

THE POWER OF PERSISTENCE: FRANK'S STORY

Frank began to experience his first symptoms of Parkinson's disease (PD) two decades ago. Only 39 years old at the time and in good physical shape, he dismissed it as nothing to worry about. But over time, more symptoms started to appear. "I realized this was something I could no longer ignore and sought out help," Frank explained.

After multiple doctor visits, tests, and second opinions, Frank was diagnosed with PD in 2007.

The diagnosis was hard to accept and led to anxiety and a fear of doing everyday things.

So Frank began working with a Movement Disorder Specialist, who helped him change the way he viewed his disease.

"I knew this was no way to live, so I decided to make a change," said Frank. "I learned to embrace my Parkinson's and kept my mind open to gain a better understanding of my symptoms and how to treat them."

With the help of the specialist, Frank developed a plan involving exercise, diet, and stress management to counteract his symptoms.

Through positive thinking, he was able to imagine himself walking without issue, which led him to be more active and less afraid.

When Frank experienced a significant setback that landed him in the ER, he didn't let it discourage him. Instead, he searched for a solution. He started talking with his doctor about deep brain stimulation (DBS) and as he learned more, he began to feel hope. **"While PD may attempt to limit me, I firmly believe that awareness and being patiently persistent in the pursuit of treatments allowed me to endure and find meaning, even in the face of adversity,"** Frank explained.

His persistence had paid off. Armed with a positive mindset and DBS, Frank regained his quality of life and ventured into creative outlets. Now, he pursues his passion for writing by sharing his poems, lyrics, and music. He even went on to release his own audiobook sharing his experience with PD.

We are thankful to Frank for sharing his story of hope and optimism.



"I knew this was no way to live, so I decided to **make a change.**"

— Frank

To read more inspiring stories like Frank's, visit apdaparkinson.org/Stories

A MESSAGE FROM OUR PRESIDENT & CEO



Dear Friend,

As we begin a new year, I wanted to tell you just how grateful I am for your loyal support. Because of your steadfast friendship, we can provide hope and strength to those impacted by PD.

In this issue of *Insights*, we talk about the important, yet sometimes overwhelming role of being a care partner for someone with PD and offer some helpful tips that can make things a bit easier. We also share the latest on diversity in PD research, and much more.

I am so proud of the work we are doing to provide life-changing support to the PD community — and I am excited to maintain this exciting momentum in the year ahead. Thank you, from the bottom of my heart, for your generosity.

Wishing you a happy and healthy year ahead,

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

Leslie A. Chambers
President & CEO
American Parkinson Disease Association



TOP TIPS FOR CARE PARTNERS

1 Expect the Unpredictable

PD is a progressive illness, meaning that the symptoms may worsen over time. However, this progression doesn't always happen in a predictable way. Educating yourself about the disease can help you be aware of what may come, but you should also know that unexpected changes may happen.

2 Get Organized

As a care partner, your responsibilities may include communicating with the healthcare team, coordinating treatments and appointments, and helping manage medications, exercise, nutrition, socializing, and more. Be sure to take advantage of various tools and tricks that can help keep you organized and efficient. Check out apdaparkinson.org/Tips for ideas.

3 Prepare for the Future

Because PD is a progressive disease and affects people at different stages of life, it's wise to be aware of what is to come. APDA has a series of blog posts entitled "*Planning for the What Ifs*" that can help you navigate some challenging topics such as finances, mental health challenges, advanced care, and more.

4 Take Care of Yourself

Caring for someone with a progressive illness can at times be physically and emotionally tiring. That's why it's so important for you to take good care of yourself. Consider joining a care partner support group, finding a few minutes to call a good friend, getting some fresh air, and exercising.

It can help to hear from other care partners who understand what you're going through. Visit apdaparkinson.org/CarePartner to learn more.

INNOVATIVE GRANT HELPS RESEARCHERS EXPLORE NEW HORIZONS

APDA recently hosted the *Diversity in Parkinson's Disease Research Roundtable* virtual program to highlight the exciting work we've been funding. We know that PD affects people of all ethnicities, ancestries, and geographies, yet for many years, research efforts failed to reflect that. Unfortunately, many clinical trials have not included people from varied backgrounds, which has led to results that may not be applicable to everyone with PD.

In 2019, APDA created its first-ever Diversity in Parkinson's Disease Research Grant, which is a special one-year grant to study the health inequities and/or differences among under-studied PD communities, across the spectrum of ethnicity, ancestry, geography, socioeconomic conditions, and gender. Six researchers who were awarded this unique grant presented their exciting work during a special program. *Visit APDA's YouTube channel to watch it at any time.*

Here are a few key learnings our researchers shared:

- ▶ There are pockets of increased incidence of PD among Black people in Atlanta. This may be due to environmental factors such as urban pollution or inadequate nutrition.
- ▶ Knowledge of the importance of rehabilitation in PD was lower in under-represented communities prior to diagnosis, but once explained, interest in rehabilitation was strong in all communities. It is therefore imperative for clinicians to explain the importance of rehabilitation to all people with PD.
- ▶ Community engagement studios are a valuable method of listening to and understanding the perspectives of community members and informing culturally appropriate and inclusive research. These studios are being employed to understand how to engage the Black community more fully in PD research.

APDA is committed to continuing this specialized grant in addition to the other critical research we fund each year.

For more information about the cutting-edge research your support helps make possible, visit apdaparkinson.org/Research.



WHAT'S HAPPENING AT APDA

APDA launches new Resource Library!



If you're looking for PD information, you can now find everything you need in one convenient place. No matter what PD topic you want to learn about, simply use the filters to find everything APDA has to offer – from videos to blog posts to printed publications. The new Resource Library is designed to help you live your best life with PD. Check it out today at apdaparkinson.org/Resources.

Will you be our Valentine?



On February 14-15, we are hosting the **APDA Virtual Parkinson's Conference** – a FREE two-day event designed to educate, empower, and engage you! It's perfect for people with PD, care partners, friends, family, and anyone who wants to learn more. We've lined up two days of great information, incredible speakers (including medical experts and people living with PD), fun and engaging activity sessions, lots of live Q&A, and so much more. Visit apdaparkinson.org/Engage2024 today to learn more and reserve your spot!





“ASK THE DOCTOR”

with Dr. Rebecca Gilbert

Q: I have trouble with my body temperature. I will be freezing, yet my wife doesn't even feel cool. Is this due to my Parkinson's disease?

Yes, poor temperature regulation can be a non-motor symptom of Parkinson's disease (PD). Our bodies are programmed to keep our internal temperature at a near-constant point, using very complex mechanisms. PD can unfortunately interfere with this regulation, and it can significantly affect quality of life when these mechanisms don't work well. Without proper temperature regulation, a person may feel that they are too hot or too cold or they may sweat too little or too much.

Although *dysregulation of temperature* is not as well-known as other non-motor symptoms in PD, such as constipation or sleep disorders, it is actually very common in people with PD. Unfortunately, there are no medications to treat this. For someone who is freezing when others are not, lifestyle modifications can help including:

- Wearing warm clothing to help conserve heat. Your base layer should be snug fitting and made of a moisture-wicking material (*not cotton*)
- Limiting time outdoors in cold temperatures

- Drinking hot beverages like tea
- Using hand warmers if gloves are not sufficient

Q: I have terrible constipation. Which medication works best?

Constipation is a very common non-motor symptom of PD, and thankfully, it is usually treatable. Start with lifestyle modifications, which include increasing your fluid intake and eating foods that contain fiber. Exercise is also vital to help the bowels move normally. If these steps are not enough, many different types of over-the-counter medications can help including:

- Stool softeners such as Colace
- Stimulants such as senna
- Osmotic laxatives such as Miralax
- Lubricants such as mineral oil

If the over the over-the-counter medications don't cut it, then talk with your doctor about trying a prescription medication for constipation.

Dr. Rebecca Gilbert is the Chief Mission 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.

UNLOCKING STRENGTH WITHIN: ADDRESSING THE EMOTIONAL SIDE OF PD

When living with Parkinson's disease (PD), it is common to focus on the physical symptoms of the disease. But it is important to know that life with PD can also present a unique set of emotional, cognitive, and social challenges that need care and attention too. However, many people tend to brush these symptoms off and don't mention them to their health care providers.

Knowing how important it is to care for one's whole self — both the physical and psychological aspects — APDA created a brand-new educational series called **Unlocking Strength Within: Strategies for Living with PD**. Throughout the series, we're covering important topics like navigating relationships, understanding and managing depression, coping with apathy, and more. Our expert speakers will also address managing grief and loss and help you identify resources for connection and support.



You can view recorded sessions on our YouTube channel and visit apdaparkinson.org/Events to see what's coming up next!



Published quarterly by the American Parkinson Disease Association, P.O. Box 61420, Staten Island, NY 10306 (800) 223-2732
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For more information, or to learn about the many ways you can support APDA, visit our website at apdaparkinson.org/Renew or call (800) 223-2732.