

## HOPE AND YOUNG ONSET PARKINSON'S DISEASE

When you envision someone living with Parkinson's disease, what comes to mind? Are they a rock climber? An American Ninja Warrior? A nurse? Or perhaps the parent of a young child? Probably not.

What you might be surprised to learn is that people with Parkinson's disease (PD) defy expectations every day — and for people like Bryan, Allison, and Steven, who are each living with young onset Parkinson's disease (YOPD), surpassing expectations is just a part of daily life.

### How do PD and YOPD differ?

Generally, PD is diagnosed later in life and most commonly seen in people over the age of 60. Of the 60,000 new cases of PD diagnosed each year, roughly 6,000 to 12,000 have YOPD, with half of those falling under age 40.

While people diagnosed with PD and YOPD experience similar symptoms, those with YOPD often must face a unique set of challenges that come along with the diagnosis. Juggling the social, financial, and mental impacts of their diagnosis at an earlier stage of life — while also managing the symptoms of their chronic, neurological disorder — can make their experience quite different from that of their older counterparts. Dating, parenting, and career progression are just a few of the additional concerns that someone with YOPD could be navigating.

### Living life to the fullest with YOPD

Bryan, Allison, and Steven are tackling their PD journeys with optimism. For Bryan and his wife, Julia, building a routine together has helped Bryan better manage his YOPD — and now he can balance his career as a nurse, being a father to their infant son, and rock climbing to stay active.



Bryan and Julia

***“YOPD creates a lot of unique challenges, and most people will not understand what we are going through, but you are not alone... Communication***

***is the foundation of [my and Julia's] relationship,” says Bryan.***

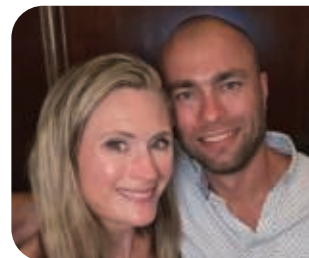
Allison and Steven's PD journeys began separately — and now they're living life to the fullest together. Allison has been living with PD since 2014, and in the years since, she has competed in *American Ninja Warrior*, ran a marathon, and started a blog that shares her story.



***“Tomorrow isn't promised for any of us,” says Allison. “Now if I want to do something, I do it. That includes having no limits in life.”***

Steven was diagnosed with YOPD in 2010, and after hearing Allison's story in a podcast, he reached out.

Now, they're sharing their love and their experiences with PD in their YouTube video series, *In Love with Parkinson's*.



Allison and Steven

While PD affects each person who has it differently, there's one thing that unites every member of our community — hope. You can watch Bryan, Julia, Steven, and Allison answer questions and share their inspiring stories in a recent episode of *Dr. Gilbert Hosts* on our YouTube channel (look for the *Dr. Gilbert Hosts* playlist).

TO LEARN MORE ABOUT YOPD, VISIT [APDAPARKINSON.ORG/WHAT-IS-PARKINSONS](https://apdaparkinson.org/what-is-parkinsons).

## A MESSAGE FROM OUR PRESIDENT & CEO

Dear Friend,

Is there anything quite as rejuvenating as the beginning of spring?

As we enter this new season of growth and renewal, I am eager at the prospects this year holds for the PD community.



There are so many promising things happening behind the scenes here at the American Parkinson Disease Association (APDA), and in this latest issue of *Insights*, we share just a portion of what you're helping us accomplish. Our success is only possible because of dear friends like you — and as you'll read here, we have a lot to be proud of.

Inside, you'll learn more about how the exceptional scientists in the PD research community are paving the way toward a future free from this chronic disorder, how we're augmenting our services to better serve the Spanish-speaking members of our community, and so much more.

With Parkinson's Disease Awareness Month upon us, I hope we can continue to count on you as we drive even more progress for our family members, friends, and neighbors on the front lines of the fight against PD. With your strength on our side, there's no limit to what we can do.

Warm regards,



Leslie A. Chambers

President & CEO

American Parkinson Disease Association

# APRIL IS PARKINSON'S DISEASE AWARENESS MONTH

There's never been a better time to show up and show your support for the PD community than right now — April is PD Awareness Month! We're uniting forces from coast to coast to raise awareness, raise funds, and raise hope for individuals and families affected by PD.

And there are so many ways to get involved! This April, show your support right from:



### Your computer

With just the click of a mouse, you can spread the word: *You're joining the fight against PD!* Follow APDA on social media and share some of the many messages we'll be posting all month long. Your posts will encourage your family and friends to make a difference and can help others feel informed and connected.



### Your living room

Know someone with PD? Let them know you care. Spend some quality time together, lend an ear or hand, or offer words of support.



### Your neighborhood

Sign up for an **APDA Optimism Walk!** Every step you take makes an impact. Find more information at [apdaparkinson.org/optimism-walks](https://apdaparkinson.org/optimism-walks).

When you're part of the PD community, every month of the year is PD Awareness Month — but this April, let's go even further to share hope and strength with everyone affected by PD!



# TAKING RESEARCH FROM THE LAB TO OUR LIVES

Sometimes, it is difficult to understand how PD research that is being done now in a lab will benefit people with PD in “real life.” In a recent episode of our popular online program, *Dr. Gilbert Hosts*, we sat down with two APDA-funded researchers to talk about their current research projects — along with two doctors who are treating patients — to discuss the potential these research projects have to dramatically improve the lives of those living with PD.

Dr. Nicole Bentley is conducting research on deep brain stimulation (DBS) and cognition, and Dr. Daniel Weintraub is an expert on the cognitive changes associated with PD. Together, they discussed DBS techniques that may improve cognitive symptoms.



“The use of brain stimulation therapies as a treatment for cognitive impairment and neurodegenerative diseases (like Parkinson’s disease) is an exciting area of research and one that is definitely worth further exploring.”

— Dr. Weintraub

One challenge of PD is the lack of a biological test to determine a diagnosis. A neurologist currently uses mostly visual clues to assess and diagnose someone with PD. Thankfully, Dr. Mohammad Shahnawaz is conducting research to develop a blood test for PD, which could fill a much-needed gap. According to Dr. David Standaert, an expert on the molecular underpinnings of PD, “**The idea that we are entering an era in which we will have blood tests for PD, is very exciting. We also need to acknowledge that this is happening based on decades of past research of what causes Parkinson’s disease.**”

With so much critical research going on, it can be hard to keep track of the many avenues currently being explored. Dr. Kevin McFarthing, a biochemist who is living with PD, told us about his passion project called The Parkinson’s Hope List ([bit.ly/ParkinsonsHopeList](http://bit.ly/ParkinsonsHopeList)), a database he created to track all of the potential therapies in research and clinical stages. Much like Dr. McFarthing, we view this exciting research with hope and optimism, and as such, APDA will continue to support cutting-edge PD research for as long as we need to.

(If you missed this broadcast, you can view it anytime by visiting our YouTube channel and clicking on the *Dr. Gilbert Hosts* playlist.)



## WHAT'S HAPPENING AT APDA

### Walk for PD

It’s that time of year again! The **2022 APDA Optimism Walk** series is kicking off this month in Georgia, with a full roster of in-person events scheduled throughout the year! To see if there is a Walk near you, visit [apdaparkinson.org/optimism-walks](http://apdaparkinson.org/optimism-walks). You know walking is great exercise, so why not come together with your local PD community and walk together for a great cause? We can’t wait to see you!

### Hot topics

Our goal is to help you feel educated, empowered, and supported throughout your PD journey. One way we do that is by providing reliable information about the aspects of PD that are most important and relevant to you through our “A Closer Look” blog. Topics include everything from tips for making daily life a little easier, to the latest in PD treatments and research, to inspiring personal stories, and so much more. New articles are posted regularly, so be sure to check out [apdaparkinson.org/blog](http://apdaparkinson.org/blog) for the latest. (You can also submit ideas for future blog topics!)



# “ASK THE DOCTOR”

with Dr. Rebecca Gilbert



**Q. What recommendations do you have for someone acting out vivid dreams (rolling out of bed, punching, kicking) during the night?**

**A.** This sounds like REM sleep behavior disorder (RBD), in which a person acts out their dreams. This is a common non-motor symptom of PD and sometimes predates other symptoms. Unless the acting out causes injury to the person or their bed partner, the actual behaviors do not have to be stopped. They are perceived by the person as part of a dream. Non-pharmacological options are: making sure the person is safe with bed rails, moving the mattress to the floor, moving the bed against the

wall, separating the person and their bed partner, etc. If medication is required, some practitioners will prescribe melatonin or clonazepam. Talk with your neurologist about these options.

**Q. Does PD ever progress quickly? In the last month, my father’s Parkinson’s symptoms have gotten much worse.**

**A.** It is unusual for a decline in PD to be rapid. Typically, when a decline is rapid, another cause can be identified. Has your father had any new medications added or dosage changes of any kind? (Sometimes medications for urination can cause hallucinations, for example.) Could he have a urinary tract infection or

other type of infection? Perhaps there is a medical illness brewing that is not an infection. Did he recently have a fall, and would brain imaging be reasonable to see if he has any injury? Is he constipated/impacted with stool? (I have seen this cause agitation.) These are all things that I would talk over with your father’s doctors in order to determine a possible cause for his increased symptoms.

*Dr. Rebecca Gilbert is the Chief Scientific 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’S SPANISH-LANGUAGE RESOURCES

APDA works tirelessly to support the PD community, but we know we are not reaching everyone. We are dedicated to finding ways to broaden our reach and meet the needs of underserved, under-resourced, and rural communities. One way we’re working toward this is with a wealth of Spanish-language resources, including:

- 15 booklets and fact sheets
- Two educational webinars
- The APDA Symptom Tracker app
- And so much more to come!

Through our dedicated focus groups and patient interactions, we’ve learned that many Spanish-speaking people with PD struggle greatly in learning about the disease and how to find the best care and assistance. Having a full range of educational materials available in Spanish can greatly increase their ability to access care and advocate for themselves.

If you or someone you know is looking for reliable PD resources in Spanish, you can visit our website at [apdaparkinson.org/espanol](http://apdaparkinson.org/espanol). You can also contact us in Spanish through our helpline at 800-223-2732 and by email at [apda@apdaparkinson.org](mailto:apda@apdaparkinson.org).



Published quarterly by the American Parkinson Disease Association, P.O. Box 61420, Staten Island, NY 10306 (800) 223-2732  
Chairman of the Board of Directors: Thomas Penett, Esq.; 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.  
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