

## STAYING CONNECTED WHILE SOCIAL DISTANCING



Challenges often force us to adapt and learn new ways of doing things. No one knows that better than people living with Parkinson's disease (PD).

### Facing new challenges

As COVID-19 became a reality and communities implemented social distancing guidelines, the American Parkinson Disease Association (APDA) faced some significant challenges. All of our in-person programs that help keep people supported, healthy and informed could no longer take place. How could we continue to serve and stay connected to the PD community?

### Jumping into action

In addition to hosting our first-ever Facebook Live (see p.3), APDA created a new weekly series of Q&A sessions, called "Dr. Gilbert Hosts," addressing topics related to COVID-19; developed a

**"We immediately jumped into action."**

fitness-focused series called "Let's Keep Moving with APDA" to help people learn

how to exercise safely at home, and much more.

According to Rosa Peña, Senior Director Programs and Services Field Operations at APDA, local chapters quickly moved support groups online or connected by phone. They also sent out weekly emails to constituents with updates about COVID-19 and ongoing programs.

### Making a tangible difference

This pandemic has impacted people in so many different ways, but for someone living with PD it can be especially frightening. We received a call from a Spanish-speaking gentleman who lost his medical insurance when his wife was laid off from the service industry. He needed a refill on his PD medication. After several phone calls to urgent care facilities and pharmacies, APDA was able to get him his medication and relieve some of the stress he and his wife were feeling.

### Innovation and creativity

All across the country, thanks to your support, APDA Chapters found ways to keep people healthy and active despite stay-at-home orders including free online yoga classes, improv class, online singing programs and more. "We immediately jumped into action and contacted all of our support group leaders to help them transition to a virtual format so attendees could still feel connected and supported," said Jennifer Gillick, Program Director, APDA Northwest Chapter.

### Looking to the future

While there's no substitute for in-person gatherings, Peña pointed out that virtual programs will continue even when social distancing restrictions are lifted. Bill Patjane, Executive Director, APDA Massachusetts Chapter, added: "The transition from in-person to virtual programs did help us to think about how we can expand the reach

**"We can expand the reach of many great offerings into communities that haven't had access in the past."**

of many great offerings, like yoga, tai chi, and professionally-led support groups into homes and communities that haven't always had access to our programs and services in the past."

One of the most important takeaways for all of us is that being at home doesn't mean being alone. APDA is here for you no matter what. "You can call us if you are having a challenging moment and we'll see what we can do for you... We're in it together, it's going to get better," says Peña.



Rosa Peña,  
Senior Director  
of Programs and  
Services Field  
Operations at APDA

## A MESSAGE FROM OUR CEO & PRESIDENT

Dear Friend,

We certainly have been through a lot together this spring. And “together” certainly looks differently than it used to. I hope you have found ways to stay connected with family and friends throughout the COVID-19 crisis. We at APDA have been working hard to find new ways to keep the Parkinson’s disease (PD) community connected to the support and resources they need to live life to the fullest, and you’ll read about just a few in this issue. Your support has helped us remain a consistent presence in these uncertain times, and we are so grateful to be able to count on your generosity.

Sincerely,



Leslie A. Chambers  
President & CEO  
American Parkinson Disease  
Association



Leslie A. Chambers

# HELPING PEOPLE WITH PARKINSON’S DISEASE OVERCOME BARRIERS

People with PD who are from underserved communities – those who are low income, speak English as a second language, live in rural areas, or are members of minority groups often face unique barriers that affect their access

to quality care. Through a generous grant from Neurocrine Biosciences, APDA conducted focus groups in Hispanic and African American communities in New York, Chicago and Los Angeles. Our goal is to better understand the experiences of Hispanic and African American PD patients, their family members, and



care partners; identify barriers to diagnosis and treatment; and explore unmet needs and gauge reactions to community outreach and service solutions. We learned so much as we listened to patients and care partners discuss their experiences with diagnosis, finding the right neurologist and coping with the disease as a family, including:



The road to diagnosis was not easy and many had to wait a long time before seeing a doctor. In addition, many expressed concern over lack of insurance and therefore, lack of access to medical care.



Many wanted to find a “one stop shop” for resources that included medical care, community assistance and help for care partners.



Finding a support group that felt comfortable and reflected the person’s culture and life experience was identified as an important need.

As a result of this research, a social group for African American men was started in one community; additional APDA publications were translated into Spanish, and the APDA Helpline 1-800-223-2732 has Spanish-speaking staff available to speak to patients and refer them to resources in their communities.

Research like this can help address unmet needs and improve access to health care for all people diagnosed with PD. APDA will continue to conduct focus groups online so we can learn of other important ways to meet the needs of patients who have barriers to care.

## WALKING SEPARATELY, BUT TOGETHER

The 2020 Optimism Walk season kicked-off with four *virtual* Optimism Walks which all took place simultaneously on May 31, 2020. After an online celebration and opening ceremony, participants in all four events walked *separately, but together* in solidarity for the PD community. Due to social distancing, participants were encouraged to walk on their own and share photos and comments on social media using #OptimismWalk so together they could still be uplifted

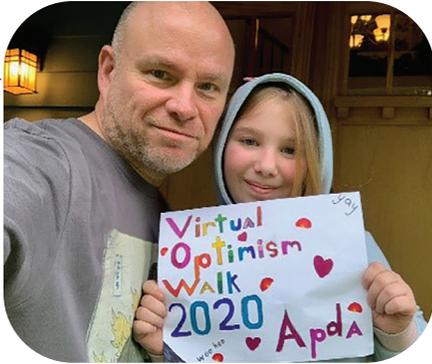
by a great sense of community and camaraderie. In a fun East Coast/West Coast unofficial competition, our virtual Optimism Walks based out of Massachusetts and Vermont were up

against those taking place in California and Washington. (It was a close call but our friends on the West Coast got the bragging rights.) To keep everyone

safe, we are transitioning the rest of our 2020 schedule to virtual Walks. Visit [www.apdaparkinson.org/optimismwalk](http://www.apdaparkinson.org/optimismwalk) for dates and details. We offer special thanks to our National Optimism Walk sponsors: Adamas

Pharmaceuticals, Amneal

Pharmaceuticals, Lundbeck and Sunovion Pharmaceuticals; as well as Neurocrine Biosciences and Acadia Pharmaceuticals who sponsored our first virtual Walks in May.



#OptimismWalk



What's happening at APDA?

### A Facebook first

Just as many of you have been learning how to work from home, connect virtually, and figure out new ways to get things done, APDA has been doing the same! We knew we had to find different ways to stay connected, so we hosted our first-ever **Facebook LIVE Q&A** as a new way to bring information directly to you. Coming to you from their homes, APDA President & CEO Leslie Chambers and our Chief Scientific Officer Dr. Rebecca Gilbert hosted a virtual discussion and answered people's questions about COVID-19 and PD. The recorded session is available on our website (look in our Educational Video Library) along with the additional virtual Q&A programs we have conducted since then. We encourage you to check them out.



## SING FOR PD

The APDA National Headquarters was filled with song as people with PD sang their hearts out during our first-ever Sing for PD class in March. A program of the Mark Morris Dance Group, Sing for PD focuses on breathing and vocal technique, rhythm, melody, song interpretation, and creativity. Instructor Joseph Peterson took the class through songs from folk, classical, Broadway, and contemporary songbooks and explored the joy of singing while teaching attendees how to better control their breath and diaphragm. The techniques and exercises taught in class can help people with PD strengthen their voices, which can be an issue for some people with the disease.

The class was a hit, with attendees commenting:

*"...All who attended got an exercise of your mouth, vocal cords, and breathing. And it was fun for everyone. Would love to see this class on a regular monthly basis."*

*"The class was amazing. Everyone was getting into it and moving and singing to the music. Loved it."*

*"It was great and fun. It was a joy!"*

Be sure to check our website for the latest virtual class offerings and other online resources.

[www.apdaparkinson.org](http://www.apdaparkinson.org)



# “ASK THE DOCTOR,”

with Dr. Rebecca Gilbert



**Q. I have heard about gene therapy for Parkinson's disease. What is this and how do I know if I am a good candidate for this?**

**A.** Gene therapy is a category of potential treatments in which a genetically-engineered virus, which contains a small fragment of DNA, is made to infect particular cells in the body. The virus then transfers the DNA fragment into the cells of the body and causes those cells to manufacture a protein based on the DNA fragment. Gene therapy is used in many different conditions, and over the years, different variations of this procedure have been tried for PD. None have succeeded to the point that it is an approved therapy, but research continues. Right now, if you are interested in gene therapy for PD, you can join a clinical trial. If you have a relatively straight-forward case of PD and you are in good overall health, you may be eligible for the available trials. Search for “Parkinson's disease” and “gene therapy” on [www.ClinicalTrials.gov](http://www.ClinicalTrials.gov) to see a list of all the gene therapy trials past and present for PD.

**Q. I have PD and have issues with falling and freezing. Is it safe for me to be on a blood thinner?**

**A.** This is a great question and one that many physicians and patients struggle with. It depends on:

1. How much you need the blood thinner (Why are you on it? What are the risks if you do not take it?).
2. Your risk of falling (Are you falling every day? Once a month? Are you able to brace your falls at all? Have you hit your head?).

Your physician will have to make a decision based on your particular risk:benefit profile. There is no one right answer here, so an open and honest discussion with your doctor is important in order to decide what is best and safest for you.

**Q. I have problems with both near and far vision. I would like to know if progressive lenses are good for someone with PD or if having two different pairs of glasses is better.**

**A.** Many ophthalmologists who are familiar with PD say that progressive lenses are more difficult for people with PD than for others because it is hard for people with PD to transition between the different lens areas. Therefore, it is typically recommended to have two different pairs of glasses.

However, everyone is different and if you find progressive lenses are easier for you and they help you see better, then that is a good solution for you.

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

**apda** 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](http://www.apdaparkinson.org/Renew).**