

VOLUNTEER NEWSLETTER

Volume 1, Issue 2



In this Issue: Meet Adam Mizock, a Parkinson's Revolution virtual rider, and read Tiffany Birge's tips on how you can make a difference while following social distancing guidelines

Upcoming Events: Weekly PD Health @ Home program, Moving Day - Virtual Walk, monthly volunteer orientation and Summer Volunteer Leadership Call



National Volunteer Week

Dear Volunteer,

In honor of National Volunteer Week, we would like to thank you for your hard work and support of the Parkinson's Foundation. We rely on the energy, skill and passion of people like you to make life better for people with Parkinson's year-round, particularly during Parkinson's Awareness Month and especially now.

In this newsletter you'll learn about some of the amazing work your peers are doing across the country and information on how you can make a difference while following social distancing guidelines during the COVID-19 pandemic.

We hope you stay safe and healthy. Thank you for your steadfast support in the fight against Parkinson's.

Sincerely,

Volunteer Newsletter Committee



Volunteer Spotlight: Rhadika Iyer



Rhadika Iyer is a member of the People with Parkinson's Advisory Council and is living with Parkinson's. Rhadika participates in Moving Day NC Triangle with her family and she is involved with work at the Foundation related to Parkinson's and mental health.

Recently, Rhadika formed a Women and PD support group in her community, partnering with her local Foundation field staff member and the University of North Carolina, a Center of Excellence. As group leader, she actively keeps in touch with her group members during the COVID-19 pandemic to ensure they feel supported and connected during this difficult time.



Parkinson's Revolution Unites Riders

The Parkinson's Foundation held its first Parkinson's Revolution event on February 8, 2020 bringing participants together to meet one goal: to make lives better for people with Parkinson's. The indoor cycling fundraiser went above and beyond to include participants from three countries and five time zones. We had 450 riders taking part simultaneously helping us fundraise for a world without Parkinson's.

One virtual rider went full force and raised more than \$12,457, becoming our top fundraiser. Adam Mizock was interested in the event from the moment he heard about it. He was diagnosed with Parkinson's in 2018 and wanted to raise funds to help with local and national efforts — including the research the Foundation is doing to improve everyday life for people with PD.

"My favorite part of the event was the way so many people came together online and in gyms around the U.S. and other countries to energize community, increase awareness and raise needed funds," said Mike. "It was inspiring to see others on social networks who were involved in the event." We thank Mike for his efforts to help us find a cure for Parkinson's!

The ride combined passion and determination to generate PD awareness and help us make life better for people with Parkinson's. We are proud to say the event raised \$130,000. Thank you to our participants, volunteers and supporters for all their efforts to make this a success!

Learn more about Parkinson's Revolution at [Parkinson.org/Revolution](https://www.parkinson.org/Revolution).

About the Author: Sarah Freyman volunteers in honor of her dad who has Parkinson's. She supports the Parkinson's Foundation Heartland Chapter's Parkinson's Prohibition Gala in Kansas City, MO.



Adam participating as a virtual rider in Parkinson's Revolution on February 8, 2020.



Why I Volunteer

For as long as I can remember I have always found joy in helping others. As a child I would volunteer at the local animal shelters walking dogs, reading to children in preschools or reading and singing to residents in senior centers. It wasn't until I grew older that I realized that volunteering made me feel fulfilled and gave me purpose. If I wasn't spending my extra time doing something helpful, I would often slip into bouts of depression and anxiety.

When Dad began experiencing some of the [early symptoms of Parkinson's](#), like many [newly diagnosed](#) people, he struggled with acceptance. We blamed other external factors, tried homeopathic remedies and did just about everything, except seeing a doctor. The only thing we knew about PD was that a certain celebrity had it and it was really bad.

When we finally received a diagnosis, we had no idea what to expect or where to start. There were so many questions, doubts and fears in our heads and my dad living in a rural community with very little support. The one thing I did know is I wanted to find a way to help and educate not just ourselves, but people who were in a similar situation.

I started learning everything I could about PD, medications, diet, exercise and research. This journey eventually brought me to the Parkinson's

Foundation. I instantly fell in love with the mission and the people associated with the Parkinson's Foundation and dove headfirst into the Aware in Care Ambassador program by joining the first training in Miami, FL.

Why do I continue to volunteer? I volunteer for myself and my dad, but most of all I volunteer for all those people with Parkinson's living with the symptoms and fear that comes with PD and not knowing where to turn. If we as volunteers can prevent one person from feeling alone and afraid, then that is the biggest success of all.

Article written by Tiffany Birge, Parkinson's Foundation volunteer.



New Ways to Volunteer

All in-person Parkinson's Foundation events have been postponed through June 30, but you can still support our work from the safety of your home. Make a difference as a Parkinson's Champion or Moving Day - A Virtual Walk participant. If you can't join a virtual event, consider donating at [Parkinson.org/Donate](https://parkinson.org/Donate).

If you are interested in learning more about virtual volunteer opportunities, contact volunteer@parkinson.org.

Volunteer Tip

The number one reason people volunteer is because they were asked! Embrace technology and use social media to ask your network of family and friends to get involved. Include a photo to catch attention and ask others to join you in the fight against Parkinson's by volunteering or donating.

Raise awareness and use the Parkinson's Foundation hashtag [#Together4PD](https://twitter.com/Together4PD).



Aware in Care Ambassadors Make a Difference

My wife Leslie and I volunteer for the Parkinson's Foundation as Aware in Care Ambassadors, and our journey to become Ambassadors was very personal. My mom lived with Parkinson's disease (PD) in Pennsylvania. After my father passed in 2003, we moved my mom to Colorado to stay with our family. At the time we knew nothing about Parkinson's.

In 2007, my mom was hospitalized for a severe bladder infection and prescribed a drug that we later learned was contraindicated for people with PD. She became extremely combative and had to be restrained. After doctors determined which medication caused the reaction and changed her treatment, she was my sweet mom again within 48 hours. However, this episode really weighed on us. We searched for answers over the next two years, until my mom passed in 2009.

Following my own Parkinson's diagnosis in 2013, we became more involved and learned about the solution to our previous hospitalization problem. The Parkinson's Foundation created the Aware in Care kit to help people with Parkinson's get the best care possible during a hospital stay. The Foundation provides free Aware in Care kits to people living with PD and their families. Each Aware in Care kit is filled with useful tools and information to help a person with Parkinson's during any hospital visit.

To further spread awareness, in 2018 the Foundation began to recruit volunteer ambassadors. Leslie and I were fortunate enough to be selected. We attended an ambassador training in San Diego, CA, and we were impressed by how thorough the kits were and how much the Aware in Care program leadership cared about what was going on in hospitals around the globe and how much they believed in this program.

Our good friend Lisa Cone is also a person with Parkinson's and an Aware in Care Ambassador. Lisa is a tremendous advocate for the Parkinson's Foundation and the kit. She became



Lisa Cone

an ambassador because she believes that going to the hospital is scary enough for the average person, having Parkinson's makes it twice as scary. She believes that the Aware in Care kit levels the playing field, so that any person entering the hospital for an emergency or for a planned procedure does not have to be concerned about PD medication timing or being given a contraindicated drug.

Lisa works closely with Dr. Lauren Seeberger at the University of Colorado, a Parkinson's Foundation Center of Excellence, on the Aware in Care program. By partnering with healthcare professionals, ambassadors are continually improving and expanding the Aware in Care initiative and making hospitals a safer place for people with Parkinson's. Leslie and I are very proud to call Lisa a friend, and we are very proud to volunteer with the Parkinson's Foundation. We firmly believe we are all making a difference.

**Order an Aware in Care kit or learn more
Aware in Care Ambassadors at
[Parkinson.org/AwareInCare](https://www.parkinson.org/AwareInCare).**

About the Author: Steve Peters is living with Parkinson's and volunteers with his wife, Leslie. Together they serve as Aware in Care Ambassadors and support the Parkinson's Foundation Rocky Mountain Chapter in Colorado.



Parkinson's Foundation and AARP New Webinar Series



Save the Date!

Webinar: Answering Your PD Questions with AARP: From Newly Diagnosed to Caregiver Resources

This educational program is intended for patients, families, caregivers and all those affected by Parkinson's disease.

Thursday, April 30

3 – 4 p.m. EST

[Register Here](#)

For additional information, please visit [Parkinson.org/AARPwebinar](https://www.parkinson.org/AARPwebinar) or contact the Parkinson's Foundation helpline at 1-800-4PD-INFO (473-4636).



Join us as we kick off this new partnership webinar series from the Parkinson's Foundation and AARP. Learn about Parkinson's symptoms, disease progression and the importance of working with an interdisciplinary care team.

Understand what you need to know about employment rights, benefits and resources for both people newly diagnosed and their care partners, as well as care partner tips and community forums you can join today!

Led by Nina Browner, MD, associate professor of neurology at the University of North Carolina and Amy Goyer, AARP's national family and caregiving expert and author, this webinar offers educational resources and advice to support you and your care partner in building a better life with Parkinson's disease today.

Visit [Parkinson.org/AARPwebinar](https://www.parkinson.org/AARPwebinar) to register today.



Ask A Volunteer

Welcome to our new column “Ask A Volunteer,” where you can submit your questions to volunteer@parkinson.org and volunteers will answer them.

For the first issue, I want to answer a question that is on all of our minds in recent days, “**How can we make a difference while following social distancing guidelines during the COVID-19 pandemic?**” After speaking with other volunteers, work-at-home employees and medical professionals, I have compiled a list of important steps you can take to stay active in your volunteer community while quarantined or when practicing social distancing.

- 1. Take care of yourself and your family:** We need you in the fight against Parkinson’s, so taking care of yourself is the most important thing you can do. Listen to your state officials and medical professionals, practice good hygiene, eat a well-balanced diet, exercise and most of all if you do become ill, stay home and check in with your doctor.
- 2. Stay connected:** For many people social distancing can take a toll on our overall happiness, especially when you feel emotionally connected to your volunteer work. Stay connected by joining virtual volunteer meetings, emailing, calling or chatting with other volunteers, reaching out to regional leaders and by reading this newsletter.
- 3. Stay informed:** Now more than ever it is critical that we continually educate ourselves on PD, COVID-19 and ways to stay healthy. Visit the [Parkinson.org/Coronavirus](https://www.parkinson.org/Coronavirus) for tips on coping with Coronavirus, the [CDC website](https://www.cdc.gov) and your local health department website for the most up to date and accurate information regarding COVID-19, precautions against it and caring for others who may have been exposed.
- 4. Embrace technology:** Many volunteers are using alternative methods to meet with patients, other volunteers and healthcare professionals. Digital meeting software, social media and recorded videos have become the new normal

for many of us, allowing us to communicate without the risk of spreading illness. If you are not great with technology, reach out to another volunteer, support staff or even family members that may be able to help. Consider starting a digital event, such as a fundraiser, support group, movement class or social gathering to help raise awareness.

- 5. Make the most of it:** The morning of March 18 my family and I were awoken to the violent shaking of a 5.7 magnitude earthquake, we were only two miles away from the epicenter. Thankfully no one was injured, and we suffered only minimal damage, but it was enough to shake us to the core.

With COVID-19, schools closing and our community practically on lock down, we decided to take a week off and focus on what is most important to us, our family. We woke up every morning and had breakfast together on the porch, we started a garden, played soccer, basketball and even had our 10-year-old son teach us how to skateboard (a hilarious ordeal). We played video games, board games, cuddled on the couch and just enjoyed being with each other.

My point is, even in times of trial and stress we need to remember to take the time to do the things we love, connect with the people we love, feel the sun on your face and revel in all those amazing little things that make life so beautiful.

As always, thank you for everything you do. Stay safe and know that we are all in this together.

Submit your volunteer questions to volunteer@parkinson.org.

About the author: Tiffany Birge began volunteering with the Parkinson’s Foundation when her dad was diagnosed with PD. She is an Aware in Care Ambassador from the Parkinson’s Foundation Rocky Mountain Chapter in Salt Lake City, UT.