Volunteers Bring Passion to Our Cause

Volunteers are the core of any nonprofit organization ... and the Parkinson’s Foundation is no different.

Our volunteers donate countless hours to improving the lives of people with Parkinson’s in their communities — often helping to shed light on unmet needs, which have prompted new Parkinson's Foundation programs.

To educate and celebrate our incredibly dedicated volunteers, we are launching our inaugural Parkinson’s Foundation Volunteer Leadership Summit this month.

The Summit’s objective is to inspire and energize volunteer leaders so that they can play an even larger role in moving our mission forward. As local community volunteers, they are the face of the Parkinson’s Foundation and are uniquely positioned to raise awareness of Parkinson’s disease.

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Approximately 125 volunteers from across the country will attend, including members from our Moving Day and local communities, Parkinson’s Champions and members of the People with Parkinson’s Advisory Council. They will participate in informational training on topics such as: community messaging, fundraising best practices, engaging and motivating people with Parkinson’s and other volunteer engagement opportunities.

One volunteer playing a key role in the Volunteer Leadership Summit is Steering Committee member, John Kolaya. John and his son, Tim, have gone above and beyond as active volunteers — they’ve truly given their hearts and souls to our community.

As a person who has lived with Parkinson’s for 10 years, John credits his well-being today to the abundance of resources and information he’s gained from the Parkinson's Foundation. Through our research, which proved exercise can slow the progression of Parkinson’s disease, John (continued on page 2)
Anna Grill’s life turned upside down at the age of 38 when a hardly discernable tremor in her left hand led to a diagnosis of early-onset Parkinson’s disease.

At first, like so many people with Parkinson’s, Anna kept the diagnosis to herself. Her symptoms weren’t that noticeable, and she did not want to worry her husband and two daughters. After 10 years of living with the disease, she opened up to her family and friends, left her corporate career, started actively managing her symptoms and learned about the work and programs of the Parkinson’s Foundation.

Anna recognized right away how critical exercise is for her well-being. She stays active by regularly attending boxing classes and fondly calls the other boxers her “family.” This program has helped Anna improve her flexibility and dexterity, and most importantly, to enjoy a high quality of life.

Anna’s outlook on life is a true inspiration. Please continue to support the Parkinson’s Foundation at Parkinson.org/ Voice and help us touch the lives of people like Anna!
In the Research Lab: Identifying Parkinson's Genetic Risk Factors in Latino Populations

Parkinson's research is evolving rapidly, and the hottest area of focus is genetics. The hope is that by studying people with certain genetic mutations, research discoveries will accelerate.

Ignacio Fernandez Mata, PhD, a Parkinson's Foundation-funded scientist at the VA Puget Sound and the University of Washington, is seeking to understand the genetic component of Parkinson's disease, with a great focus on those with a minority ethnic background, such as Latinos.

A number of genetic mutations have been identified that can modify a person's susceptibility to developing the disease — but these genes have been discovered in populations of European or Asian ancestry. As a result, little is known about their role in Latino or non-European ancestry.

Dr. Mata has been studying Parkinson's disease genetics for nearly 15 years. He is the coordinator of the Latin American Research Consortium on the Genetics of Parkinson's Disease, a Parkinson's Foundation-funded collaboration among 11 institutions in seven countries across South America. He and his team are currently working on the first Genome-Wide Association Study in Latino patients with Parkinson's that will show for the first time which susceptibility genes are important in these populations. In addition, in families with many affected members, they are also sequencing all known genes that cause the disease, with the goal of identifying new genetic variants that cause Parkinson's.

Genetic studies are crucial to understanding those molecules that are involved in biological processes affected in Parkinson's disease. Understanding the disease mechanisms better will help scientists design novel treatments. There are already several ongoing genetic-based clinical trials, which are the basis of personalized or precision medicine.

Dr. Mata said, “This study will be crucial to understanding the role of genetics in Latinos with PD ... help reduce existing health disparities, allowing Latinos with Parkinson's disease to be active participants in precision medicine.”

The Parkinson’s Foundation is proud to support early-career investigators like Dr. Mata. Investment in young scientists doing outstanding research will speed up advances to better treat and cure Parkinson's disease.

Read more about ongoing research funded by the Parkinson's Foundation at Parkinson.org/ResearchWeFund.

THERE ARE SO MANY WAYS TO GIVE BACK!

1. Renew your support using the enclosed reply form! Your financial contributions are crucial — they help fund more cutting-edge research and increase quality care.

2. Start a fundraiser! Our Parkinson's Champions start community fundraisers or participate in athletic events to raise money for the cause. Learn more at Parkinson.org/Champions.

3. Become a volunteer! There are many opportunities to get involved — check them out at Parkinson.org/GetInvolved.

4. Start giving monthly! Feel good knowing that you’re helping people with Parkinson's every month of the year. Just check the box on the enclosed reply form or visit Parkinson.org/Voice.
Benjamin Corbett, a college senior, is wise beyond his years.

Maybe that can be attributed to one great teacher he had – Mr. Porter. Mr. Porter was a 7th grade teacher that everyone loved. He made learning interesting … and he had a lasting impact on Ben.

So, when Ben learned that Mr. Porter had early-onset Parkinson’s disease, he took it personally.

Ben was already intimately familiar with the effects of Parkinson’s disease, because his grandfather has it. When he was little, Ben thought it was normal for older people’s hands to shake. Once he was older, he realized the toll this disease can have — it caused his grandfather to give up some things he loved, like working as an architect.

This heightened awareness, combined with Ben’s innate compassion, compelled Ben to take action — for both his grandfather and his beloved teacher. Through a quick Google search, Ben found the Parkinson’s Foundation. We swung into action, helping him start Kickin’ for Parkinson’s, a soccer fundraiser between two rival schools in Rochester, NY. The event, now in its third year, brings the community together (particularly Mr. Porter’s former students) and has raised awareness and over $4,000 for Parkinson’s research.

Ben’s efforts haven’t stopped with Kickin’ for Parkinson’s. He has also participated in Moving Day events, and on a more personal level has given back in countless ways to his grandfather, Mr. Porter — and his teacher’s two young sons — by helping them to see the bright spots, especially on difficult days.

Ben is glad that he’s been able to make a difference for people with Parkinson’s in his hometown and pay tribute to his teacher, Mr. Porter.

As he told us, he believes, “The best thing anyone can do for people with Parkinson’s is to not give up on them. Always be supportive and optimistic — and don’t be afraid to reach out and ask for help.” Ben added, “The Parkinson’s Foundation is ready to help, and I want their reach to grow. And I hope those who love people with Parkinson’s continue to take action on behalf of their loved ones!”

To read more about Ben and other volunteers, please log onto Parkinson.org/MyPDStory.

CONTRIBUTION FORM

☐ YES! I want to help improve care for people like John, Anna and Mr. Porter, who are living with Parkinson’s, and advance research toward a cure. Enclosed is my tax-deductible gift to the Parkinson’s Foundation in the amount of:

☐ $35  ☐ $75  ☐ $150  ☐ $500  ☐ Other $_____

Name

Address

Address

City     State  Zip

Please make your check payable to the Parkinson’s Foundation. You may also give online at Parkinson.org/Voice. All gifts are tax deductible as allowed by law.