

“LIKE OUR SECOND FAMILY”

One Couple’s Journey with APDA

For Trudy, the news that she had Parkinson’s disease (PD) came at the end of a 3-year struggle to diagnose her symptoms. Having been given various diagnoses (including at one point, Lyme disease) you can imagine the frustration she was feeling.

“I didn’t want to accept it,” she says, “I still thought they were wrong.”

Married to her husband Bill for 47 years and living on Staten Island, NY, for just as long, the couple liked to dance, exercise, and go for long walks. It was unclear how PD would affect their way of life.

That’s when a friend with PD introduced the couple to the American Parkinson Disease Association (APDA). They were looking for information, for answers – and for others who understood what they were going through.

Facing an uncertain future

They had questions about treatment. As Bill explains, “A big part of the disease is the medication...no one person takes the same medicine, or the same dose. And...every time you go see the neurologist, they’re constantly doing something with the medicine to tweak it.”

Trudy adds, “Some of the medicine makes me feel better, but then I get bad dyskinesia [uncontrolled, involuntary movement] from it.”

“People who understand me”

At APDA, Trudy and Bill have been able to attend educational programs and hear from doctors and social workers to learn more about living with PD. They also participated in dance, yoga, art, and Tai Chi classes.

The opportunity to connect with others has been equally if



not more important than the information and exercises they learned.

Bill has benefitted from the support groups for care partners. “It’s a safe place where you can go and speak your mind, and not worry about anybody giving you any negative feedback.”

Trudy says that to her, APDA means “Camaraderie. Support. Just getting together with people [who] understand me.”

“Like our second family,” Bill echoes. Trudy says that other people with PD know that the disease is more than just a tremor, and that just because she looks fine doesn’t always mean she feels fine.

When she’s feeling down, or unmotivated to go to a class or group, Bill will encourage her...and she’s always glad she went.

Hope, optimism...and determination

They both remain upbeat about the future. Bill says, “Hopefully new medicines down the line will, I don’t know about curing it, but make life a little bit easier for the patient.”

Trudy is participating in a clinical trial to explore the effectiveness of MRI-focused ultrasound therapy for PD patients like her.

Despite their challenges, they make an effort to maintain an active lifestyle and participate in whatever activities they can. They practice the dance moves they learn at class between sessions and try to get out and walk every day.

Bill’s advice to others in similar situations? “Just keep moving!”

Programs like the ones that Trudy and Bill have participated in are only possible because of generous donations from

people like you to APDA. Thank you for making it possible for us to support them as they continue to live life to the fullest.

“Sometimes I feel depressed. But then we go to the class, and we start talking, dancing, and laughing.”

– Trudy



A message from
President & CEO,
Leslie A. Chambers

Dear Friend,

With the colder weather upon us, I hope that it warms your heart to read about Trudy and Bill and their relentless optimism and how your donations have helped APDA support them in their PD journey. You'll also read about how you are making it possible for us to help individuals in those first early days of a PD diagnosis.

Wherever people are in their experience with PD, your generosity allows them to live life to the fullest. Thank you for making all important work possible. We are so grateful.

Sincerely,

Leslie A. Chambers
President & CEO
American Parkinson Disease Association

DEADLIEST CATCH CAPTAINS FUNDRAISE FOR A CURE



Pictured: Chuck Bundrant (center) surrounded by the captains, APDA Northwest staff and others.

APDA's Northwest Chapter held a unique "Captains for a CURE" fundraiser and auction on Saturday, September 14, 2019, hosted by Fremont Mischief Distillery, Trident Seafoods, Cameron Catering, and four of the captains from the Discovery Channel's popular Deadly Catch TV show. The goal was to raise \$250,000.

They surpassed that goal by \$175,000, raising an astonishing \$375,000 to provide support, education and research to help people impacted by PD in the Northwest.

The motivation behind the event came from the four captains who came together to honor their friend and hero, Trident Seafoods founder and chairman Chuck Bundrant, who was instrumental in helping them (and many others) get started in the fishing industry. Chuck lives an active life full of hope and optimism despite struggling with an atypical form of Parkinson's disease, progressive supranuclear palsy with parkinsonism (PSP).

As a result of the funds raised at this event, APDA is funding a research grant in honor of Chuck Bundrant. This grant has been awarded to Van Andel Institute in Grand Rapids, MI, to study a mutation in a protein called VPS35 that is known to cause Parkinson's in some families. APDA believes that further studying this protein can have implications for PSP, and funding this research is a wonderful way to honor Mr. Bundrant.

"The Bundrant family are longtime supporters of APDA since 1999, when a fellow fisherman was first diagnosed with PD. Seven years later in 2006, Chuck received his own diagnosis and their support has never wavered," states Jean Allenbach, Executive Director, APDA Northwest Chapter. "The "Captains for a CURE" event was a special way to bring together a very passionate group of people who wanted to make a real difference for the local Parkinson's community."

APDA is thankful to Fremont Mischief Distillery, Trident Seafoods, Cameron Catering, and the four captains for their generous support and partnership that helped make this event such a success.



RECENT WEBINAR HIGHLIGHTS

Parkinson's Experts Brought Directly to You

Your support makes it possible for APDA to be side-by-side with anyone facing the challenges of PD, no matter where they live, through robust online offerings. In particular, our *Spotlight on Parkinson's Disease* webinar series brings the best PD experts right to your home.



Curious about clinical trials?

For our most recent webinar, renowned neurologist Dr. David Standaert from the University of Alabama at Birmingham Movement Disorders Center (and Chairman of the APDA Scientific Advisory Board) presented *Spotlight On Clinical Trials: Opening the Door to New Treatments*, an information-packed discussion about the benefits of clinical trials for PD.

What about exercise?

For those who are struggling to work some exercise into their lives, we've got *Spotlight on Parkinson's Disease: Getting Motivated to Move!* Presented by Terry Ellis, PT, PhD, NCS, Boston University College of Health and Rehabilitation, Sargent College, this webinar can help people with PD, family members, and care partners understand the benefits of exercise and movement for people with PD.

All of our past webinars are archived for your convenience, including the two most recent webinars mentioned above. Visit www.apdaparkinson.org/webinars to check them out.

And if you want a heads up before the next live program, follow us on social media and check our website frequently to learn about upcoming webinars. If you participate in the live webinars, you can submit questions to the expert presenter in real time.

SPECIAL HONORS

Cathi-Ann Thomas MS, RN, CNRN, a dedicated, longtime member of the APDA family, won the prestigious Mary Ann Garrigan Award from the Theta at-Large Chapter of Sigma, a global nursing excellence organization. The award recognizes a Theta-at-Large member who has demonstrated excellence as a contemporary leader in nursing.



For almost 20 years, Cathi has been the Program Director of the Parkinson's Disease and Movement Disorder's Center at Boston University School of Medicine (BUSM). She has also been the Coordinator of the APDA Information & Referral Center in the Department of Neurology at BUSM since 1985. Cathi has devoted her career to caring for patients with movement disorders and teaching nurses and physicians about these conditions. At the same time, Cathi has been publishing peer reviewed articles in medical and nursing journals with her colleagues.

In addition to her administrative responsibilities, Cathi provides direct care to patients and through her practice she demonstrates the knowledge, skills, and attitude that are the hallmark of an excellent nurse. Many of the patients who are seen in the Center have been treated there for years. Cathi is not only familiar with their disease progression, but also with them as people. She combines caring and compassion with the encouragement they need to strive for the best quality of life and it is clear that she is their trusted care provider.

We are so proud of Cathi for this achievement and so thankful that she is such an important part of the APDA family.

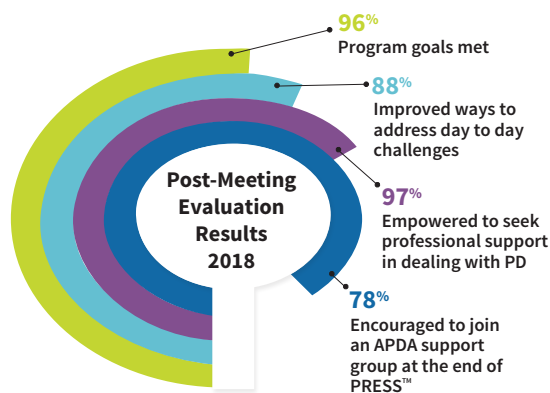
YOU HAVE PARKINSON'S...NOW WHAT?

To meet the unique needs of people diagnosed with PD within the last five years, **APDA created a specialized eight-week psychosocial support group program**, facilitated by a credentialed professional, called PRESS™ (Parkinson's Roadmap for Education & Support Services). After positive pilot programs in 2017, more than 45 programs have been offered in 16 states. We will continue to expand and offer this program to additional locations in 2020.

From participant evaluations we can see first-hand the **positive impact the program is having on the lives of people with PD and their families**, the stories of transformation, and the social connections that have formed. Many of these connections continue after the group has ended. There is no doubt that PRESS is truly making a difference in the lives of many people diagnosed with PD.

The data shows that a resounding **93.4% of participants felt they met the goals** they set at the beginning of the program and 86% experienced an improvement in the way they address day-to-day challenges of living with PD. We are encouraged by these results and use the feedback we receive to further improve and expand the PRESS program. Our hope is that more people can have the opportunity to participate in this program that provides critical support and education in the first five years of living with PD.

If you want to learn more, or to find out if there is a PRESS program near you, please contact Heather Grey at hgray@apdaparkinson.org.





Ask the **DOCTOR**

Q & A with Dr. Rebecca Gilbert

Q. My Dad had Parkinson's disease, and I just learned that my Grandma — his mother — also had PD. I do not currently have any symptoms of PD, but should I get genetic testing?

A. This is actually a very complicated question, as there are a number of genes that have been associated with PD, but most people with PD do not have one of the currently identified genetic mutations. If someone's father and paternal grandmother have PD, that makes it more likely that an identifiable genetic mutation is involved, although you might not have inherited it. In addition, most PD mutations have what is called reduced penetrance, which means that only a subset of people who inherit the mutation actually manifest the disease. Currently, it is not standard of care for someone who does not have any symptoms of PD to get genetic testing.

For someone who already has PD, the answer about whether to get genetic testing may be different. There are clinical trials that are ongoing now and others that are set to start which are investigating treatment of PD in people who carry specific mutations. Genetic testing of potential participants in the trials is therefore necessary. If one of these trials is successful in treating PD associated with a specific genetic mutation, that will of course change the whole landscape of genetic testing for PD and make it much more widespread.

Q. My mom has periods of getting really hot and sweaty until her clothes are wet. Is this a symptom of Parkinson's?

A. Yes, it can be. There are many non-motor symptoms of PD that are due to problems in the autonomic nervous system – this is the nervous system that controls body functions without us thinking about them – urination, control of blood pressure, sleep etc. One of these body functions is sweating and it can be dysregulated in some people with PD.

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.

Published quarterly by the American Parkinson Disease Association
135 Parkinson Ave., Staten Island, NY 10305 (800) 223-2732
apda@apdaparkinson.org | www.apdaparkinson.org
Chairman of the Board of Directors, Patrick McDermott
Chairman of the Scientific Advisory Board, David G. Standaert, MD, PhD
President & CEO, Leslie A. Chambers

American Parkinson Disease Association is exempt from federal income taxes under Section 501(c)(3) of the Internal Revenue Code.

What's happening at APDA



That's a wrap!

The 2019 APDA Optimism Walk season wrapped up on a high note with strong results! Some of the end-of-season highlights include our inaugural Cape Cod Optimism Walk with more than 200 walkers joining us for the very first time; our Greater St. Louis Optimism Walk which now in its third year boasted almost 800 registrations; our Iowa Optimism Walk which blew past its goal and raised almost \$67,000 – just to name a few. Planning for the 2020 Walks is underway with early events taking place in South Florida, Southern California, Hampton Roads, VA and Atlanta, GA. Visit www.apdaparkinson.org/optimism-walks for the full event schedule.

Need support?

Every PD journey is different, but one thing holds true for all – your experience can be positively impacted with the right support. Friends, family and coworkers can help, but a group of your peers – people who are impacted by PD, people who “get it,” can be invaluable. From sharing stories and exchanging ideas and helpful tips, to helping you navigate tricky situations or just sharing some laughs – a support group can help you live life to the fullest. Need help finding a PD support group? APDA is here for you – contact your local APDA Chapter or I&R Center or call us at **800-223-2732** today.