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6 Ways to Engage with the Parkinson’s Community

FEATURE

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Parkinson’s Foundation Community Grant Spotlight

Why Adam Rides for the Parkinson’s Revolution

PD Health @ Home: Effective Ways to Reduce Fall Risks with Parkinson’s
Event Calendar

**APRIL**

11 Champions @ Home 5k  
Register: ChampionsatHome.org

17 Moving Day Ventura County  
Register: MovingDayVenturaCounty.org

20 Expert Briefings Webinar: Mental Well-being and Memory  
Register: Parkinson.org/ExpertBriefings

24 Parkinson’s Unity Walk  
Learn More: Unitywalk.org

25 Moving Day Central NY  
Register: MovingDayCentralNY.org

**MAY**

1 Moving Day Kansas City  
Register: MovingDayKansasCity.org

Moving Day Twin Cities  
Register: MovingDayTwinCities.org

5 Power Over Parkinson’s Virtual Gala  
Register: Parkinson.org/POPgala

15 Moving Day Tampa Bay  
Register: MovingDayTampaBay.org

Moving Day Sacramento  
Register: MovingDaySacramento.org

19 Care Partner Town Hall: Preparing for the Journey  
Register: Parkinson.org/Summit

22 Moving Day USA  
Register: MovingDayUSA.org

**JUNE**

12 Moving Day Omaha  
Register: MovingDayOmaha.org

Parkinson’s Revolution  
Register: Parkinson.org/Revolution

Virtual events are open to all and available online. For a full list of events visit Parkinson.org/Events.

Stay up to date on COVID-19 and Parkinson’s at Parkinson.org/COVID.

**2021 Care Partner Summit | Cumbre Para Cuidadores**

Events throughout May  
Throughout May, engage with expert panels and meet other care partners! Join us for a series of online events created just for care partners.  
Register at Parkinson.org/Summit.

**Moving Day, A Walk for Parkinson’s**

Help us spread Parkinson’s awareness and raise critical funds at contactless or virtual events taking place across the country. Let’s celebrate movement, together!

View all events at MovingDayWalk.org.
Update from Our People with Parkinson's Council Chair

Accepting my Parkinson’s disease (PD) diagnosis was difficult, but when I did, I was motivated to find ways to make a difference in our community. After taking on engaging and meaningful volunteer efforts in my hometown, I knew I wanted to serve on the Parkinson’s Foundation People with Parkinson’s Council.

As council members, we provide the Foundation with the perspective of people living with Parkinson’s. My involvement opened my eyes to the needs of people with PD, care partners and families. I have seen many people live well with this disease. Regular exercise, a healthy diet, seeing a movement disorder specialist, seeking social outlets and being open to mental health support are vital to our wellbeing.

Every council member is exceedingly passionate about a different aspect of Parkinson’s awareness. For me, it is my interest in PD GENERation, the Foundation’s genetics study. The goal is to use genetics as a tool to help us uncover what could help slow or stop the progression of Parkinson’s.

This year especially, I look forward to April, when we celebrate Parkinson’s Awareness Month — working to reach the 60,000 people who will be newly diagnosed in 2021. Thanks for helping us raise awareness this year, together.

- Gretchen

6 Ways to Engage with the Parkinson’s Community

This spring, commit to trying a new way to engage and stay involved with your local or national Parkinson’s community:

1. **Try something new.** Join us for new weekly PD Health @ Home events designed for people with Parkinson’s and their loved ones. Visit [Parkinson.org/PDHealth](http://Parkinson.org/PDHealth).

2. **Become a Parkinson’s Champion.** Host your own event to raise critical funds and awareness to help advance Parkinson’s care and research. Visit [Parkinson.org/Champions](http://Parkinson.org/Champions).

3. **Follow us.** Never miss PD-related news or stories when you like us on Facebook, Twitter and Instagram. Visit [Parkinson.org/Social](http://Parkinson.org/Social).

4. **Help your local Parkinson’s Foundation chapter.** Volunteer, attend a local virtual event and meet new people. Visit [Parkinson.org/Chapters](http://Parkinson.org/Chapters).


6. **Stay Connected.** Find an online community where you can ask your questions and explore trending Parkinson’s topics. Visit [PDconversations.org](http://PDconversations.org).

Learn more at [Parkinson.org/GetInvolved](http://Parkinson.org/GetInvolved).
As we age, falls become a concern for everyone. People living with Parkinson’s disease (PD) face increased fall risks due to disease-related motor and non-motor symptoms, and sometimes from medication combinations. Learning strategies to minimize falls can help you move with confidence.

As part of the Parkinson’s Foundation newest program, PD Health @ Home, a series of weekly virtual wellness online events, we explored “Falls: Risk, Prevention and Recovery.” Physical therapist Stephanie Evans, PT, DPT, of University of Iowa Health Care, a Parkinson’s Foundation Center of Excellence, hosted the Wellness Wednesday event, highlighting strategies to reduce falls.

Parkinson’s and Falls

PD-associated movement, or motor, changes — including stooped stance, shuffling, short or rapid steps and freezing — create higher fall risks. Falls or near falls can lead to injuries and hospitalization. Addressing movement challenges boosts independence for people with Parkinson’s and can lessen care partner burden. “If you are falling there are things you can do about it — there’s hope,” Stephanie said.

Share any movement challenges with your neurologist, who can often adjust medications or offer treatment options, including physical and occupational therapy. Physical therapy can help improve and maintain movement. Occupational therapy can help you more easily navigate your daily environment.

Find Your Starting Point

Complete a baseline risk assessment with your healthcare team. This can help people with movement challenges pinpoint physical, environmental, cognitive or medical risk factors. Your Parkinson’s doctor or the Parkinson’s Foundation Helpline at 1-800-4PD-INFO (473-4636) can provide referrals to a physical therapist.

Through questions and observation, a physical therapist with specialty Parkinson’s training can determine what is causing mobility issues and tailor therapy to help. A physical therapist can also recommend appropriate assistive devices if needed, including the right cane or walker.

Taking Action at Home

Short, easy exercises modified to a person’s needs, done consistently, are key to success, so is a safe exercise environment. Ask your physical therapist to explore these exercises or safely practice them with your care partner at home:

- Smaller steps and shuffling gait can increase trips and falls. Try stepping over a line for practice and lengthen your stride each trip. This widens your base of support, improving posture and balance.
• People with Parkinson’s can sometimes find it difficult to rise from a chair. Try leaning your head forward first, focus your eyes on your toes and then stand up.
• If you experience a loss of balance when taking your first step after rising from a seated position, first stand tall, pause, then move forward with a big first step, maintaining a wide base of support.
• When your steps suddenly begin to shorten while walking, you may be headed for a “runaway train-type” movement. As you notice this, try to stop, stand upright, then start again — taking slow, wide steps.
• To get over a freezing episode (the temporary, involuntary inability to move), try shifting your body weight from one leg to another. Alternatively, try stepping over an imaginary line ahead of you.

It is also helpful to look at the times, situations and places that cause movement difficulty and address them. For example, remove or rearrange any obstacles, such as rugs or furniture, that might increase challenges.

PD Health @ Home
Weekly PD Health @ Home events are created to help the PD community while at home, addressing mental health, symptoms management and PD-tailored exercise videos.

“I think that PD Health @ Home Wellness Wednesdays and all the extra events the Parkinson’s Foundation has been hosting — so much on exercise, too — has just been an excellent resource or alternative for people who are not getting their regular in-person care right now,” Stephanie said.

Register for upcoming PD Health @ Home expert-guided Mindfulness Mondays, Wellness Wednesdays and Fitness Fridays — all designed to empower the Parkinson’s community — at Parkinson.org/PDHealth.

Tips for Daily Living: How to Maintain Your Physical Strength While Social Distancing

Physical therapist Stephanie Evans, DPT, of University of Iowa Health Care, a Parkinson’s Foundation Center of Excellence, shares tips to help you stay strong during social distancing:

Keep your medical appointments.
When possible, attend your physical, occupational and speech therapy appointments — telehealth appointments are great! With Parkinson’s, maintaining movement and voice is important.

Set manageable exercise goals.
“If people set their goals too high, they end up becoming frustrated or overwhelmed and then don’t follow through,” Stephanie said.

Find an exercise activity you like!
People tend to stick with movement they enjoy, whether it’s dance, yoga or boxing.

Continue balance exercises.
“They’re short and sweet — so people can easily manage getting them into their day,” Stephanie said. A physical therapist can personalize exercises for you.

Multitask. Exercises that increase strength and postural stability or allow stretching and strengthening at the same time are ideal.

Adapt your home. Create a safe environment for movement. Eliminate trip hazards by removing rugs or rearranging furniture. An occupational therapist can help.

Try new Parkinson’s-tailored exercise classes at Parkinson.org/FitnessFridays.
Prominent Parkinson’s Geneticist to Lead Hispanic Parkinson’s Advisory Council

“There are literally millions of people hoping that what we’re doing is going to make a difference,” said Ignacio Mata, PhD, from the Cleveland Clinic Lerner College of Medicine, a Parkinson’s Foundation Center of Excellence, about the Parkinson’s Foundation flagship genetics study in relation to Hispanic and Latino populations.

PD GENEration: Mapping the Future of Parkinson’s Disease has the goal to improve care and advance our understanding of Parkinson’s disease (PD). It is the first study to offer genetic testing and counseling at no cost to participants, in both English and Spanish.

Much existing genetic information centers on mostly men of European origins. In addition, most studies are conducted only in English. “There is a huge gap in what we know about genetics and diseases in other populations,” Dr. Mata said. “Parkinson’s is one of these diseases. If we have several million Hispanics in this country, they should be represented in genetic studies.”

Dr. Mata leads the newly-established Parkinson’s Foundation Hispanic Parkinson’s Advisory Council working to address the needs of Hispanic people with Parkinson’s and their care partners in Parkinson’s Foundation programs, including PD GENEration. The council consists of researchers, doctors and social workers — all who work with Hispanic communities.

“We have PD GENEration protocols in place so that from day one everything can happen in Spanish — your appointment, study consent, meeting with a genetic counselor who reviews your results,” said Dr. Mata.

Understanding genetic differences in Parkinson’s is central to ending this disease, Dr. Mata said.

The PD geneticist has worked to diversify genetics research since 2005, when he launched the groundbreaking Latin American Research consortium on the Genetics of Parkinson’s Disease (LARGE-PD), the first large-scale gene study of Latino populations.

The Parkinson’s Foundation believes in Dr. Mata’s research and was there at the start: awarding him a $150,000 grant in 2009 to jump start LARGE-PD and a $300,000 Stanley Fahn Junior Faculty Award in 2016 to continue his success in genetics. “Those two grants really started it all,” Dr. Mata said. Now spanning 12 countries and 4,000 participants (2,000 people with PD) the LARGE-PD study, like PD GENEration, is designed to better understand genetic and environmental causes of Parkinson’s across different groups.

“If you know that you’re a carrier for a Parkinson’s genetic mutation, you and your family can participate in clinical trials and help advance the treatment of Parkinson’s,” Dr. Mata said. “That is a powerful thing to do.”

The Parkinson’s Foundation continuously publishes new Spanish PD resources, including its blog, podcast, books and articles. “In the long term we want to make research and clinical trials more accessible to Hispanics, but also help ensure they can access therapies, support groups and team care in their native language.”

Learn more about PD GENEration for Spanish speakers at Parkinson.org/PDGENE and access all our Parkinson’s resources in Spanish at Parkinson.org/Español.
1. The first symptom of Parkinson’s is a tremor.  
   - True  - False

2. Which specialists should a person with Parkinson’s regularly visit?  
   - Physical Therapist  
   - Movement Disorder Specialist  
   - Occupational Therapist  
   - All of the above

3. Parkinson’s disease only affects senior citizens.  
   - True  - False

4. How many people are diagnosed with Parkinson’s every year in the United States?  
   - 4,500  
   - 20,000  
   - 60,000  
   - 1 million

5. Knowing if you have a genetic link to Parkinson’s can help tell if your children might develop the disease.  
   - True  - False

6. How many veterans are living with Parkinson’s in the United States?  
   - 13,000  
   - 57,000  
   - 110,000  
   - 164,000

7. Parkinson’s only involves physical symptoms.  
   - True  - False

8. Which type of exercise helps slow Parkinson’s progression?  
   - Tai Chi  
   - Boxing  
   - Walking  
   - All of the above

9. What percent of Parkinson’s cases are caused by genetics?  
   - 0%  
   - 10-15%  
   - 20-25%  
   - 45%

10. How many people with Parkinson’s disease receive hospital care each year?  
    - 10,000  
    - 80,000  
    - 240,000  
    - 300,000

Check your quiz answers at Parkinson.org/AwarenessQuiz.
Co-Managing PD Symptoms Can Boost Movement Skills

Shakiness, slowness and stiffness – key Parkinson’s disease (PD) motor symptoms – can be challenging. Your Parkinson’s disease doctor and other PD healthcare experts, such as an occupational therapist (OT), can provide integrative strategies to ease movement.

This article is based on a Parkinson’s Foundation Expert Briefing series, Symptom Management: Is it PD, Medication or Aging: “Exploring Motor Symptoms Co-Management: Occupational Therapy and Neurology” presented by Lisa Warren, MHS, OTR/L, Occupational Therapist and Rehabilitation Manager, University of Florida Health Rehab, Norman Fixel Institute for Neurological Diseases, a Parkinson’s Foundation Center of Excellence.

PD Motor Issues
There is no specific test to identify Parkinson’s disease, but telltale primary motor signs include:

- bradykinesia, or slowed movement
- tremor and shakiness
- rigidity or stiffness
- postural instability

A movement disorder neurologist looks for bradykinesia coupled with either stiffness or tremor when considering a PD diagnosis.

Improving Movement
Your neurologist and occupational therapist have different tools to help you tackle Parkinson’s movement issues – tools that can work better when used together.

Bradykinesia: This PD-associated physical slowness might manifest as unusual stillness, decreased facial expression or difficulty moving.

Your doctor can review your PD medications to ensure optimal delivery and might recommend taking prescriptions up to an hour before tasks requiring dexterity. An occupational therapist can suggest dexterity-boosting activities, such as shuffling cards or practicing penmanship.

Tremor: People with Parkinson’s generally experience tremor as shaky hands, legs or chin, often occurring at rest. It fluctuates in severity.

Getting Dressed Safely
Motor symptoms tied to Parkinson’s disease (PD) can complicate daily actions. If you experience PD-related shakiness, slowness or balance issues, give yourself extra time for necessary activities, including dressing.

These tips can make dressing easier, too:

- Wait to dress until your medications take full effect.
- Dress from a seated position. Use a supportive chair with arms.
- If you more experience stiffness in an arm or leg, dress that part first.
- Choose clothing that eases dressing, such as elastic-waist pants and slip-on or Velcro-closure shoes.
- Select non-skid socks instead of bathroom slippers, which can fall off your feet.
- Consider using a button hook, dressing stick, zipper pull or sock aid to simplify dressing.
- Steer clear of socks with tight elastic bands.
Doctors often treat resting tremor with combination carbidopa/levodopa medication therapy. This temporarily replenishes dopamine to ease movement. If you experience medication-resistant tremor your doctor might explore other therapies, including deep brain stimulation (DBS) – a surgical procedure that can improve movement.

Emotional and physical stress can also increase tremor. An OT can suggest therapy specific to you, including meditation or ways to adapt an activity you love.

**Rigidity**
PD-related stiffness can cause painful cramping, such as dystonia – the muscle spasms and clenching associated with Parkinson’s.

Combat rigidity by taking your medication on time, daily. If that doesn’t work, your doctor may augment your medications or recommend Botulinum toxin injections. This can sometimes relax overactive muscles in PD.

An occupational therapist can demonstrate stretches to help you safely warm up your muscles. Stretch frequently and find an exercise you enjoy. Regular exercise eases many symptoms of Parkinson’s.

**Postural Instability**
People who live with PD can also experience balance changes that increase injury risk. Your healthcare team can help you keep moving safely.

Your movement disorder neurologist should perform a balance test that involves touching your shoulders at every visit. Your reaction to this test helps your doctor discover stability issues and determine appropriate treatment.

An OT can recommend consistent, year-round exercise focusing on maintaining and improving balance.

**Find an Occupational Therapist**
Are you looking for a more personalized plan? If so, request a referral for occupational therapy from your neurologist or movement disorder specialist. Ask them if they can recommend an occupational therapist with knowledge of PD. You can also contact your state OT association, or local rehabilitation facility or home care agency, to find an OT. You can find more information on the American Occupational Therapy Association website at [www.aota.org](http://www.aota.org).

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**PD GENEration: Mapping the Future of Parkinson’s Disease**

*PD GENEration: Mapping the Future of Parkinson’s Disease* is a Parkinson’s Foundation initiative that offers genetic testing and genetic counseling at no cost for people with Parkinson’s disease (PD). When you participate, you can help scientists in their journey to advance understanding of PD, leading to new, more effective PD therapies.

**Enroll now:**
[Parkinson.org/PDGENEration](http://Parkinson.org/PDGENEration)
One Parkinson’s disease (PD) program has it all. From a wide-ranging weekly fitness class led by Parkinson’s-trained instructors — including Stretch & Strengthen and Rock Steady Boxing — to a speech pathologist-led Tremble Clefs singing group, the Tampa Bay Parkinson’s Disease Newly Diagnosed Wellness Initiative makes building bonds amid social distancing easy.

The program is a collaboration among the Tampa Jewish Community Centers (JCCs) and Federation and the University of South Florida, a Parkinson’s Foundation Center of Excellence. Among the program’s many popular group activities are also meditation classes and PD support groups facilitated by a licensed clinical social worker, and monthly lunch-and-learn educational talks.

The Parkinson’s Foundation community grant recipient rapidly transitioned to virtual programming in spring 2020.

Pnina Levermore, Tampa JCC and Federation Active Adult Program Manager, has seen the popularity of the programs increase, with participants logging in to virtual events from out of state. Over time, when the city begins to reopen, participants will still be able to choose between virtual and in-person activities.

“The Parkinson’s Foundation community grant is a lifeline,” Pnina said of the $18,000 grant used to help deliver programming.

“It means everything. The grant enables us to provide experienced, trained, caring professionals who offer these critical fitness classes for the Parkinson’s community, and it allows us to reach out to the public ... so that people whose lives are affected by Parkinson’s can be aware of these resources.”

The connections forged among the Wellness Initiative’s 300-plus members are so strong that a few moved to Tampa after just trying classes out. “We encourage participant input and initiative,” said Pnina.

One participant who lives with PD researched her own fine motor challenges, worked on them and — in response to requests from the community — now leads a weekly workshop on fine motor skills and handwriting. “That workshop has been meeting for over a year and has been a great resource for dozens of participants.”

Since 2011, the Parkinson’s Foundation has funded 436 community-based programs that make life better for people living with PD. The Foundation will award more than $1 million in community grants in the 2021 grant cycle that support education and outreach programs addressing unmet needs in local PD communities.

Learn more about Parkinson’s Foundation Community Grants at Parkinson.org/CommunityGrants.
Why Adam Rides for the Parkinson’s Revolution

Adam Mizock is excited to be back in the saddle, virtually connecting and training with riders across North America. He is currently fundraising for Parkinson’s Revolution — a cycling experience that generates Parkinson’s disease (PD) awareness and raises funds for groundbreaking PD research.

“This is a great opportunity, and I wouldn’t miss it,” said Adam, who uses exercise as medicine to manage his Parkinson’s. “The ride brings people together to help fight Parkinson’s, but there is more to it. It is important that we keep our eyes on the future, and that we live high quality lives today.”

Adam defends his title this year as the top 2020 Revolution fundraiser when he raised $12,500. “People actually appreciate being asked to give to a good cause,” he said.

“Small gifts really add up and spread good feelings all around.” Adam suggests utilizing social media, email and holiday card lists as starting points. “When you ask for donations, remember to tell people why you’re doing it. Your story matters.”

For those unsure if they want to clip in, “Use the ride to incentivize your own exercise plan, meet people, and do something good in the world today,” Adam said.

Join the Parkinson’s Revolution on June 12. Virtual and contactless in-person events will take place across the nation. Sign up today at Parkinson.org/Revolution.

On April 13, Shawn Williamson or "Sparanda" and his gaming crew will raise funds and awareness in honor of his mom who is living with Parkinson's. He will be live streaming as he plays “Kingdom Hearts,” during which viewers can donate at Parkinson.org/Gamer.

Become a Parkinson’s champion at Parkinson.org/Champion.

Nkiru has donated her last three birthdays on Facebook in honor of her mom who is living with Parkinson’s. “We keep hope that every day we come closer to new advances to help those with Parkinson’s live easier lives,” Nkiru said. Start a Facebook Fundraiser at Parkinson.org/FB.

Make a difference in people’s lives and create a meaningful legacy through planned giving.

A bequest is one of the most popular and flexible ways you can make a gift through your will or trust that helps further the work of the Parkinson’s Foundation. We have partnered with FreeWill, which allows you to write your legal will online, at no cost.

FREEWILL.COM/PARKINSON
Join the Conversation.
PDConversations.org

- Join the conversation in one of our eight discussion groups.
- Find a community with others who share your interests.
- Check out the top five trending topics.

We’re here for you.

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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) Monday through Friday from 9 a.m. to 8 p.m. ET to speak to a Helpline specialist in English or Spanish.

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