

PARKINSON'S DISEASE IN A POST-PANDEMIC WORLD: WHAT'S NEXT?



Vaccination rates against COVID-19 are on the rise and reaching promising levels across the nation. A return to “normal” is something we’ve all been looking forward to, and we hope to continue to head in that direction even as variants emerge and give us pause.

As more information becomes available and safety guidelines continue to shift, the American Parkinson Disease Association (APDA) is working to ensure that the Parkinson’s disease (PD) community remains informed as we all turn this new page.

What can people with PD do to stay safe?

Dr. Joel Perlmutter, a member of APDA’s Scientific Advisory Board, spoke with Dr. Rebecca Gilbert, Chief Scientific Officer at

APDA, about how people facing PD can be prepared for an evolving COVID-19 world.

“Everyone needs to be vaccinated against COVID-19. It’s very important.”
— Dr. Perlmutter

“These vaccines are very safe, and the risk from vaccination is far, far, far less than the risk from COVID-19,” Dr. Perlmutter says.

Looking ahead

After a long, challenging year, it’s normal to feel uncertain about

switching gears and returning to pre-pandemic life — especially when you’re living with PD.

Dr. Gilbert advises, *“If you’re concerned or unsure, you always have the option to err on the side of caution and wear your mask — or not attend an indoor event. We’re all finding our way, and it will happen at different rates for different people.”*

Remember to be patient with your family members and friends, as we all are operating at different levels of comfort. Make self-care a priority — because it’s so important to stay active and maintain overall health, particularly for people with PD. Consider meeting with a mental health professional to discuss how you’re feeling (virtually if needed), trying out a new tasty and nutritious recipe, or getting active with a physical activity you enjoy, like yoga or going for a walk. Or connect with friends in the PD community at an APDA event!

APDA Optimism Walks, along with many support groups and exercise classes, are returning in person this fall, and we’re looking forward to seeing you again! To learn more about living with PD in a post-pandemic world, we invite you to watch Dr. Gilbert and Dr. Perlmutter’s full Q&A session on APDA’s YouTube channel. Be sure to visit apdaparkinson.org/optimism-walks or apdaparkinson.org/community to join people impacted by PD across the nation this fall (in person or online) and reconnect with our community.

A MESSAGE FROM OUR CEO & PRESIDENT

Dear Friend,

We can all agree that this past year has been one of whirlwind change. But it's thanks to your dedication to the PD community that APDA can continue working tirelessly to help everyone touched by PD live life to the fullest.

Living with PD can come with its own set of challenges and questions — and the added layer of uncertainty brought on by this past year has left many individuals and families affected by PD feeling unsure. With help from compassionate friends like you, we can continue offering information and support as many of us begin to navigate COVID-19 vaccines and living with PD in a post-pandemic world.

Thanks to your loyal friendship, APDA can also continue sharing strength with people impacted by PD and inspiring hope for what lies ahead. I am as optimistic as ever that a brighter future is possible for everyone facing PD — and I know that we're getting closer every day.

Sincerely,



Leslie A. Chambers
President & CEO
American Parkinson Disease
Association



LEVODOPA AND THE FUTURE OF PD RESEARCH

Tremors, issues with balance, and slowness are just some of the trademark symptoms of PD. It's caused by a loss of critical neurons in the brain that use dopamine to communicate. **That's where levodopa comes in — as a way to replenish that dopamine and improve motor function in people with PD.**

In the early days of levodopa research, scientists were unsuccessful in using the drug as a treatment for people with PD. But thanks to the work of Dr. George C. Cotzias many years ago — and the generosity of APDA supporters which helped fund his work — levodopa became (and continues to be) a critical tool in PD symptom management for countless men and women living with the disorder.

His contributions to PD research have made an incredible impact on countless lives, and in his honor, APDA created the Dr. George C. Cotzias Memorial Fellowship. Since Dr. Cotzias' landmark discovery in the 1960s, APDA has been proud to support 30 researchers with this fellowship. The PD scientific community has further explored and built upon his work, creating new and creative ways to administer this life-changing drug and exploring other topics related to PD research and patient care.

“Levodopa became (and continues to be) a critical tool in PD symptom management.”

With your continued support, PD researchers and scientists can continue working to unlock the secrets of PD, develop better treatments, and, one day, discover a cure for this neurological disorder. Visit apdaparkinson.org/research to learn more.





LIFE WITHOUT LIMITS: ONE VETERAN'S STORY

"I jumped out of a perfectly good airplane and free fell at 150 mph. I zip-lined at the Grand Canyon. I went paragliding off a 1,800-foot mountaintop and flew for over 20 minutes. I have walked over 5,220 miles."

These are just a few of the amazing things Bob has accomplished since his PD diagnosis in 2018, which is presumably connected to his military service and exposure to Agent Orange. And as a Vietnam War veteran, architect, husband, and father, Bob wasn't about to let PD slow him down — *"Life happens!"* is one of his mottos.

Like so many people living with PD, Bob knows that staying active is one of the best things he can do to lessen the impact of his disorder. So one of his favorite ways to stay active became daily walks.

Bob recalls, *"I was sent to physical therapy, and in about an hour's time I learned how to walk... correctly. After that session, I came home, put [my trekking poles] by my back door, and have not used them since."*

And when he isn't walking, Bob is attending PD support groups, tuning in for APDA webinars, and tending to his garden. *"I really do enjoy the Take Control presentations very much — and the Dr. Gilbert Hosts webinars,"* says Bob. *"My takeaways from APDA presentations and publications are always very positive and thought-provoking."*

Bob stays connected to the PD community, and he encourages other veterans living with PD to seek the help they need and the benefits they've earned in their service to our nation through the VA. (Veterans exposed to Agent Orange during military service may be at an increased risk of PD. To learn more about resources for veterans with PD, visit apdaparkinson.org/veterans.)

He also urges us all to start living life to the fullest: *"Do what you like to do for as long as you can. Do not take your diagnosis of PD as a death sentence. Learn new things. Exercise!"*

Bob's story is just one of many inspiring stories from our PD community across the nation. Do you have one too? If so, we want to hear it! Visit apdaparkinson.org/stories to share your journey of hope and optimism with others.



FEEL GOOD AND FIND COMMUNITY WITH APDA EXERCISE GROUPS!

With APDA exercise groups like yoga, tai chi, boxing, and more, there's a way for everyone with PD to feel their best and lessen the impact of the disease — and in addition to the physical benefits, exercise can help people with PD get involved and connect with others in the PD community.

Dr. Adena Leder, a movement disorder specialist and certified Rock Steady Boxing instructor, organized a boxing program at the New York Institute of Technology (NYIT) College of Osteopathic Medicine, home to one of APDA's Information & Referral Centers. She says, *"It is fun and social. The more often [patients] come, the better they feel!"*

There's a PD exercise group out there for everyone! They're free, fun, and a great way to find a supportive community of understanding friends while getting the exercise that is so very important for people with PD. To see what classes are available in your area, visit apdaparkinson.org/community, or visit apdaparkinson.org/events to find a virtual fitness class you can take from anywhere!



“ASK THE DOCTOR”

with Dr. Rebecca Gilbert



Q. I was diagnosed with PD a few months ago by my primary care physician, and I have my first appointment with a movement disorder specialist this week. Can you suggest ways to prepare for this visit?

A. I would do three things to help make your visit the most productive and informative:

1. Bring along a “scribe” — a family member or friend who will take notes. Then you can review the notes afterward at your own pace.
2. Make a list of questions that you have and bring them along. Toward the beginning of the visit, mention to the doctor that you have this list, and you would like a few minutes at the end to discuss the things that have been on your mind.
2. Before the visit, make a list of any symptoms you have and how often you have them. It can be hard to remember everything at the appointment, especially if you’re

a little nervous. You can download the free APDA Symptom Tracker app to help you keep track of your symptoms.

Q. I have had PD for about 10 years, and recently, I have been experiencing frequent falls. Why is this happening?

A. Falls can be dangerous, and it’s important to try to minimize them. There could be a number of reasons why you are experiencing frequent falls. Here are a few:

- Loss of postural reflexes, or the loss of the ability to right oneself when thrown off balance, is a very common part of PD.
- Drops in blood pressure is a common non-motor symptom of PD that can cause dizziness as well as passing out.
- Decreased visuospatial skills, which interferes with your ability to navigate your way around obstacles, can contribute to falls.

- Freezing of gait is an abnormal pattern of walking associated with PD in which there are sudden, short, and temporary episodes of an inability to move the feet forward despite the intention to walk. This can cause falls.
- Dyskinesias, or extra unwanted movements, can be a side effect of PD medication and can be throwing you off balance.

All in all, you need to discuss your falls with your neurologist who can investigate exactly what is causing your falls and try to correct it either with adjustments in medication, physical therapy, or an assistive device.

Dr. Rebecca Gilbert is the Chief Scientific Officer at APDA. She oversees APDA’s research portfolio in conjunction with APDA’s Scientific Advisory Board. She also provides medical and clinical expertise to support APDA programming as well as print and web content.

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PARKINSON DISEASE
ASSOCIATION
Strength in optimism. Hope in progress.

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