

ALWAYS MOVING FORWARD

Bill and Cathy stay optimistic and move forward by building their community

For Bill, it started with a tremor that was easy to ignore. But as the years went by and his symptoms began to worsen, he decided to make an appointment with a movement disorder specialist at their local hospital.

“It never occurred to me that it was Parkinson’s but...it made sense,” says Cathy, Bill’s wife of over twenty years. “He had slowed down a little bit and was having rigidity. That was a relief to get the diagnosis because then we knew what we were dealing with.”

Finding a community of hope

A retired tugboat captain and marine pilot, Bill is the kind of person who faces challenges head on. So when he got his Parkinson’s disease (PD) diagnosis, he went to work. Bill began going to a physical therapist who specialized in PD, and they both began doing online research into the disease.

On the American Parkinson Disease Association (APDA’s) website, they came across the Good Start Program, an educational program for individuals recently diagnosed with PD and their family members held at APDA’s Northwest Chapter.

During the meetings, they got to hear from neurologists, speech pathologists, physical therapists, and other medical professionals.

“It’s been helpful [to] meet people who have had Parkinson’s for 10 or 15 years, and to realize that life with PD can still be a great journey.”

– Cathy

Bill and Cathy also participated in APDA’s Optimism Retreat, a conference focused on movement and well-being for individuals impacted by PD, and they were part of the pilot program for APDA’s Parkinson’s Roadmap for Education and Support Services (PRESS™), an eight-week support group addressing the psychosocial needs of people newly diagnosed with PD.

Staying active and optimistic

Cathy recommends that people diagnosed with PD find a good physical therapist, make sure their neurologist is a movement disorder specialist, stay active, get enough rest, and most importantly, build a support system.



IN THIS ISSUE:
Dr. Gilbert answers
your questions
about coronavirus
and PD.

Through APDA, Bill and Cathy have had the opportunity to share their experiences in a supportive environment of people who know exactly what they’re going through.

“If you’re the care partner and you’re feeling a little overwhelmed, I think it’s really important that you find somebody that you can talk to, whether it’s another care partner or a therapist or a family member or somebody,” she says.

They also take great comfort in playing with their grandchildren and staying active. Bill goes to Rock Steady Boxing three times a week, and they both go to Tai Chi for Balance and water exercise twice a week.

“The boxing class I go to is like a big support group,” explains Bill.

Working to help others with PD

Bill and Cathy also participate in APDA’s Northwest Optimism Walk, a fun event designed to raise money and awareness to help end PD. “It’s a very doable walk for all kinds of abilities,” says Cathy. “We have done it on our own and we’ve also done it as part of a team.”

They plan to participate in the Walk every year and also support special events like APDA’s Magic of Hope Gala, where, Cathy says, “we were amazed at the donors and their generosity.”

Supporters like you have a remarkable impact on the lives of people with PD. Thank you for helping Bill and Cathy continue to live life to the fullest.



A message from
President & CEO,
Leslie A. Chambers

Dear Friend,

These are unprecedented times. More than ever, I'm so grateful for your support and for all that you've done to inspire men and women living with PD. Thanks to your generosity, people like Bill and Cathy --who you'll read about in this newsletter --have a vibrant community of people they can turn to for support.

Although PD is an incredibly challenging disease and COVID-19 has added an additional layer of concern, we remain optimistic because we know that scientific breakthroughs are on the horizon and we're working tirelessly to support the PD community during times of uncertainty and always. Thank you for your partnership on our journey to a cure.

Sincerely,

Leslie A. Chambers
President & CEO
American Parkinson Disease Association

APRIL IS PARKINSON'S DISEASE AWARENESS MONTH

Why does that matter?

It seems that every major disease has a special month. A month that is dedicated to the cause, where for a moment, people pay attention. They may walk, fundraise, wear a certain color or attend an event. For the PD community, April is our month.

But for all of us at APDA, April doesn't really matter. Because for us, *every single month of the year* is Parkinson's Disease Awareness month. *Every day*, we're working to improve the lives of people impacted by PD. Not just in April. Today, whatever day it is that you're reading this, APDA is on the front lines, helping people in their local communities through support groups and educational programs, through exercise and movement classes – programs and services that not only provide insight and information but also create social connections that are so valuable



Ask the DOCTOR

Q & A with Dr. Rebecca Gilbert



Q. I am 67 years old. Am I more at risk from COVID-19 than other people my age because of PD?

A. PD motor- and non-motor symptoms can be exacerbated by any medical illness, including a viral respiratory illness, like COVID-19. This means that in addition to the respiratory symptoms of the virus, people with PD may feel that they are slower and stiffer than usual and that their medications don't seem to be working as well. Recovery from the illness can be more drawn out.

Because of these reasons, people with PD are always strongly encouraged to protect themselves from any infection as much as possible. Vaccines such as the flu vaccine and the Pneumovax vaccine (for bacterial pneumonia) are strongly recommended. (COVID-19 does not yet have a vaccine because it is so new).

Q. Should I try to stay away from my grandchildren because of COVID-19?

A. According to the CDC, children are not more susceptible to COVID-19 than adults, and when they are infected they typically have mild symptoms (or no symptoms at all). A child who is infected with COVID-19 therefore may not appear ill, while still being able to transmit COVID-19 to someone else. This makes it complicated for older adults who want to be near children. In addition, children are less likely to practice good infection control procedures like covering their mouth and nose when coughing and sneezing, throwing away dirty tissues and washing or sanitizing hands frequently. For these reasons, as much as possible, it is advisable for older adults or people with underlying medical issues to stay away from children who have any symptoms of respiratory illness.

For the latest information on COVID-19 and how it may be affecting the PD community, please check our website (apdaparkinson.org) for updates.

For more information, visit our website at www.apdaparkinson.org, or call (800) 223-2732. To make a donation online, visit www.apdaparkinson.org/Renew.

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What's happening at APDA



South Florida symposium success

APDA's South Florida Chapter hosted the *5th Annual Parkinson's Symposium: A Comprehensive Approach to PD* in Boca Raton this January. Approximately 250 participants heard from experts including keynote speaker Dr. Carlos Singer, Professor of Neurology, Director of the Division of PD & Movement Disorders, University of Miami Health Systems, who spoke about PD and autonomic symptoms (above). Entertainment was provided by The Parkinson's Choir who kicked off the program with a series of songs and a great solo rendition of "New York, New York."

Expanding services in California

APDA is proud to announce a new APDA Information & Referral (I&R) Center in Santa Monica at the Pacific Movement Disorders Center at the Pacific Neuroscience Institute at Providence Saint John's Health Center. This new I&R Center enables us to serve more people in Southern California through in-person support groups and programs including PRESS™ and Connecting Through Art, as well as information and referrals throughout the area. For more information visit www.apdaparkinson.org/ca.

to living your best life with PD. APDA also hosts special events like galas, golf tournaments and Optimism Walks that raise critical funds (some of which had to be postponed, but we're working hard to reschedule as many as we can!). Whether it's midnight on a Tuesday in May, or 2pm on a Sunday in June, APDA is always here for you with webinars, educational materials, our Smart Patients online support group, our Symptom Tracker phone app and more. We are here for you whenever you need us, not just in April.

However, we still love April! Any effort to raise awareness for PD is so important so we still wholeheartedly support and celebrate Parkinson's Disease Awareness Month. It's a chance to take advantage of a special moment when there is extra focus on the disease and an opportunity to educate a broader audience about PD and about the support APDA can provide. You'll see our Chapters and Information & Referral Centers ramp up efforts to raise awareness about PD, and we hope you'll help us spread the word.

WHAT CAN YOU DO FOR PARKINSON'S DISEASE AWARENESS MONTH?



Spread the word about PD by sharing a link to our website or one of our publications or webinars with a friend who might benefit from learning more.



Make this the month when you finally make that **appointment with a neurologist** that you've been putting off.



Been hesitant to go to a **support group or exercise class**? There are lots of online options if in-person classes are still on hold in your area. This April, take the plunge and give it a try. Call APDA at **800-223-2732** if you need help finding one.



Know someone who is a care partner? **Check in on them** and see how they're doing.



Make a **donation to APDA**. The more funds we raise, the more people we can help, and the need is especially great in these challenging times.

For the latest updates on Parkinson's Disease Awareness Month, go to apdaparkinson.org

PARKINSON'S DISEASE: PLANNING FOR THE WHAT-IFS

APDA's *A Closer Look* blog tackles the challenges of advanced Parkinson's disease

It's hard to think about the tough stuff. The what-ifs, the worst-case scenarios, the unknowns.

PD is progressive, which means that it gets worse with time. However, for many of you, the worsening is gradual, maybe even imperceptible at times. This affords you many years of good living – exercising, spending time with family, maybe even working.

Yet for some, PD can become advanced and much more difficult to navigate than what is described above, both in terms of motor and non-motor symptoms. And while you should not dwell on all of the negative possibilities that may lie ahead, it is wise to be aware of what may come so you can be prepared for tougher times, if that is in your future.

To help you, APDA has created a special series of blog posts that address different aspects of advanced PD -- advice for how to plan ahead and how to navigate the bigger challenges that may come your way.

As part of the popular *A Closer Look* blog, Dr. Rebecca Gilbert, together with Dr. Pravin Khemani, a Movement Disorders specialist in Seattle, WA, address this sensitive topic and arm you with useful information that will help guide you should you need it now or much further down the road.

Topics include mental health, immobility, end of life issues, planning and prognosis and more. Four segments of the series have already been posted, with more to come. Check them out at www.apdaparkinson.org/blog. You can also subscribe to the blog to make sure you don't miss any future postings.

