AMERICAN PARKINSON DISEASE ASSOCIATION

INSIGHTS

REAL STORIES. REAL STRENGTH. LIFE WITH PARKINSON'S.

We know that some of the most powerful insights about PD come from the people affected by it. Their perspectives can be incredibly valuable to those on a similar path and others who want to learn more about PD.

With this knowledge, we were inspired to create *Parkinson's Perspectives*, a new blog series dedicated to sharing the real stories and lived experiences of people impacted by PD. We'd love to introduce you to a few of them:

JEROME CHAMBERS has been living with PD symptoms for nearly a decade and was officially diagnosed in his early 40s.

Jerome shares what life was like prior to the PD diagnosis. *"I was working two jobs. I've always been high-energy and active,"* Jerome shares.

> **Life was busy and full. My family had always looked at me like I was Superman.**
>
> Jerome Chambers

"When a doctor first told me it was Parkinson's, I got angry," he explains. *"Accepting the diagnosis was hard."*

Over time, that initial shock and frustration gave way to a determination to understand what the diagnosis meant for his future. *"Accepting the diagnosis didn't mean giving up. It meant facing it head-on and figuring out how to keep moving forward."*

According to Jerome, his recent DBS surgery was life-changing, giving him back a sense of confidence and freedom. And he now lives by a new rule: "when you're feeling down, you get 24 hours to cry, pout, and kick your feet. After that, you get up and do something. That mindset changed everything for me. It shifted me from feeling like a victim of the disease to someone determined to live fully despite it."

DIANA WHITED has been living with PD symptoms for over a decade and was officially diagnosed in her mid 60s. As a mother of two and grandmother of five, she's committed to staying active and engaged.

"I am intentional about staying active and try to plan a mix of activities each week, including physical activities such as cardio, strength, balance, and gait exercises, as well as cognitive exercises and social connection," Diana shares.

Staying active isn't always easy, but Diana finds ways to modify her plans so she can keep doing what she loves. *"It's about striking a balance between what I want to do and what my body will allow me to do,"* she says.

To learn more about Jerome, Diana, and other inspiring people with PD, visit **apdaparkinson.org/Blog** and look for the *Parkinson's Perspectives* blog posts.

August is Make-A-Will Month

Creating a will is one of the most meaningful ways to care for the people and causes you love. Planning ahead brings peace of mind and ensures your wishes are clearly documented, helping protect your loved ones while creating a lasting impact for the future.

August is National Make-A-Will Month, making it the perfect time to create or update your will. At APDA, we understand the importance of planning ahead, which is why we're offering our community free access to Giving Docs, a secure online platform that helps you create a legally valid will and other important planning documents from the comfort of your home for free.

You do not need to include a gift to APDA to use this free resource, but if you do, your legacy can help fund research, provide education and support services, and strengthen the community for everyone impacted by Parkinson's disease.

A future without Parkinson's starts with planning for what matters most today. Begin your plans at **GivingDocs.com/APDA**

A MESSAGE FROM OUR PRESIDENT & CEO

Dear Friend,

As we move through the summer months, I'm reminded of the incredible progress being made in the PD community and the vital role supporters like you play in making that progress possible. Your generosity helps bring hope, education, and support to individuals and families affected by PD every day.

In this edition of ***Insights***, we explore how advocacy is driving meaningful action as the Advisory Council on Parkinson's Research, Care, and Services convenes its inaugural meeting. You'll also get an inside look at APDA's participation at the World Parkinson Congress 2026, which brought together the PD community from around the globe, you'll hear inspiring perspectives of people living with PD, get answers to top questions from Dr. Gilbert, and more.

Thank you for helping APDA continue to advance our mission and serve the PD community. Together, we are expanding access to resources, supporting groundbreaking research, and creating a future filled with greater hope and possibility.

Warm regards,

Leslie A. Chambers
President & CEO
American Parkinson Disease Association

NATIONAL PARKINSON'S ADVISORY COUNCIL FIRST MEETING SETS THE STAGE OF CHANGE

Progress is officially underway! The first meeting of the Advisory Council on Parkinson's Research, Care, and Services in June marked an important step forward in the national effort to prevent, diagnose, treat, and ultimately cure Parkinson's disease and related disorders. During the inaugural meeting, Council members were introduced, including three leaders affiliated with APDA, and federal agency representatives shared updates on existing Parkinson's programs and initiatives.

Council members discussed the initial work plan for the Council's annual report and national plan. Another focus of the meeting was the opportunity for the Parkinson's community to help shape the National Plan to End Parkinson's by identifying the most pressing gaps and opportunities in research, care, and services through public comment. Public comments from people living with Parkinson's, care partners, researchers, clinicians, and advocates will play a critical role in guiding the Council's recommendations for the National Plan – but act fast, the deadline to submit a public comment to inform the National Plan Strategy is August 22, 2026! The next Council meeting will take place on August 24 – you can view the meeting live at hhs.gov/live.

APDA will continue to keep the community informed with updates, key takeaways, and opportunities to engage with the Council as it moves forward with its work. To stay connected to all of APDA's advocacy and public policy efforts, be sure to sign up for APDA Advocacy Action Alerts at **apdaparkinson.org/advocacy**, as well as the National Institutes of Health National Plan to End Parkinson's listserv.

Have questions about getting involved in PD advocacy? Contact us at advocacy@apdaparkinson.org

APDA connects with the Global Parkinson's Community at **WPC 2026**

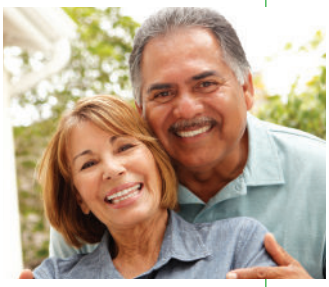
The APDA team was proud to join nearly 4,000 attendees from 62 countries at World Parkinson Congress (WPC), where people living with Parkinson's Disease (PD), care partners, researchers, and healthcare professionals came together to learn, connect, and inspire one another.

As a Double Platinum Champion Partner, APDA hosted a session on overcoming barriers to exercise, showcased nine research and program posters, and celebrated longtime partner Dr. M. Moral Mouradian, recipient of the WPC Distinguished Collaborative Research Award.

Most importantly, we were honored to meet and reconnect with members of the PD community from around the world. And we are grateful for the opportunity to let more and more people know that APDA is here for them every step of the way.

If you're feeling a bit left out and wish you had participated, visit **wpc2026.org** and start planning now to join us for WPC 2029 in Quebec City!

APDA LAUNCHES NEW SPANISH-LANGUAGE WEBSITE



We're excited to announce the launch of our new Spanish-language website, expanding access to trusted PD information and resources for Spanish-speaking individuals, families, and care partners.

The site offers educational content about PD, treatment options, symptom management, caregiving, and support services, all presented in Spanish to help reduce language barriers and improve access to reliable information. Visitors can also learn about APDA programs, events, and resources available in their communities.

This important step reflects APDA's ongoing commitment to serving the diverse PD community and ensuring that more people can access the knowledge and support they need throughout their journey.

Visit **apdaparkinson.org/espanol** to explore the new site and share it with anyone who may benefit from these valuable Spanish-language resources.

WHAT'S HAPPENING AT APDA

Have you seen it yet?

If you haven't already seen **APDA's new "Do What You Love" public service announcement**, watch it today! It celebrates the resilience, strength, and optimism of people with PD and encourages them to keep doing the things they love, even if they have to do them differently. We hope the PSA moves you, inspires you, and helps you or a loved one feel seen and celebrated. We encourage you to share it with your personal PD community. The more people who know that APDA is here to help, the better! (The PSA is available in both English and Spanish.) Visit **apdaparkinson.org/PSA** to watch now!

Save the Date!

APDA's 4th annual *Virtual Parkinson's Conference* will take place on September 16-17. Mark your calendars now and get ready for two great days of impactful discussions, presentations, hot topics, thoughtful movement and mindfulness sessions, and so much more. Registration will open soon, so stay tuned!

"ASK THE DOCTOR"

with Dr. Rebecca Gilbert

Q. How safe is knee replacement surgery for people with Parkinson's?

A. Many people with PD can undergo successful orthopedic surgeries. However, there are additional challenges that can affect someone with PD who is having surgery, and the best way to ensure an uneventful surgery and hospital stay is to anticipate these potential issues and strategize on how to avoid them. It is therefore recommended to have your neurologist speak to your surgeon and anesthesiologist prior to the surgery.

Your neurologist can emphasize the importance of maintaining your PD medication schedule as much as possible, as well as the importance of avoiding particular medications during the hospitalization that can adversely affect people with PD. Other issues such as management of blood pressure fluctuations, post-surgical delirium, urinary dysfunction, swallow dysfunction, and constipation can be discussed as well. These issues are reviewed in more detail at **apdaparkinson.org/Surgery**.

Q. When I walk, sometimes I feel like I'm not able to move my feet because they are stuck to floor. How can I get them unstuck?

A. This sounds like you are experiencing *freezing of gait*, an abnormal gait pattern in PD where the person takes tiny steps in place and is not able to generate a big step forward. The best approach to getting out of a freeze is a technique called cueing, or using an external stimulus to restart your normal gait pattern. The cue could be visual (e.g. a line on the floor that the person steps over), auditory (e.g. a rhythmic beat that the person marches to), or tactile (e.g. shifting weight from side to side). A physical therapist can teach you these strategies, so it would be worthwhile to ask your neurologist for a referral to physical therapy.

You can read more about freezing of gait here: **apdaparkinson.org/Gait**.

Q. My neurologist wants me to have a DaTscan. Should I be concerned about the risks of this test, especially as it relates to my thyroid?

A. DaTscan is an imaging test that uses a nuclear tracer to visualize the dopamine circuitry in the brain. This tracer can also be absorbed by the thyroid, which could cause damage to the thyroid. However, to protect the thyroid, a thyroid-blocking medication is given prior to injection of the tracer. When performed this way, the DaTscan test does not pose any significant danger to the thyroid.

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.

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, visit our website at apdaparkinson.org/Renewal or call (800) 223-2732.