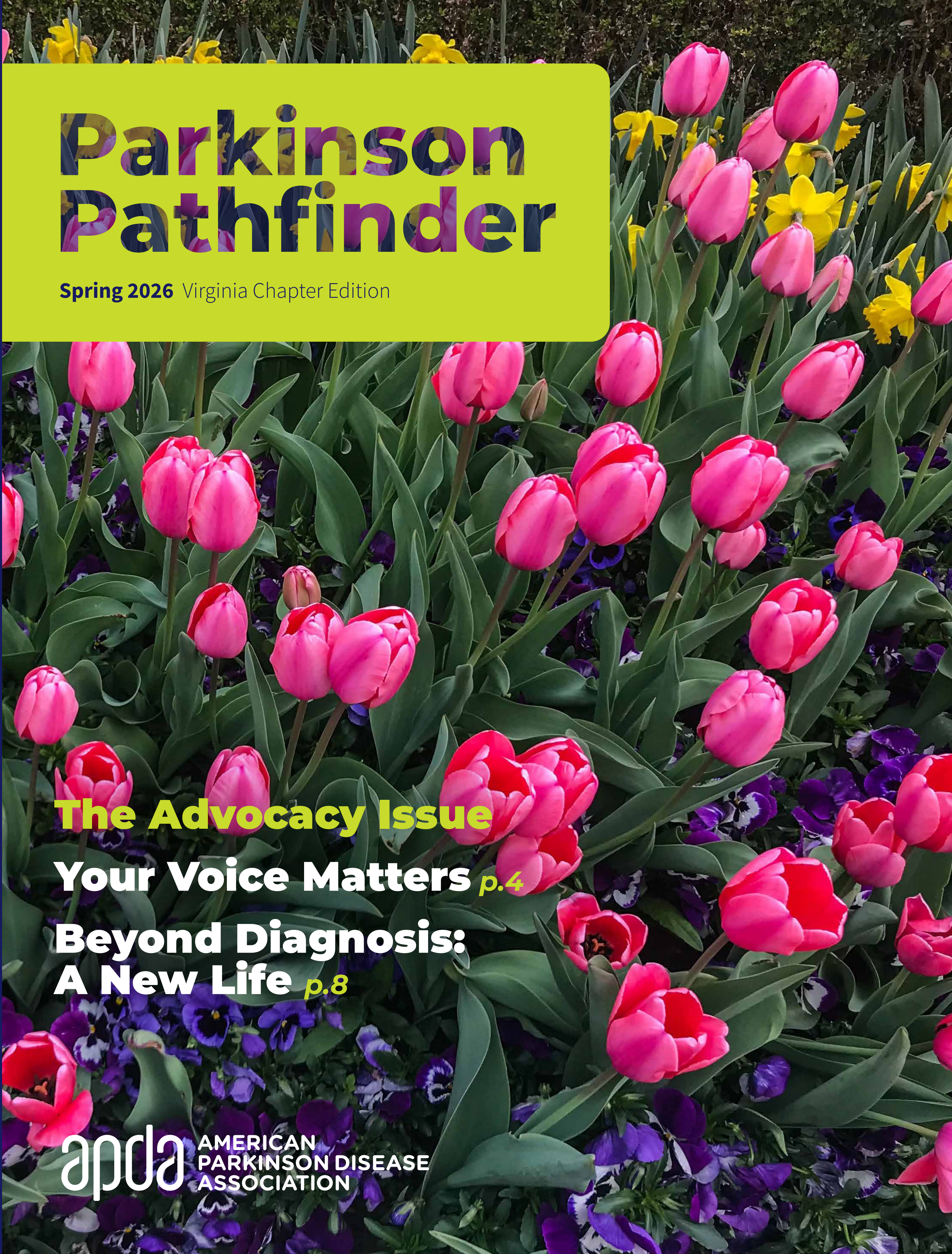
Parkinson Pathfinder

Spring 2026 Virginia Chapter Edition



The Advocacy Issue

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AMERICAN PARKINSON DISEASE ASSOCIATION

Spring 2026 Virginia Chapter Edition

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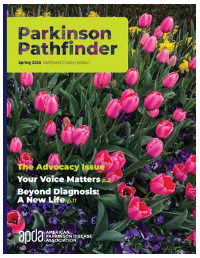

COVER PHOTO

"Tulips in Krems, Austria" by **Jim Blake**

Jim lives in Forest Lake, MN, and has been living with Parkinson's since 2020. He regularly attends Rock Steady Boxing and Ping Pong for Parkinson's, and also enjoys whitewater kayaking, slalom waterskiing, and hiking. One of Jim's favorite hobbies is photography.

APDA'S MISSION

Every day, we provide the support, education, research, and community that will help everyone impacted by Parkinson's disease live life to the fullest.

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

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Whether your advocacy takes place in a conversation, a support group, a research setting, or out in the wider world, it matters.

April is Parkinson’s Awareness Month, a time to deepen understanding of Parkinson’s disease and to shine a light on the experiences of the millions of people and families affected by it. It is also a meaningful opportunity to talk about advocacy — not only in the public sense, but in the everyday choices people make to speak up, seek support, share their stories, and help others feel less alone.

In many ways, advocacy begins with awareness. The more people understand Parkinson’s, the more compassion, support, and progress become possible. Advocacy can look like participating in research, contacting legislators, educating your community, or raising your voice for better care and resources. It can also be quieter and deeply personal — asking questions at a doctor’s appointment, encouraging a loved one, or choosing to share your experience so someone else feels seen.

In this issue, you’ll read about advocacy in action through stories of individuals helping to shape the future of Parkinson’s through clinical trials and policy efforts. You’ll also find updates on APDA’s broader advocacy work, along with stories that reflect the strength, creativity, and resilience of this community. Together, these articles remind us that advocacy is not just about systems and large-scale change. It is also about connection, courage, and hope.

We’ve also included our Creative Contributions section, where we celebrate the talents and perspectives of people in the Parkinson’s community. Whether through art, writing, photography, music, or another form of expression, these contributions offer another powerful reminder that every voice matters. If you like to contribute to a future edition, please email me at lbadran@apdaparkinson.org.

As you read this issue, I hope you feel informed, encouraged, and inspired. Whether your advocacy takes place in a conversation, a support group, a research setting, or out in the wider world, it matters. Every voice adds to the momentum. Every story helps build understanding. And together, we can continue creating a future filled with more awareness, more support, and more hope.

With hope and gratitude,

Lianna Badran

Lianna Badran
Regional Director, Marketing & Communications

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APDA Advocacy Action Update

Since its inception in August 2025, the APDA Department of Public Policy and Advocacy has been pursuing advocacy efforts that elevate the profile of Parkinson's disease and securing commitments for enhanced research funding that will improve the lives of those living with Parkinson's. From co-hosting the Parkinson's Policy Forum to advocating for the seating of the National Parkinson's Plan Advisory Council on Parkinson's Research, Care, and Services, and securing key appropriations and regulatory wins, the team is working hard on behalf of people living with Parkinson's disease.

The National Parkinson's Plan

In January, APDA collaborated with the Michael J. Fox Foundation and the Parkinson's Foundation on a multi-organization sign-on letter led by that urged the Department of Health and Human Services (HHS) to seat the National Parkinson's Plan Advisory Council on Parkinson's Research, Care, and Services. This was followed by a Congressional Sign-On letter led by Congressional Champions Gus Bilirakis, R-FL, and Paul Tonko, D-NY. Shortly after the letters were received, invitations were issued to Advisory Council participants. We anticipate that HHS will make an official announcement regarding the seating of the Advisory Council this spring.

Momentum for the work associated with the Council continued with the passage of the FY2026 (Fiscal Year 2026) federal spending package, which was signed into law on February 3, 2026. The spending package included a $5 million commitment for the Advisory Council's work which includes the evaluation and prioritization of federally funded initiatives in Parkinson's research, prevention, diagnosis, treatment, clinical care, and institutional-, home-, and community-based programs. The Advisory Council will also identify ways to reduce the financial burden of Parkinson's disease, improve health outcomes and quality of care, and address environmental triggers and underlying factors contributing to Parkinson's disease.

◀

Participants from the 2026 Parkinson's Policy Forum in Washington, DC

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From left to right: APDA's Public Policy and Advocacy Team, Emma R. Plourde, Anne Hubbard, and Sharlene Bagga-Taves in front of the U.S. Capitol in Washington, DC.

The team joined the Michael J. Fox Foundation, the Parkinson's Foundation, and the PMD Alliance as hosts for the 2026 Parkinson's Policy Forum, held March 15-18.

FY2026 Appropriations Wins

In addition to securing the $5 million commitment for the Advisory Council. The FY 2026 spending package also reinstated the Congressional Directed Medical Research Program (CDMRP) Parkinson's Research Program (PRP) with a $16 million commitment. Previously, the program had been cut as part of the Full-Year Continuing Appropriations and Extensions Act of 2025. The FY2026 funding package reinstates the program with a $16M commitment. The PRP was established to support high-impact Parkinson's research that alters disease progression, improves disease symptoms, and develops treatments that benefit Service Members and their families, Veterans, and the general public.

The FY2026 federal spending package also included $5 million for the National Neurological Conditions Surveillance System (NNCSS). In 2016, as part of the 21st Century Cures Act, Congress authorized the Centers for Disease Control (CDC) to initiate development of the National Neurological Conditions Surveillance System. The NNCSS is evaluating a range of data sources and analytic methods to develop an efficient approach for collecting and synthesizing surveillance data that will enhance understanding of neurological disorders and facilitate further research. The FY2026 $5 million appropriation is allocated for additional surveillance, epidemiology, and informatics analysis to be used for both Parkinson's disease and Multiple Sclerosis.

Finally, the November 2025 continuing resolution included $80 million for the Veteran Affairs (VA) Administration's Neurology Centers of Excellence – $16 million of which is designated for the VA's six Parkinson's Disease Research, Education, and Clinical Centers (PADRECCs), a $1.5 million increase over FY2025 funding. The PADRECCs were created in 2001 to serve the estimated 110,000 Veterans affected by PD by providing state-of-the-art clinical care, education, research, and national outreach and advocacy. They assist Veterans in effectively managing PD and other movement disorders by way of VA pharmacy benefits, physical, occupational, and speech therapies, medical equipment, surgical services, and other valuable resources.

Secure Medicare Coverage for External Infusion Pumps

In the fall of 2025, APDA advocated for Medicare coverage of external infusion pumps for transdermal delivery of carbidopa-levodopa. Due to our advocacy, the Centers for Medicare & Medicaid Services (CMS) issued a local coverage determination establishing coverage for the pumps, effective January 1, 2026.

Removal of DBS from WIsER Model

APDA advocated for the removal of Deep Brain Stimulation (DBS) from the Wasteful and Inappropriate Service Reduction (WISeR) model. The WISeR model is a Centers for Medicare & Medicaid Services (CMS) Innovation Center initiative designed to reduce unnecessary, low-value care in Medicare, which would have applied to six states over a six-year period. The initiative would have unnecessarily delayed access to DBS. ■

If you are interested in learning more about PD advocacy news and ways you can get involved, please visit apdaparkinson.org/advocacy.

Your Voice Matters:

How Patient Advocacy is Reshaping Research and Policy

Advocacy Through **Parkinson's Clinical Trials**

With **Barbara Sarhan, PWP**

Q: What type of trial did you join, and what drew you to it?

A: I have participated in several clinical trials supporting Parkinson's disease research. These include drug and behavioral programs.

- **Drugs.** The first was through Oregon Health & Science University (OHSU) in Portland. I qualified because this was before I had started taking any medications for PD. I wanted to participate to further research and because I felt safe at OHSU, where I receive neurological care.

  The second drug-related trial is the Topaz trial. This research focuses on bone-related issues in people with Parkinson's at the University of California, San Francisco.

- **Behavioral.** The most fun program was doing Improv for Parkinson's patients on Zoom. I had taken an Improv class at my local Senior Center once before, and when this came up, I was just very curious as to how that could help with PD. I am also in an ongoing VA trial. This is the CLIMB trial that is gathering data for researchers.

  Their participants are people with PD (whether you are a veteran or not) and amputees. This is a once-a-year visit to the VA in Seattle. They conduct paper surveys and the usual finger-tapping type of physical examinations. Then I get hooked up to about a dozen sensors, from head to toe, and they film me as I walk around while they direct.

- **Genetic.** I've participated in the Parkinson's Foundation PDGeneration testing and had genetic counseling. I've also done the Michael J Fox Foundation (MJFF) 23andMe testing. That's easy to do from home.

- **Online surveys** on various things come my way, and I always try to do those. There are those that come regularly from the MJFF. I also did their "smell test".

- I've recently been recruited for some **advanced testing** in MJFF's Parkinson's Progression Markers Initiative (PPMI) study. I'll be going to Phoenix for some heavy-duty testing at Banner Health.

Q: What did participation look like, and how did you fit it into daily life?

A: Obviously, the effort required to participate varies by program type.

- Improv was online on Zoom with people from around the country and even someone in England. That takes a smartphone, or better yet, a computer with a camera and microphone. This study was conducted by PhD student Robert Cochrane at the University of Nevada, Las Vegas, whose father has Parkinson's. Robert recounts this journey in his book *Acceptance*, and yes, I have an autographed copy.

- For the Topaz study, a nurse came to my home, did a bit of examination (especially checking my jaw), and then I got an infusion with the drug that is being tested. I also had to take Vitamin D for a while (which they provided). Now, I just answer a survey about every six months about whether I've taken certain types of medications or broken any bones.

- For the VA trial, I drive from Olympia to the VA in Seattle once a year. They do paper surveys that are part of checking my status on the Unified Parkinson's Disease Rating Scale (UPDRS) to assess my Parkinson's progression. Then I get hooked up with the sensors. It is sort of weird, but not a problem. They have a camera set up to film me as I walk up and down the designated line at various speeds and while I turn. There is also a part where they film your balance in various stances, with eyes open or closed. This study will last for five years.
- The MJFF smell test was fun. You contact them, and they send you the kit to use. You scratch off a part of the booklet and figure out which of the four scent choices you are smelling. There are 40 samples. When you've done that, you go online and record your answers.
- The drug test at OHSU was the most complex study so far. It was testing a tweaked GLP-1 medication that I injected into my abdomen weekly for about 36 weeks. I had to go to Portland several times for testing. This included cognitive and mood tests, blood draws, and an EKG. I also did two DaTScans and MRIs. This was a double-blind study, so I didn't know until afterward that I had been on the placebo rather than the actual drug being tested. By the way, the drug they hoped would slow progression did not work. Oh well. How many times did Edison try to find what to use to make a light bulb work?
- The PPMI study in Phoenix will include all the usual cognitive, mood, physical, and laboratory tests. The lumbar punch (spinal tap) they'll do had me hesitate, but I looked into that and said why not. This is also a long-term study and could include trips to Phoenix over five years.

Q: Was travel, time, or costs a barrier, and what support helped?

A: I haven't really found any barriers to participating in trials. I do think that travel can be a major barrier to participation, just as it can be to get to your medical appointments. Maybe researchers can find more ways to do things virtually or help arrange for travel so more people can find it easier to participate. I recently learned that I qualified for the PPMI study in Phoenix, and the program will cover travel costs and make the arrangements. Maybe I can add a day or two on my own dime and try a hot air balloon ride! The dates are being worked out, but I should be in Phoenix sometime in April.

Q: What surprised you—either in a good way or a hard way?

A: One thing that surprised me was realizing that the Unified Parkinson's Disease Rating Scale (UPDRS) was used in research and at my neurology appointments. In research, it's formalized. When I had an appointment with my neurologist, a week or two after doing the VA study, I realized she was covering much of the same ground. It was just a much more fluid and subtle process in my appointment.

Q: How did participating change your outlook on PD research or your own care?

A: I think a good appointment will cover more than some finger tapping and a walk down the hall to observe your gait. Before your appointment, also consider your non-motor symptoms and ensure you address all that is most important to you. I have also gone back to the information I gathered when first diagnosed in 2020. When a new symptom came up, I wondered why. I've taken another look at the side effects of my medications. Surprise, my medications could be affecting my B vitamin levels. I got my primary care provider to test me for that- yep, I'm now low on B vitamins and taking a supplement. That has perked up my energy level. So, I thank whoever has done this research in the past, and I hope to pay it forward in some way. I'm still working on implementing all the exercises I know I should be doing based on other studies.

Q: What would you tell someone considering a trial but worried about a placebo, safety, or being a "guinea pig"?

A: As you can see, you can participate in research at the level you are comfortable with, sometimes never even leaving your recliner. It can be fun, but it is always interesting. You often are given some compensation for your time, such as a gift card or free genetic counseling. There's a variety of trials or studies underway. Some require little effort or risk, while others are more complicated. Just do what you are comfortable doing. Explore the sites that list trials. Add your name to the state registry of Parkinson's patients, and you may get invitations to participate in a trial where researchers are looking to recruit participants. You pick and choose. ■

About Barbara: I have always enjoyed learning and helping others to succeed. Being in clinical studies supports those interests. For me, the Serenity Prayer doesn't work… like Angela Davis, I want to change the things I can't accept. I'm a retired IRS employee and have also worked in public welfare, libraries, and more. I'm 79, single, don't have kids, and recently returned to full-time work. My hobbies are birding, genealogy, reading, and being lazy.

Advocacy Through
Parkinson's Policy

With **Amy Lavallee, PWP**

Q: What specific Parkinson's-related policy or issue did you advocate for, and why did it matter to you personally?

A: I advocated for the National Plan to End Parkinson's (now the National Parkinson's Project). This plan coordinates multiple agencies in a shared effort to prevent, treat, and cure Parkinson's. This Plan was passed in 2024 and has sat idle since. So, just this past year, I joined a coalition of delegates from all states to advocate for the next stages of this Plan. In addition, we asked for a ban on Paraquat, a chemical known to be linked to Parkinson's. By supporting this Project, we are creating a roadmap for all of us to follow in a united fight against PD.

Personally, I wanted to share my story. Inform them that this is the fastest-growing neurological disease, and there are more and more people my age getting diagnosed. Our hope and future rest on the advancement of science and technology, which will give us better medications and medical devices, and this can only happen if we invest in research.

Q: Where did you focus your efforts (city/state/federal), and how did you choose that target?

A: I am currently focusing my efforts on the federal level. I believe that if we can create the change at that level, it will filter down to the local governments. I think the important thing is that all of our PD communities and agencies stay together with a cohesive message

Q: Tell us about one meeting with a lawmaker or staffer that moved the needle—what did you share and how did they respond?

A: Our group shared some very powerful, emotional stories, and all the staffers responded positively to our message. There was one young woman who was reaching for the tissue box. I think most were surprised to learn that I am a person with Parkinson's, but in this case, I think she could relate to my story as a young mom just getting started on her adult life. I shared how I was diagnosed at the age of 34, not long after having my third child. How this diagnosis derailed my future life, career, and role as a mother.

Another powerful impact our testimonies had was the role of paraquat. Many of the staffers were unaware of what it was and its role in Parkinson's. They were even more surprised to learn that it is banned in most countries, yet we still use it. All of the aides were thankful to hear our stories and pass them on to the lawmakers.

Q: Which data or stories proved most persuasive (wait times, prior auth barriers, telehealth access, out-of-pocket costs, caregiver needs, research funding, etc.)?

A: We would start our sessions with a brief overview of Parkinson's and its impact on the country. Sharing that 90,000 people a year are diagnosed with Parkinson's, the size of a football stadium, and that the economic burden of this disease is $52 Billion, was a very sobering fact. Then, hearing our stories and looking at the diversity of our group helped them see that this disease affects everyone.

Investing in research and access to care is a NEED. Parkinson's rates are rising faster than Alzheimer's, and there is currently no way to stop it. There is a shortage of Movement Disorder Specialists; the aides were surprised to hear that it took years for some to get diagnosed, that some patients wait 9+ months to be seen, and some have to travel hours.

Q: What coalition or partnerships (APDA chapter, clinicians, caregivers) helped you gain traction?

A: The Partnership of MJFF and ADPA has made advocacy easier. MJFF laid out the groundwork at the national level, and the ADPA brought it to local communities. They provide us with information and data to incorporate into our personal stories. They teach us how to be productive with our meeting time and how to make persuasive arguments. They arrange meetings (if they are in person) or provide scripts for letters and phone calls. They take a lot of the work out of it for us, so we can focus on sharing the needs of the Parkinson's community.

> **"Advocacy gives me a purpose."**
>
> **AMY LAVALLEE**

Q: What was the outcome so far, and what's the next step you're working toward?

A: The outcome in 2024 was amazing; we had passed the National Plan to end Parkinson's. I was elated. I cried tears of joy that day; in that moment, it felt like all of the hard work had mattered. Since then, it has been sitting idle, so the next step is to keep pushing for the implementation of this Project by getting the advisory council seated and increasing the funding.

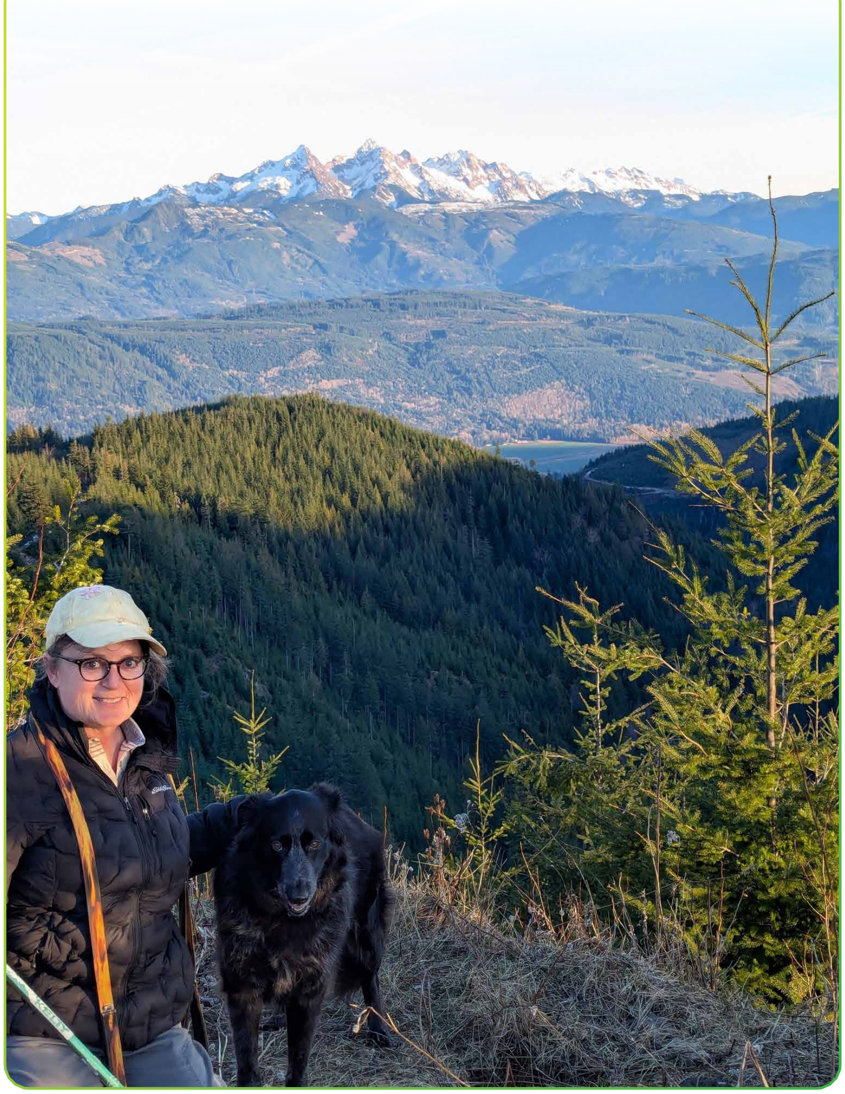
Q: How has advocacy affected your own PD journey—emotionally, practically, or in your care access?

A: When you are diagnosed with Parkinson's, you feel out of control. There is no stopping this disease, so I looked for ways to turn this into something positive. Advocacy was one of the ways. I feel empowered, and even though my life took an unexpected detour, I've found a meaningful way to be useful. I want my children to see me as a warrior, to learn that no matter what is thrown at you in life, you have a choice in how you respond. Advocacy gives me a purpose.

Q: What's your advice for someone who wants to start but feels intimidated?

A: Getting into advocacy work can be overwhelming; you don't know where to start or what to ask for. Start by writing letters or making phone calls, as I mentioned, the scripts have already been written for you. Use the template and personalize it. Sign up for emails and notifications from the organizations that support PD advocacy, and answer when they ask for help. Decide on what issue is most important to you and at what level. You may feel like your voice isn't loud enough, but collectively our voices will be heard.

About Amy: Amy Lavallee is a Parkinson's advocate and Community Liaison who brings ten years of lived experience with Parkinson's to her work. She connects the community with education, research, and wellness resources, and is committed to raising awareness and advocating for the needs of people affected by Parkinson's. Amy has been involved in policy advocacy for the past six years.



Beyond Diagnosis:

How My Dog's Unexpected Service Rewired My Life

An Interview with **Laurel Saville**

To learn about Local Parkinson's support groups and other community activities in Virginia, visit our website, https://www.apdaparkinson.org/community/virginia/

When Parkinson's upends life, saying "yes" to anything new can feel impossible—especially when you're grieving, exhausted, and unsure what your body will do next. In this interview, award-winning author and accidental dog behaviorist Laurel Saville shares how a foster "yes" at a noisy shelter became the start of an unexpected partnership with Willow, a dog who began inventing her own quiet ways of helping—no formal service training required.

Through Laurel's candid, often funny reflections on REM sleep behavior disorder, living alone, and navigating symptoms in public, you'll see how companionship can meet you right where you are: not by fixing Parkinson's, but by helping you feel understood, useful, and connected again.

Saying Yes When Life Is Falling Apart

When you first met Willow at the shelter, you were grieving multiple losses and newly diagnosed with young-onset Parkinson's. What made you say yes to fostering her at a time when you felt so depleted, and how might that moment feel familiar to others with Parkinson's who are scared to commit to anything new?

LS: It's so easy to find reasons and excuses to say "no" to things in life. It's even easier when you have PD! Because symptoms can affect basically any part or system in your body, it's tempting to tally up your losses and fret about innumerable possible futures, all of them grim.

I try to follow the wisdom of two clichés: comparison is the thief of happiness, and all we really have is the present moment. So, I don't compare who I am today with who I was pre-PD or who I might be without PD. And I look for reasons and ways to say yes to whatever good, fun, and interesting things life throws in my path.

So, in that moment of standing at Willow's kennel door, looking into expectant face, being bombarded by frantic dog barks pinging off the shelter's concrete surroundings, when my thoughts threatened to swerve off into "I can't because I'm less than I was," I steered them back toward all the things I could offer this adorable puppy with the goofy demeanor and the old soul eyes.

In spite of everything I'd lost, I still had so much that she needed: a quiet, country home, an acre of fenced yard, a few dog-savvy ducks and a cat to play with, lots of long walks in the woods, access to plenty of other dogs, and, well, me. I hadn't lost my ability to share and to care, and maybe even to love.

Plus, when you're at a moment in life when all you want to do is lock the doors, turn off the phone, climb under the sheets, and cry, having a silly puppy around is pretty wonderful medicine for pulling you out of that dark space and back into the light.

Being Understood When Your Body Won't Cooperate

You describe Parkinson's as a 'software problem' and Willow as someone who learned to read your glitches—especially during REM sleep behavior disorder and nightmares. How does it feel, as a person with Parkinson's, to be understood so precisely by your dog when your own body and even other people don't always 'get' what's happening?

LS: Dogs have several qualities that make them uniquely and naturally suited to the role of service, especially when it comes to health issues. Of course, they have those incredible noses that are hundreds of times better than ours and more accurate than any piece of machinery we've ever made to detect odors. Dog noses also work differently from ours, allowing them to extract much more information from smells then we or our machinery can. And dogs are more attuned to and guided by their sense of smell then we, vision-oriented primates are.

In addition, dogs have transferred their hard-wired social behavior to the humans in their lives and are dependent on these humans for everything from food to access to the outdoors. They spend all their moments with us watching and anticipating what we do … especially when it involves movement toward the things they love, like food and open doors!

Dogs excel at observing, noticing, enquiring, and validating our behavior. Simply getting up and following us out of a room, pricking up their ears at the sound of our voices, and wagging their tails when we reach for the leash or a packet of cheese is incredibly validating and rewarding to us. Humans are, or have become, pretty terrible at witnessing, listening to, and supporting each other. Which is why we are so often blind to changes in other people that signal they are in distress or ill health.

Dogs know us deeply, so they notice when we change. Dogs also often go to great lengths to let us know that they've noticed. There are endless stories of dogs doing things like persistently nudging a body part that is later revealed to be cancerous, or periodically yet frantically licking the mouth and nose of a child who is later diagnosed with diabetes. Willow is special, but not unique.

Especially as someone who lives alone, I really cannot adequately express my gratitude for having her beside me as I go off into what can be a very scary sleep state, knowing she'll notice and wake me up before things get too bad. I often wonder how many dogs try to tell their human that something is wrong, but eventually give up when their human doesn't respond, because it's never occurred to them that their dog might have something important to say. It's a sad loss for both dog and human.

DID YOU KNOW?

Companion animals reduce anxiety and depression in people with Parkinson's and also increase physical activity and social engagement.

Giving Care While Needing Care

Many people with Parkinson's worry about becoming a burden. You write, 'It's not enough to be loved; I want to be loving.' In what concrete ways has caring for Willow—feeding her, training her, taking her on adventures—changed how you see your own value, even on days when symptoms are loud, and energy is low?

LS: As all the studies and our own experience tell us, caring for someone or something other than yourself is critical to mental health and happiness. I'm single, live alone, have no kids, and have very few family members, none of whom are close by. I have plenty of human pals, but Willow is really my primary relationship. And honestly, plenty of my human friends get uncomfortable when various symptoms appear. I don't blame them, but it does mean that now I'm concerned about them and my body.

The great thing about having Willow — or any dog — as my constant companion is that she doesn't care about my symptoms. If I slow down on a hike, it doesn't matter because she's not trying to get to the top or checking her watch. If I take a long and awkward time making her dinner, she doesn't try to take over or hurry me up. If I'm having an off day, she's content to curl up on the sofa nearby and bliss out on whatever I can offer in the way of chest and belly scratches. So, caring for her gives me all the pleasures and benefits, with none of the emotional baggage and expectations that caring for humans often entails.

From Isolation to Everyday Community

Willow pulls you into the world—agility, truffle hunting, walks, classes, even just being out in the neighborhood. For someone with Parkinson's who feels isolated or embarrassed by symptoms, what kinds of small, dog-driven (or routine-driven) moments have helped you feel part of a community again?

LS: Willow is a special dog, but any dog will help you stay connected to the world. Getting her out for walks keeps me in nature and chatting with strangers. Friends with dogs want to visit and join us on our truffle hunts. Getting her to the groomer, or the vet, or out of town when it's fireworks week here where I live, puts things on my calendar. People who might be reluctant to approach a stranger, especially one who walks in a weird way, are put more at ease by the beautiful and friendly black dog at my side.

Redefining What Love Looks Like with Parkinson's

You describe Willow inventing her own 'service dog' behaviors—lying across you, wedging herself between you and the edge of the bed—without formal training. What has this taught you about what love looks like when you live with Parkinson's: the kind of love that fits around meds, sleep problems, and an unpredictable body?

> **"It's not enough to be loved; I want to be loving."**
>
> **LAUREL SAVILLE**

LS: I don't know how much Willow truly knows about what's happening to me when an REM Sleep Behavior Disorder (RBD) episode starts up, but she clearly knows something is wrong. The fact that she has not acclimated to my nighttime outbursts, as common as they've become over the years, shows that she understands the difference between "normal" and "not normal" behavior from me.

Fortunately for both of us, my RBD doesn't seem to stress her out. She just calmly and persistently does whatever it takes to break me out of the grip of the dream state. Often, this is no easy task. A nightmare tends to jolt me awake, but my fun RBD episodes are just as vivid as the icky dreams and I'm much more reluctant to pull myself out of a dream where I'm flying, superhero style, or gracefully skating at high speed down a winding river in a evergreen forest, or being romanced by some Hollywood heartthrob, or having so much fun that my laughter is what sets her off.

Sometimes I cycle through several rounds of shallow wake, then fall back into RBD cycles before I can finally heed her requests to get up. Sometimes I'm so drowsy and annoyed that I'll tell her to knock it off, but she remains "selectively disobedient," scratching at the door or shoving at me in bed because she knows what's best for me, no matter how much I protest otherwise. Is that not love?

A Message to Others Living with Parkinson's

If you were sitting with someone newly diagnosed—or someone further along who feels worn out—what would you want them to know about finding their own version of companionship and community, even if it doesn't look like yours?

LS: I am not a Pollyanna, glass-half-full sort of person. I despise toxic positivity. But I do know that most of my feelings and the direction of my thoughts are under my own control. I can wake up in the morning and lament how much I could do today if only I didn't have PD, or I can assess what I am capable of and get on with it. There is always room for something good, even if it's just a text sending thoughts of love and appreciation to a friend, while I lie on the sofa, waiting out some awful symptom.

Doing something good for yourself is pretty wonderful, but doing something, no matter how small, for someone else is invigorating, fulfilling, and leads you naturally down the path towards gratitude. Death is coming for all of us. But until the Grim Reaper appears, I want to work with whatever I have, no matter how small it seems somedays, to bring myself to life and life to myself.

Laurel Saville is an award-winning author and somewhat accidental dog behaviorist. She advocates and educates for better treatment of our canine companions through understanding, empathy, and kindness. Her most recent book, "How to Live with a Dog, stories and solutions for humans with dog problems and dogs with human problems," is available for pre-order and will be published on May 5.

Flying

by **Bill Clugston**

Under a brilliant blue autumn sky, puffy cumulus clouds stretched into the distance. Below the clouds, the checkerboards of eastern Washington farm fields faded into the towering Cascade Mountains on the horizon. This sounds like an eagle's-eye view, but in this case, it's through your first-person view (FPV) goggles from a drone's camera!

Aviation and photography have been lifelong interests of mine. I anticipated a retirement where I could pursue both of these interests — at least until my Parkinson's Disease diagnosis came along.

A Parkinson's Disease diagnosis isn't an end. It is a modified path. I purchased my first photography drone in 2017, three years after my Parkinson's diagnosis.

The first flights were around a local park, but already, I could see a new direction revealing itself to me. While I am slow on the ground, I can be fast in the air and photograph new sights that I could never see from the ground! I quickly progressed to flying to locations in the Cascade Mountains, local rivers, and other challenging locations. A new truth also arrived: drones require piloting skills like any other aircraft! Two crashes encouraged me to enroll in an online course to understand how to fly my drone and obtain my FAA drone license (also known as a 107 certificate).

Having the drone license allowed me to share my drone photographs and fly in areas I might not otherwise have access to. In addition to access, I can fly heavier drones (weighing more than 249 grams or .5 pounds) with better and more versatile camera equipment. For example, my DJI Mini Pro 4 is under the 249-gram no-registration limit. You can fly it without a license, but the camera is only slightly better than a high-end cell phone. My Mavic 3 Pro, on the other hand, is 2 pounds and flies with a professional-quality camera by Hasselblad. It is a flying digital single-lens reflex camera. In many ways, a drone can frame almost any shot as a tripod in the sky.

How does having PD affect my flying? In my case, the disease has only slightly affected my drone piloting. Drones use a small computer, the flight controller, to control the motors, level the aircraft, and determine direction and altitude. The flight controller has gyroscopes and a barometer to smooth out commands from the pilot's radio control – it can even smooth out momentary tremors from a person with PD! In fact, many consumer drones can fly a preprogrammed path loaded from a laptop.

Flying strengthens skills eroded by PD. Moving the controls improves finger dexterity. Flying across the landscape and navigating home to the landing site gains spatial awareness. FPV freestyle drones provide further challenges to enhance cognition and reflexes. These are aerobatic aircraft flown exclusively by flying with goggles (with a visual observer nearby). They are fast, maneuverable, and feel like a "roller coaster in the sky!" They can also be flown while sitting securely in a chair, which is a real plus for someone with balance issues.

What do I use my drones for? Photography and videos are my primary uses. I'm currently building a collection of aerial geology photos for the Washington Geological Survey and updating their online gallery. With every flight, I'm seeing Washington state through new eyes, unrestricted by the limits Parkinson's Disease attempts to impose on me. Even if I can't walk like I used to, I can still fly!

Usta Could

So I now have this crazy ailment
Known to some as just P.D.
Thanks to Mr. Parkinson
The first to define the disease

Now I happen to have this condition
I suspected that someday I might
Because my father met this big dragon
Now it's looking to mess up ***MY*** *life*

It's revealed by so many symptoms
Each one unique to treat
Many have worked to make life better
For us…but now it's just got to be ***BEAT!***

So many things have changed for me
So many quirks…none good
So many times I say "I can't do that"
The way that I Usta could

I can't keep a fast pace at anything
At times can't work with my wood
I can't ride a bike or even walk a big dog
The way that I Usta could

Sometimes I don't recognize myself
The way I walk, turn, and shake
The drool, the falls, the stiffness of limbs
The insomnia that keeps me awake

I wonder what people say and feel
When they encounter someone with P.D.
Do they show compassion or just pity?
For though I walk like a turtle, I want to scream so loud…
"Hey It's still just ME"

They say I'll likely get worse with time
Dementia, delusions, loss of control
It's all part of this spiral we know as P.D.
But I'm ***NOT*** *gonna sink down that hole*

I will live life to the fullest
Try to taste life as we should
It's time to rejoice in what we ***Can Do***
Instead of what we Usta could

I don't know the way of the path I am on
I'm not bitter and do not fear
I know that my God and my fellow man
Will come through and always draw near

I don't want to go down a forgotten one
My life has much value and good
So let us continue to love, and be loved
The way that we Usta could.

For though I walk like a turtle I want to scream so loud
"Hey I'm still just ME!"

Creative Contributions

Art from the APDA Virginia Community

Do you like to draw, paint, or take photographs? Are you a cartoonist or poetry master? If so, we'd love to share your work here!

Email lbadran@apdaparkinson.org with your creative submission today!

Background for Poem "Usta Could"

I was honored to be part of a panel to talk about my journey with Parkinson's Disease (PD). It took place on October 29, 2019, at the Virginia Commonwealth University School of Pharmacy in Richmond, VA. About 120 or so students were present, with remote access to two other campuses in VA. The three-member panel spoke for about an hour. The graduate students were very interested and inquisitive. It was arranged by Emily Peron, an Associate Professor at the VCU School of Pharmacy.

What a great experience to help these students understand the human side of this disease! At the time, I had P.D. for about 18 years, the longest of the panel members. The other speakers both gave great talks and were also richly blessed by the students' responses.

This is a poem I penned just the night before the panel talk (no pressure!). For me, poems are often the best way to convey deep feelings succinctly. I hope that it helps to shine light on the emotions and tough parts of dealing with a major motion disorder like PD. The poem title "Usta could" is a takeoff on the phrase "Used to Could," meaning "I used to be able."

John Giannico
Brightwood, VA

APDA Virginia Upcoming Events

OPTIMISM WALK AMERICAN PARKINSON DISEASE ASSOCIATION

Norfolk

May 2, 2026 | Norfolk, VA

Check-in: 8am | **Ceremony and Walk:** 10am

Norfolk Optimism Walk

Saturday, May 2
Norfolk, Virginia

APDA WILLIAMSBURG

Virginia Parkinson's Conference

Saturday, June 6, 2026

9:00 a.m. - 4:00 p.m.
College of Education at William & Mary
301 Monticello Ave, Williamsburg, VA 23185

APDA Williamsburg Conference

Saturday, June 6
Williamsburg, Virginia

OPTIMISM WALK AMERICAN PARKINSON DISEASE ASSOCIATION

Suffolk

September 12, 2026 | Suffolk, VA

Lake Prince Woods
Check-in: 9 am | **Ceremony and Walk:** 11 am

Suffolk Optimism Walk

Saturday, September 12;
Suffolk, Virginia

Parkinson's Education Day

Friday, June 26
Fredericksburg, Virginia
Registration coming soon!

APDA Roanoke Conference

Saturday, September 19
Salem, Virginia

AMERICAN PARKINSON DISEASE ASSOCIATION
VIRGINIA CHAPTER
Strength in optimism. Hope in progress.

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Virginia Beach, VA 23451

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Honor a Loved One. Inspire Hope.

A memorial or honorary gift is a meaningful way to celebrate the life of someone dear to you while making a lasting impact in the fight against Parkinson's disease. Your tribute not only honors their memory but also brings hope and support to individuals and families affected by Parkinson's.

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Thank you for honoring your loved one in a way that truly makes a difference.

All memorial and honorary donations to the American Parkinson Disease Association (APDA) are tax-deductible to the fullest extent allowed by law.

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