SUMMER 2025

A NEWSLETTER FOR FRIENDS OF PARKINSON'S FOUNDATION

Parkinson's Foundation Genetics Study Expands to Latin America

arkinson's disease (PD) affects people in different ways, which is a challenge when trying to develop new treatments and therapies. That's where the Parkinson's Foundation genetics research initiative, PD GENEration: Mapping the Future of Parkinson's Disease, comes in.

Because of you, this innovative global study provides genetic testing and counseling (in English and Spanish) at no cost for those who have been diagnosed. Through PD GENEration, we are also building a large and diverse global PD genetics registry, a critical need for scientists to discover new patterns behind the disease and ultimately pursue novel or more tailored treatments.

Diversity of data — having genetic information about PD from people around the world — creates a strong basis to propel research breakthroughs. However, Hispanic and Latino members of the PD community often face distinct barriers to living well with the disease. Plus, members of this community are underrepresented in research.

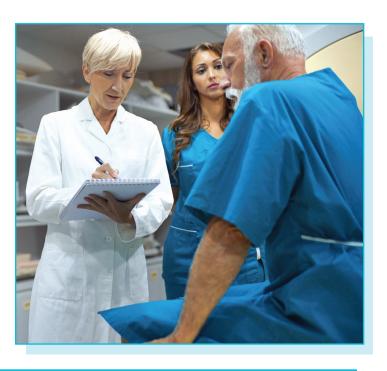
The Foundation has partnered with the Latin American Research Consortium on the Genetics of Parkinson's Disease. Together, we're expanding PD GENEration to new countries and more PD communities.

This effort strengthens the PD genetics database and advances our goal to provide anyone with Parkinson's — anywhere in the world — with genetic testing and counseling they can benefit from today.

Last year, we expanded PD GENEration testing and counseling to Colombia, Chile, Mexico, Peru and El Salvador. We worked with the Indiana University School of Medicine to design and implement specialized training programs at these sites. Overall, PD GENEration has enrolled more than 20,000 people globally and we have learned that around 13% of people have a Parkinson's related genetic variant, which is far greater than earlier scientific estimates of 5-10%.

PD GENEration will soon add new sites in Argentina, Brazil, Honduras and Uruguay to further our reach throughout Latin America.

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



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he Parkinson's Foundation recently announced the appointment of Sneha Mantri, MD, MS, as the first-ever Chief Medical Officer (CMO). In this role, Dr. Mantri will help set the strategic direction of the Foundation's care portfolio and ensure its initiatives remain impactful, scalable, sustainable and measurable.

"Early in my neurology residency, I found myself drawn to the stories of people with Parkinson's disease," said Dr. Mantri. "While the fundamental mechanism of the disease—loss of dopamine production—is the same for all people with Parkinson's, the impact of the illness itself is unique to each person."

With that in mind, Dr. Mantri wants to ensure that healthcare professionals are prepared to care for diverse populations with complex conditions like PD.

As a movement disorders specialist, she's interested in ways to improve the quality of care for those with chronic neurodegenerative conditions. A particular concern is how to translate clinically effective treatments

and lifestyle changes — like high-intensity exercise — into the real world.

A nationally recognized clinician-educator, Dr. Mantri is an associate professor of neurology at Duke University, a Parkinson's Foundation Center of Excellence, whose work focuses on interprofessional care, the patient/family perspective and health humanities initiatives. She will continue to see patients on a limited schedule at the Duke Movement Disorders Center.

"We are pleased to add the vital role of Chief Medical Officer to our executive leadership team and are excited to welcome Dr. Mantri," said Parkinson's Foundation President and Chief Executive Officer John Lehr. "Her proven dedication to improving the health and well-being of people with PD will be instrumental in advancing the Foundation's mission supporting the one million people living in the U.S. with this disease."

Read more about Dr. Mantri at Parkinson.org/CMO

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People Power: Exploring the Benefits of Exercise and Community

om Dobrinski had ongoing arthritis and spine issues, along with knee replacement surgery. He was having difficulty turning in bed and showing fewer facial expressions, but he and his wife Shari didn't think it was unusual.

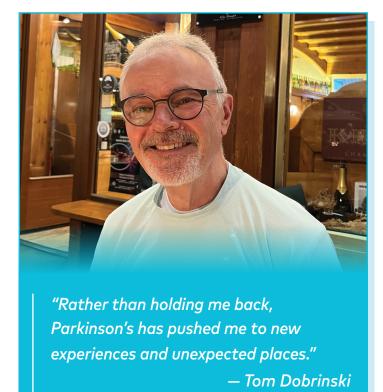
Tom brought up these changes at his annual physical in 2020. To his surprise, the doctor told him these were typical signs of Parkinson's. He was referred to the Northwestern Medicine Parkinson's Disease and Movement Disorders Center, a Parkinson's Foundation Center of Excellence. Six weeks later, his PD diagnosis was confirmed.

The couple knew little about PD, but they were willing to do anything to slow its progression. Tom started medication and committed to a routine to stay active. He also enrolled in the early intervention program at Shirley Ryan Ability Lab, a physical rehabilitation center in Chicago focused on specialized treatment for those with PD.

Tom found a wealth of resources, education and support on Parkinson.org. It also led him and his family to events like Moving Day, A Walk for Parkinson's. Through our Center of Excellence at Northwestern University, he learned about the benefits of staying active through Tai Chi, ping pong, improv, boxing and dance classes.



Tom likes to stay active alongside his friends and family.



He also joined conversation groups where people with PD share their experiences and enrolled in a program that counts steps and heart rate. He's even hiked in Patagonia, Mont Blanc and the Dolomites since his diagnosis.

For Tom, it's all about exercise and community. He's grateful to have met many inspiring people through the Parkinson's Foundation and stresses that the camaraderie is invaluable.

Tom's advice for anyone newly diagnosed with PD? Don't go through it alone. Engage with the community, exercise regularly and use the resources the Foundation provides. While his wife Shari has been his biggest supporter throughout his Parkinson's journey, the PD community has given him more than he could ever have imagined.

Find Parkinson's resources near you! Visit Parkinson.org/InYourArea or call our Helpline at 1-800-4PD-INFO (1-800-473-4636)

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Focus on Care: Meet Cindy, Parkinson's Care Partner and Advocate

indy George set out to learn as much as she could about Parkinson's disease after her husband, Dale, was diagnosed 13 years ago.

The Utah couple realized there were no support groups near their home. So, they established the Davis County Parkinson's Support Group, starting with just six people. Today, there are 40 members, virtual attendees and a 150-person email list.

Their support group led them to the Parkinson's Foundation and Moving Day Salt Lake City, which helped them grow their local PD community.

"I don't want anyone to feel alone," Cindy said.
"Moving Day brings awareness to Parkinson's
and helps connect people to this amazing
community. Dale was honored at Moving Day,
and it just melted my heart. People with PD
are superheroes who deserve to be recognized,
and that's what happens at Moving Day.
It highlights the importance of exercise for
people with Parkinson's and provides so much
education and information."

The devoted caregiver and PD advocate also became a coach at Rock Steady Boxing, a nonprofit gym with locations around the country that provides a unique exercise program specifically designed for PD, to support Dale — and helped bring a speech therapy class to their area. Cindy and Dale are determined to help other people with Parkinson's find the valuable resources they need to confront the disease head-on.

"Parkinson's is in our face every single day," Cindy said. "We have moments when we grieve it, but it led us to our Parkinson's family, and that's really positive."

Let's get moving. Register for a Moving Day event near you at Moving DayWalk.org



Cindy and Dale at Moving Day Salt Lake City.

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