



Your Voice. Your News.

FALL 2023

A NEWSLETTER FOR FRIENDS OF PARKINSON'S FOUNDATION

Expanding Our Global Care Network

Thanks to your loyal support, the Parkinson's Foundation continues to expand and enhance our Global Care Network.

This network — featuring more than 50 Centers of Excellence, along with our Comprehensive Care Centers and our Network of Excellence locations — advances the Foundation's mission to ensure that all people with Parkinson's disease (PD) have access to quality care where and when they need it.

Our latest trailblazing effort within the Global Care Network is the Community Partners in Parkinson's Care program, which educates and prepares staff at home care agencies and senior living communities around the country to provide the best possible care to those with PD.

The Foundation's Vice President and Chief Education and Training Officer Eli Pollard explains, "As the disease advances, many people with PD seek home care services or senior living communities. But many of these organizations and their staff have limited knowledge about PD and best care practices."

Training the Trainers

The program was formerly the Struthers Parkinson's Care Network, part of the Struthers Parkinson's Center in Minnesota (a Parkinson's Foundation Center of Excellence). Community Partners in Parkinson's Care includes more than 100 home care agencies and individual senior communities across North America.

At each of these locations, we offer a full curriculum of PD education through virtual and in-person training. We educate site champions



using the train-the-trainer model. They, in turn, educate at least 70% of the staff at their individual site.

According to Joan Gardner, RN, BSN, national program co-director alongside Rose Wichmann, PT, "We are proud to include members of individual organizations as well as full corporate networks who are trained to prepare, empower and motivate staff with ongoing support from PD experts."

As our nation's population ages — and the incidence of PD increases by 50% — the need to reach out to even more home care agencies and senior living communities will only continue to rise. With your generosity, the Community Partners in Parkinson's Care program will keep growing to make a life-changing difference to more people with PD and their families.

For more information about the Parkinson's Foundation Global Care Network, visit [Parkinson.org/Network](https://www.parkinson.org/Network)

People Power: Refusing to Sit on the Sidelines

Mark Kelm is living with young-onset Parkinson's disease while raising three children with his wife. "Like so many others' experience," Mark says, "my Parkinson's rigidity, tremors and balance issues make daily life tasks more taxing for me."

Yet, he's determined to lead the fullest life possible. "It can be easy to allow these symptoms to make me sit on the sidelines of life. I'm sure many others have felt the same way. I have come to understand, however, 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," Mark said.

Like you, Mark is making a significant impact to fight PD.

Mark's involvement began soon after his diagnosis, when his oldest daughter volunteered with the Parkinson's Foundation Minnesota and Dakotas Chapter. Mark recalls, "She inspired us to participate as a family in the Moving Day Twin Cities walk. That day, we became more aware of other opportunities to connect and volunteer."

Several years later, he watched his youngest daughter invite her school friends to cheer on the participants at Moving Day. This motivated Mark to "keep going and serve in my own way. Moving Day, a walk for Parkinson's, was only the beginning of my volunteering journey and becoming more active in the PD community."



For instance, Mark has helped organize a Parkinson's Casino Night, Trivia Night, and most recently, started a Parkinson's Awareness Day at Target Field with the Minnesota Twins. The U.S. Army veteran has also volunteered on the Congressionally Directed Medical Research Programs' Parkinson's Research Program.

"As I look back on my journey with PD so far," Mark said, "I'm so glad that I didn't sit on the sidelines and instead jumped right into an amazing journey that has helped me make new friendships across the nation."

Our heartfelt thanks to this inspiring and devoted advocate for helping lead the way on our urgent journey to end PD forever!

To learn more about how you can volunteer with the Parkinson's Foundation, visit [Parkinson.org/Volunteer](https://www.parkinson.org/Volunteer)



ABOUT MOVING DAY *We care. We fight. We move.*

Moving Day is an empowering annual fundraising walk event that unites people around the country living with Parkinson's disease, their care partners and loved ones to help beat PD.

Moving Day is more than just a walk. It's a celebration of movement — proven to help manage Parkinson's symptoms. For more information on how to get involved with Moving Day in your community, please visit [MovingDayWalk.org](https://www.MovingDayWalk.org)

Focus on Care: From the Perspective of a Movement Disorders Specialist

Movement disorders specialists (MDS) are neurologists who specialize in conditions such as Parkinson's. With their extensive training, they have experience diagnosing the disease and treating it at every stage.

According to Janis Miyasaki, MD, a movement disorders specialist and Professor of Neurology and Medicine at the University of Alberta, "It's important for people with PD to see an MDS."

"The average family doctor will see less than five people with Parkinson's disease in their entire career," Dr. Miyasaki said. "That doesn't allow them the comfort level of seeing a patient, diagnosing them and guiding them through PD stages to help them maximize their quality of life."

"After watching patients deteriorate after decades of living with PD, it breaks my heart when other physicians say, 'There's nothing more we can do for you.' I feel there is always something we can do for our patients."

*— Dr. Janis Miyasaki
Movement Disorders Specialist*

An MDS is more knowledgeable about leading-edge therapies that have been developed in recent years to improve life for people with PD.


In addition, they work alongside physical and occupational therapists. Dr. Miyasaki explains, "I communicate with these specialists because they might see a symptom or challenge that we may not have seen in the clinic visit."



These symptoms could include anxiety and depression because PD can result in changes in the brain. Pain from changes in the spine, hands and feet can also develop as Parkinson's advances. An MDS who's trained in palliative care can assist with pain control.

Dr. Miyasaki herself is a pioneer in applying palliative care principles to PD, which she stresses can help better manage the disease's progression. Her movement disorders clinic is renowned for being the world's first program to incorporate specialized care in treating PD.

"I started as one lonely voice in 2007," she said. "But now there are dedicated clinics that provide palliative care to people with Parkinson's. I'm currently involved in a research project to initiate palliative care at all the Parkinson's Foundation Centers of Excellence in the U.S. I hope that everyone who participated now understands the benefits of palliative care."

To find a movement disorders specialist near you, contact our Helpline at 1-800-4PD-INFO (1-800-473-4636) 

Community Grant Supports Local Wellness Program

With your dedication, you're helping the Foundation improve the lives of people around the country through our ambitious community grants program.

One recent grant was awarded to *The Tampa Bay Parkinson's Disease Newly Diagnosed Wellness Initiative*. This is a collaboration between the Tampa Jewish Community Centers and the University of South Florida, a Parkinson's Foundation Center of Excellence.

The life-enriching initiative has more than 250 participants. It helps those just diagnosed with PD benefit from a comprehensive approach focusing on the physical and emotional challenges that the disease brings.

The program's multifaceted offerings include weekly exercise classes and support groups for the newly diagnosed and their caregivers. Plus, there are educational activities where Foundation resources are shared and distributed.

In addition, participants themselves plan an array of social programs. These programs encourage individuals, family and friends to feel active, connected and empowered in a strong, welcoming PD community.

Wayne MacLaughlin, for example, attends up to four classes a week. He describes how, "during my last appointment, my doctor was so impressed



with my breathing that he said it was the best breath I had ever taken with him. I have seen a big improvement in my ability to manage my disease and function better since starting the program."

Another participant, Richard Montalbano, said, "After four months of active participation, I get many positive comments from family and friends about the significant improvements in my physical appearance, movements and speech."

Find a Parkinson's wellness class in your area. To see the full list of community grant recipients, visit [Parkinson.org/CommunityGrants](https://www.parkinson.org/CommunityGrants)

SAVE THE DATE A Day to Reach Further

Join us September 19 as we come together to Reach Further toward a cure for Parkinson's disease. Rally your friends and family to take part in *A Day to Reach Further* to learn about our innovative research programs and push us closer to our goal of raising an additional \$30 million. Visit [Parkinson.org/ReachFurther](https://www.parkinson.org/ReachFurther) to learn more.

CONTRIBUTION FORM

YES! I want to support the innovative work of the Parkinson's Foundation so people with Parkinson's can live the best lives possible. Enclosed is my tax-deductible gift of:

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