AMERICAN PARKINSON DISEASE ASSOCIATION

INSIGHTS

SHARE YOUR PARKINSON'S STORY



When it comes to Parkinson's disease (PD) and the estimated 1 million people in the U.S. living with it, a story can make a world of difference. Your shared story helps raise awareness and can provide support to someone recently diagnosed who is perhaps unsure or afraid of what is to come. And it can provide hope and camaraderie to the care partner who is struggling to balance it all. One story can touch dozens, even hundreds of people.

You can make a difference

That's why the American Parkinson Disease Association (APDA) has made it easier than ever for YOU to share your Parkinson's story. Visit **apdaparkinson.org/stories** to view stories shared by others and use our new story-sharing tool to add yours. By adding your story of optimism, together, we can help people look closer at those affected by PD and see that there is so much more to a person than just their PD diagnosis.

Stories of hope

Here are just a few of the stories you'll see in our Story Gallery.

Juanita, who praises the power of her support network, says, *"Just knowing that my friends and family love and support*

me... every day... gives me a reason to fight every day."

Kermit, pictured below/right, says, "Rather than withdrawing and feeling depressed, I made it a goal to engage life more – living each day to the fullest, embracing and savoring every moment, and surrounding myself with people who nourish me."

Allyssa, who started dancing at age 38, was inspired to get trained to teach classes for people with PD and states, *"I have been so humbled at the drive and determination of my students."* She adds, *"My students are truly the light of my life."*

Brian is an avid cyclist and swimmer despite living with PD the majority of his life. His optimism is inspiring. He states, "We can accomplish anything if we just try. Everybody's journey with PD is individual. And what works today may not work tomorrow. We must keep looking for answers that work for us."

People want to hear your story

Whether you're living with PD or you're a care partner, friend, family member, or even a medical partner, we hope you'll let the world know what inspires your **#PDOptimism**.

Once your story is published, our new story-sharing tool makes it even easier for you to share your published story with your friends and community through Twitter and Facebook.

We hope you'll join us in establishing a bold, optimistic, and authentic library of voices today. We know every story is powerful and we can't wait to read yours.



"Your shared story helps raise awareness and can provide support to someone recently diagnosed who is perhaps unsure or afraid of what is to come."



A MESSAGE FROM OUR CEO & PRESIDENT



Dear Friend,

For so many, this past year has been full of uncertainty and change. The COVID-19 pandemic has been disruptive in so many ways – but it's thanks to your support that APDA has remained a constant resource for so many.

As you may already know, 60,000 people in the U.S. are diagnosed with PD each year, and this year, that diagnosis may have felt especially daunting since many have also been grappling with quarantining at home, concern about potential COVID-19 risks for people with PD, and/or trying to figure out how to see a doctor during a pandemic. But with your help, APDA has been providing the care and resources that help people with PD move forward and live life to the fullest. For that, I am so grateful.

In this issue of *Insights*, you will learn more about what APDA has done to ensure that people with PD can depend on us and will continue to receive the support, education, and research that will help them live their best life. Together, we have created a wealth of virtual programs and informational sessions to keep people with PD and their families informed, engaged, and supported. You will also learn about the inspiring stories of people with PD and how your story can make a difference.

As you read, please know that our work would not be possible without you. With your support, there is no limit to what we can accomplish.

Sincerely,

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Leslie A. Chambers President & CEO American Parkinson Disease Association

WHAT'S HAPPENING AT APDA

Optimism Walk Update

All 2020 Optimism Walks are being held virtually, and there's one last chance for you to join us – no matter where you live! Register today for our October APDA Virtual Optimism Walk taking place on Saturday, October 17 at 11:00 am ET. You'll join an inspiring group of participants from our St. Louis, Connecticut, Iowa, and Long Island Walks (and beyond) as we come together for a fun Online Ceremony & Celebration and then set out to walk locally in our own neighborhoods. Photos and stories from across the country will be shared using #OptimismWalk to add to the camaraderie and sense of community! Register today at www.apdaparkinson.org/optimismwalk.

OPTIMISM WALK

Get Involved > Optimism Walk



APDA OPTIMISM WALK



ALL 2020 OPTIMISM WALKS ARE GOING VIRTUAL! Join us from WHEREVER you are!

Due to the COVID-19 pandemic and for the safety of our participants, all remaining 2020 Optimism Walks have gone VIRTUAL! Take a look at the list below to find the Walk that works for you! Join us!

KEEPING IN TOUCH ONLINE

Virtual events have been a great source of information and activity as we all work to adhere to various health regulations and social distancing guidelines. For APDA, keeping people with PD and their families connected, motivated, and informed has been a top priority. As a result, APDA has created many virtual programs and resources, including two special series: *Dr. Gilbert Hosts*, a live Q&A series featuring expert guests, as well as *Let's Keep Moving with APDA*, a series of fitness-focused webinars to help people exercise safely at home.

Stay Informed with Dr. Gilbert

Early on in the pandemic, we saw that our PD community was very concerned about COVID-19 and had a lot of questions about their personal risk. *Dr. Gilbert Hosts* began as an online series of expert interviews and Q&A sessions to educate people weekly on specific issues related to COVID-19 and PD. Due to the popularity of the program, it is continuing monthly through the end of 2020. You can register for upcoming programs or watch previous sessions online at **www.apdaparkinson.org/dr-gilberthosts**.

Each episode features Dr. Gilbert and an expert in the field of PD to discuss timely topics and answer questions from the audience.

Coming up next on October 19, Dr. Gilbert will speak with a care partner about the challenges and blessings of caring for someone with PD. We hope you'll join us. All sessions are recorded and



archived in the Educational Video Library on our website, in case you miss an episode.

Keeping Active with APDA

In partnership with the APDA National Rehabilitation Resource Center for Parkinson's Disease at Boston University, *Let's Keep Moving with APDA* was created to help people with PD and their families stay motivated and learn how to exercise properly at home. These short (approximately 30 minutes long) sessions are led by licensed physical therapists and include lots of great Q&A's from the audience.

Available through APDA's Educational Video Library (www.apdaparkinson.org/videos), you can view any of the *Let's Keep Moving with APDA* sessions, including topics like *Be Active at Home: Exercise tips for people with PD; How to Stay Motivated for Physical Activity with Social Distancing; Setting up for Success at Home: Creating an Exercise-Friendly Area; a three-part series on balance and PD;* and so much more.



CREATING A LEGACY

If you wish to leave a legacy that will touch the lives of so many, please consider including APDA in your planned giving (i.e., your will). There are several easy ways to make an impactful gift that will not only help in the fight against PD, but could help you, your estate, and your heirs. Giving through a will or trust, life insurance policies, a charitable gift annuity, and excess retirement funds are just several options. To learn more about planned giving and which options are right for you, contact your financial advisor, or reach out to APDA's Office of Planned Giving at apda@apdaparkinson.org or 718-981-9202. You can also visit our website at apdaparkinson.org/legacy for more info.



"ASK THE DOCTOR"

with Dr. Rebecca Gilbert

Q. I have PD. Now that the country is "opening up," what should I do? Should I start to venture out or continue my current practices of staying at home and only going out for walks if I can safely stay six feet away from others?

A. Various states are "reopening" as the rate of new cases of COVID-19 slows down. (It should be noted that in some places in the U.S., new cases are not slowing, yet reopening is taking place anyway.) It is important to reiterate that the risk for a complicated course of COVID-19 is not the same for everyone. People who are over 65 and have underlying medical conditions will need to continue to be careful even if their city is opening up. Small studies from around the world are examining whether PD is an underlying medical condition that increases the risk factor for worsened COVID-19. For those with advanced symptoms, the answer seems to be yes. For those with mild symptoms, the jury is still out. The PD community will therefore have to be more careful than the general population as we ease

back into "normal" life. If you are in a situation in which there are other people around, wearing masks and staying more than six feet away are important, and don't forget to wash your hands frequently. These measures reduce (but do not eliminate) the risk of transmission and should continue even if others around you are not complying.

Q. Since my diagnosis of PD in 2014, my eyesight has been affected in a number of ways. One thing I now have trouble with is following the ball when I play golf. I try to focus on the ball, but I can feel my eyes losing their focus. Is this related to PD? Is there anything I can do about it?

A. I wonder if the problem is what we call *convergence insufficiency* – you are able to see the ball at a distance, but not when the ball is closer to you, because your eyes don't work together to see close objects. Ask your neurologist for a referral to a neuro-ophthalmologist who can test for this and other eye movement conditions. Sometimes prisms in your glasses can help with this problem. Q. My husband has had PD for 14 years and recently started to have sudden falls where he crumbles to the floor. They are very scary for me to watch, but he seems to be OK once he is on the floor. What could be going on?

A. Sudden falling could be due to a number of issues, and your husband definitely needs a complete medical evaluation to figure out what is going on. One possibility is that he is experiencing drops in blood pressure while he is walking, which is a common non-motor symptom of PD. Talk with his neurologist about what is going on because this problem needs to be solved quickly. Sudden falls can cause serious injury such as a broken bone or traumatic brain injury and could quickly spiral into a major problem.

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.

AMERICAN PARKINSON DISEASE ASSOCIATION Strength in optimism. Hope in progress.

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For more information, or to learn about the many ways you can support APDA, please call (800) 223-2732 or visit www.apdaparkinson.org/Renew.