains of these mice and monitor how those tangles spread and cause damage in the brain over time, but also how that spread affects brain-wide inflammation. These experiments will allow Dr. Talley to compare inflammation changes and alpha-synuclein spread between age groups.

"These experiments will provide foundational knowledge that can inform on when and where anti-inflammatory therapeutics could be used to remedy disease in PD patients," said Dr. Talley.



Jingxin Wang, PhD

University of Kansas Center for Research, Inc, Parkinson's Foundation Impact Award

Preventing Alpha-Synuclein Chain Reactions with Biochemical Precision

In Parkinson's, when the protein found in the brain called alpha-synuclein clumps, it forms tangled fibrils (microscopic fiber-like structures) that spread to other proteins, making them clump. Ultimately, this chain reaction will lead to the onset of PD symptoms.

Jingxin Wang, PhD, theorizes that preventing the spread of these fibrils can be key in developing new PD therapies, and ultimately halting the progression of Parkinson's. Recent research has shown that alpha-synuclein fibrils only cause progressive disease when there is additional alpha-synuclein present. Dr. Wang and his team developed biochemical tools for reducing alpha-synuclein levels in neurons using ribonuclease targeting chimeras, or RIBOTACs for short. These RIBOTACs aim to deplete alpha-synuclein RNA in the cell, which prevents the formation of new alpha-synuclein proteins. Dr. Wang and his collaborator, Dr. Xiaobo Mao at Johns Hopkins University, will test the effectiveness of these RIBOTACs through the use of mice neurons. A week later, they will then test the RIBOTACs ability to prevent the spread of alpha-synuclein clumping. These results will show if RIBOTACs have the therapeutic potential to reduce or prevent PD progression.

"Receiving this esteemed award from the Parkinson's Foundation is a significant milestone in my journey as a researcher," said Dr. Wang. "As a trained chemist, I am particularly excited about harnessing the potential of RNA degrading technology to target Parkinson's."

How Gil Built a Parkinson's Support System to Help His Wife

Upon retirement, Gil Kim was ready to move back to Mississippi to be closer to his two grandchildren, Colebea, 10, and Oliver, 7. Gina Kim, Gil's wife, was not quite as ready. After being diagnosed with Parkinson's disease (PD) in 2011, Gina and Gil had built an intricate support system that worked for them, physically and mentally.

"We were never the type of people who would take a prescription and just wait," Gil said.

"Thanks to the Parkinson's Foundation, we had a wealth of resources at our fingertips. We knew exercise was vital, so Gina became a boxer, pole walker, and a practitioner of Tai Chi."

- Gil

Living in Atlanta, GA, they had a nearby movement disorders specialist (a neurologist trained in PD), Rock Steady Boxing gym and support groups. But eventually, Gina agreed to move to Mississippi, if Gil helped her build a support system.

Utilizing experience from his 40-year career with the Army Corps of Engineers, Gil created a blueprint. "I was replicating a model that worked," he said. He reached out to his Parkinson's Foundation Georgia chapter to help plan a PD symposium in

Mississippi. Next, he and Gina launched a monthly support group, that has since amassed a steady 60 participants. They then applied and received a Parkinson's Foundation community grant called "What's Up, Doc?" The series of meetings brought together the newly diagnosed with the local PD community.



Gil is familiar with Parkinson's Foundation resources because he has relied on them for more than a decade. "Every week or two I hear from another Mississippian looking for help and hope," Gil said. "I always suggest they call the Helpline and recommend they sign up for PD Health at Home virtual events — these are game changers for people in rural areas, like Mississippi, where other resources are not available."

While Gil is dedicated to his PD community, he also makes moves on a national scale, helping guide the Parkinson's Foundation through serving on its People with Parkinson's Advisory Council and regionally on the Gulf Coast Chapter Advisory Board. "It's an honor to get involved — all of this involvement is dedicated to making life better for my wife," he said.

In just four short years since their move, Gil and Gina have brought resources and events that bring people together, including helping launch Mississippi's first-ever Moving Day, A Walk for Parkinson's. But they have also found unlimited joy in grandparenting.

"My wife's Parkinson's is gradually progressing, and we love traveling, so a few years ago we began taking one grandchild at a time on a trip," Gil said. They design each trip, complete with itineraries built around history, to cater to their grandchild's individual interests. "We took our grandson to New York and our granddaughter to Paris. I know PD is depressing for a lot of people, but you have to look at everything going forward. I'm sharing our story with them."

Connect to your local community and ways to get involved at Parkinson.org/GetInvolved.



Jeff and Lisa Help Ensure Access to Support and Vital Resources

Navigating a Parkinson's disease diagnosis can be daunting, but finding the right resources and a supportive community makes all the difference. When Jeff Byal was diagnosed with PD in 2020, he and his wife, Lisa, started looking for any resource they could find to help Jeff live well with PD, which led them to the Parkinson's Foundation.

"We believe knowledge is power," Lisa said. "The more you know, the better you can deal with your current situation. The Parkinson's Foundation offers great resources for people at any stage. And from a care partner standpoint, the connection to a community that can help you navigate this journey is vital."

Jeff and Lisa hope more people will take advantage of the resources the Parkinson's Foundation offers,

find solace in the Parkinson's community and donate to support the Foundation's vital research, care and education programs, just as they have.

"The more we tell our story, the more people we find out are impacted by Parkinson's," Jeff said. "This is one of the fastest-growing neurological diseases, which is horrible. We support the Parkinson's Foundation because it not only provides vital information to people, but also connects them to a community they can turn to for support."

With your support, we can help people live better with PD. To make a donation, visit [Parkinson.org/Donate](https://www.parkinson.org/Donate) or contact Kate Nelson, Senior Director of Major Giving, at knelson@parkinson.org.

LEAVE A MEANINGFUL LEGACY THROUGH YOUR ESTATE

Join the Parkinson's Foundation Legacy Society when you designate the Foundation 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](https://www.parkinson.org/PlannedGiving) or email us at legacy@parkinson.org.



Christian Spence, a University of Georgia senior and intern at a Parkinson's research lab, is a Parkinson's Champion for his dad, Mark. He is preparing to run the Longest Night 50K Ultramarathon on December 16. To inspire donations, he's getting creative — raffling a PlayStation 5. He's raised more than \$11,000 to help beat PD!



Steve Goode traveled more than 15,000 miles on motorcycle as a Parkinson's Champion, raising more than \$20,000 in honor of his mother, who lived with PD. "Although she most likely would not have approved of this motorcycle trip (she was still a mother) secretly she would be extremely proud of my commitment to this cause."

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

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PD GENEration: Mapping the Future of Parkinson's Disease

Help us change the
course of Parkinson's



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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.

P **Parkinson's Foundation**

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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