

Finding Hope Together: One Couple's Journey

In 61 years of marriage, Sue and Larry have faced their share of challenges — raising a daughter while working full time, Sue's return to school and career shift, Larry establishing a new business mid-career while battling prostate cancer, and losing their parents and Larry's beloved sister. With it all, the couple forged on with things they loved most: family celebrations, travel, boating, attendance at the Metropolitan Opera, and generally enjoying life. Then, eight years ago, what began as difficulty standing up and acute foot freeze soon proved to be something serious.

Facing adversity as a care partner

Larry's Parkinson's disease (PD) diagnosis was something they didn't see coming. With no experience as a care partner and a husband who was fast developing new medical needs, Sue knew she had to educate herself about PD and prepare for possible and

"APDA doesn't just talk the talk, it walks the walk in the tangible reinforcements it provides."

— Sue

probable changes to their lives.

While Larry was facing down his enormous challenges, Sue was confronting a complex set of difficulties of her own as a new care partner. *"We established a good routine and were managing well. Larry still had a good measure of autonomy, and I was able to continue my psychotherapy practice part time. Then, one day, while I was at the office, I was unable to reach Larry by phone. That was a turning point for me. I realized I no longer wanted to be that far from home and Larry for so many hours at a time. I wanted to take charge of Larry's care, to maximize quality time and enjoy the special intimacy of being his care partner. So I took the hard next step of closing my office and retiring from my practice."*

Sue turned to the American Parkinson Disease Association (APDA) — via an APDA Information & Referral Center Coordinator, Julie Garofalo, RN and an APDA monthly support group at Stony Brook Southampton Hospital — for advice, encouragement, camaraderie, and resources. Sue and Larry dealt with their losses, together and separately, with the help of family, counseling, and in Sue's words, *"the diverse, comprehensive, educational, and therapeutic programs offered by APDA."*

The journey to hope

With the help of APDA, Sue found the resources and the community that she and Larry needed to maintain a good quality of life. Importantly, they also



With the help of APDA, Sue and Larry are able to enjoy many good times.

found fun, friendships, and optimism through APDA and its local partner, the director of the Stony Brook Center for Parkinson's Disease, Sarah Cohen. With APDA's backing, Sarah tirelessly and creatively organizes support groups, exercise classes, and a host of innovative courses and experiences like "Paint for Parkinson's" at the Parrish Art Museum and "Sing Loud for PD," a choral group for people with PD and their care partners.

"SING is magic! What a joy to see people across the nation light up on Zoom weekly, as we used to in person prior to the pandemic. In short, APDA's engagement and support help make survival possible," said Sue.

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A MESSAGE FROM OUR CEO & PRESIDENT

Dear Friend,

During our 60th anniversary year, I am celebrating our community and its strength.



Since our founding, APDA has fought to bring hope and optimism to people affected by PD. It's thanks to your partnership that we've made great strides in advancing life-changing research and providing support and resources to people with PD and their families.

I hope that after reading this issue of *Insights*, you will feel as motivated as I am to continue our work together! Inside its pages, you will find inspiration in the PD journey of one couple and read more about how you can get involved for Parkinson's Disease Awareness Month this April.

As we commemorate this landmark year, please know that it is your compassion that enables us to keep moving forward. People like you inspire me every day.

Thank you so much,

A handwritten signature in black ink that reads "Leslie A. Chambers".

Leslie A. Chambers
President & CEO
American Parkinson Disease Association

60 YEARS OF PROGRESS — TOGETHER

One thing has been made perfectly clear in APDA's 60 years of delivering on our mission: It is the strength of our community and loyalty of our supporters that allow us to continue to bring hope, optimism, and invaluable resources to people with PD and their loved ones.

As the largest grassroots network dedicated to fighting PD, we know that the outlook for the future — for the advancement of crucial research, life-changing support programs, as well as our efforts to ensure that underserved communities receive the PD care they need — is all thanks to people like you.

Here are just a few of the achievements people like you have made possible:

- In the last year, **44,600 individuals were able to find a sense of community through support groups nationwide, while nearly 70,000 people participated in exercise classes designed to improve PD symptoms.**
- Since 1961, APDA has also been involved in many major PD scientific breakthroughs, investing nearly \$51 million in research over the years. During the 2020-2021 funding year alone, **your generosity has made it possible for APDA to grant more than \$1.4 million to the most promising clinicians and scientific projects.**
- APDA has made great strides in better understanding the needs of underserved communities with the Diversity in Parkinson's Disease Research Conference and many African American and Hispanic focus groups. In addition, we also **recently funded the first-of-its-kind Diversity in Parkinson's Disease Research grant.** Many APDA resources are available in Spanish to keep the Latinx PD community engaged and informed.

As we commemorate our 60th anniversary, know that we are more determined than ever to continue this fight. While there is still so much work to be done, with the support of people like you, APDA will continue to work tirelessly to provide the support, education, and research that will let everyone with PD live with hope and optimism.



GIVING MONTHLY MEANS DAILY SUPPORT

BECOME A MONTHLY DONOR TODAY AND SHOW YOUR SUPPORT FOR PEOPLE WITH PD.

✓ It's fast ✓ It's easy ✓ And you'll make a difference every month!

"My husband, Armando, has Parkinson's disease. It is important for us to do our part, and giving a gift monthly makes it easy. We are hopeful that, one day, there will be a cure." — Dircineia M.

By becoming a monthly donor, you're helping everyone impacted by PD live life to the fullest, every day of the year. When you join this community of dedicated supporters, you'll be among friends like Diane P., who is committed to making a difference in the fight against PD each month.

"It is a privilege for me to support APDA with a monthly donation because of all that they do to provide incredibly helpful resources and the latest information about Parkinson's disease." — Diane P.



She continues, *"It helped greatly when I was the*

caregiver for my husband who had Parkinson's, and perhaps even more now as I lead the Parkinson's Support Group in my community. Through my monthly gift, I am able to give back and offer hope to others."

Visit apdaparkinson.org/monthly or call **(800) 223-2732** to become a monthly donor today.

WHAT'S HAPPENING AT APDA



Meet the Researchers: Virtual Research Roundtable

In February, we hosted a virtual roundtable event (via Zoom), featuring four APDA-funded researchers. Missed it? Don't worry — you can find the recording in our Educational Video Library at apdaparkinson.org/videos and watch it anytime!



Virtual Events — Anywhere, for Anyone!

Visit apdaparkinson.org/events to check out APDA's new Virtual Events Calendar! No matter where you live, we've got you covered with educational programs, expert Q&A sessions, and an assortment of exercise and movement classes (yoga, tai chi, dance, and more). All programs are free to join.



Let's Watch, Then Walk!

On May 22, get moving with us for a **Virtual Optimism Walk!** The Virginia, Massachusetts, and Northwest Optimism Walks will join together for a fun and inspiring online celebration, and then we'll walk safely on our own, sharing photos and messages throughout the day using #OptimismWalk. Visit apdaparkinson.org/optimism-walks to register and learn more.

DID YOU KNOW that April is Parkinson's Disease Awareness Month?

Parkinson's Disease Awareness Month is the time of year when our community comes together to raise our voices — and raise awareness of PD. Join us! You can make a difference for your friends, neighbors, and loved ones impacted by PD by taking action in a host of ways:

- **Spread awareness about PD!** Share an article from apdaparkinson.org on your social media or through email — or even just start a conversation about PD with a friend or neighbor.
- **Follow APDA on social media** to stay updated on the latest PD news and information. Like, share, comment, and get to know the PD community.
- **Register for a Virtual Optimism Walk** and walk wherever you are! Join thousands of people across the nation and raise funds for people with PD. apdaparkinson.org/optimism-walks
- **Reach out to someone you know who has PD** or is personally affected by the disease to say hello, offer support, or just lend an ear.
- **Make a generous gift to APDA** and help people with PD live life to the fullest.



“ASK THE DOCTOR”

with Dr. Rebecca Gilbert



Q. I have a progressive problem with excessive fluid flowing in my nose, mouth, and throat glands. Can this be related to PD?

A. Yes, it can. *Sialorrhea* (too much saliva) is a well-recognized problem in PD. People with PD can have problems controlling saliva because the muscles of the oral cavity, face, and neck may have less control than normal, and there may be a delay in the person's ability to trigger a swallow. Sometimes, there is excess saliva in the mouth because swallowing is less frequent, due to the general slowness of movement that accompanies PD. The sialorrhea may be mild and result in a simple issue such as a wet pillow in the morning; or in some cases, it can be severe, leading to excessive drooling which may cause embarrassment and social isolation for some.

Rhinorrhea (runny nose) is a lesser-known PD problem. It is important to note that the rhinorrhea of PD is *not* associated with a viral infection or environmental allergies — or any other common cause of runny nose.

There are potential treatments for both of these problems, so do not wait to

talk to your doctor about them. Steps can be taken to lessen the impact of your symptoms.



Q. How do you begin to assemble a team of providers? My mother has medications but no advice on adjusting dosages, no therapies, etc.

A. There are many different types of providers that can make up a PD healthcare team — from physical and occupational therapists to social workers and neuropsychologists, and more. The most streamlined way to build your mother's healthcare team is to find a movement disorders specialist who can then refer you to other practitioners as needed. Do not hesitate to be proactive and ask her movement disorder specialist about this and let him/her know you very much want to round out her medical care with other specialists and support.

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Looking forward to a brighter future

By reaching out for help, the couple felt better equipped to handle most PD-related eventualities. “APDA provides the latest research, medical information, and updates on the various therapies and support available,” said Sue. “Because of APDA, we have found an invaluable cohort of brave and spirited people in our situation. APDA doesn't just talk the talk, it walks the walk in the tangible reinforcements it provides,” Sue continued. “If I were to encapsulate their approach to programming, I would say they focus on what we can do and not what we can't. It's wonderful.”

Thanks to supporters like you, APDA can provide the support, education, and research that help people like Sue and Larry live life to the fullest. Visit apdaparkinson.org to learn more about how you can help.

Larry walks Omaha Beach in Normandy, France, on the eve of the 75th anniversary of D-Day.



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

Published quarterly by the American Parkinson Disease Association,
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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 apdaparkinson.org/Renew.