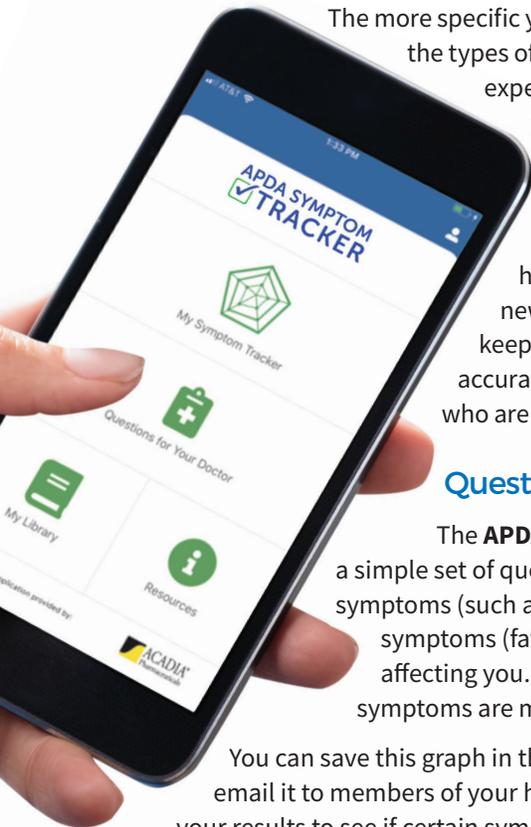


# How are you tracking?

## Better symptom monitoring at your fingertips



The more specific you can be with your health care team about the types of Parkinson's disease (PD) symptoms you're experiencing, the better your doctor(s) can tailor your treatment plan specifically to you.

But it can be hard to remember how certain symptoms have or have not affected you since the last time you connected with your health care team. That's why APDA developed a new mobile phone app that makes it really easy to keep track of your symptoms frequently and more accurately, and share that information with the people who are treating you.

### Questions for you

The **APDA Symptom Tracker app** guides you through a simple set of questions that has you rate how certain motor symptoms (such as tremor, rigidity, balance) and non-motor symptoms (fatigue, anxiety, depression, and others) are affecting you. It then creates a simple graph to indicate which symptoms are most impacting your quality of life.

You can save this graph in the "My Library" section of the app, and also email it to members of your health care team. Over time, you can compare your results to see if certain symptoms are getting worse, and determine which symptoms need to be addressed more urgently than others.

### Questions for the doctor

The APDA Symptom Tracker also has a special "Questions for the Doctor" feature that generates a list of suggested follow-up items for you to review with your doctor about symptoms you are currently experiencing, but also about preventative care. You can bring a printout of the questions with you to your appointment so you don't forget to ask any that are important to you.

The app also features a useful list of resources that connects you directly to a wealth of quality, credible PD information.

The APDA Symptom Tracker can help you have more meaningful conversations with your healthcare team and better manage your disease. Download the free app from the Apple App Store or Google Play today!

*The development of this app was made possible by generous support from Acadia Pharmaceuticals.*

## APDA SYMPTOM ✓ TRACKER

“  
*The more my patients can tell me about their symptoms, the more I can help them. The APDA Symptom Tracker app will be a useful tool that will benefit not only the patient, but it will help me as their doctor.*”

– Rebecca Gilbert, MD, PhD,  
Chief Scientific Officer, APDA

A message from our  
President & CEO



Dear Friend,

I hope your summer is off to a great start! I am excited to share with you all of the important developments in PD research and patient support that you are making possible — including a new mobile app, diversity efforts, cutting-edge research and more! None of this would be possible without you! Thank you for everything you do to help people with PD live life to the fullest.

Sincerely,

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

Leslie A. Chambers

President & CEO

American Parkinson Disease Association

## Research to prevent falls Spotlight on Dr. Aasef G. Shaikh

What if the next generation of Deep Brain Stimulus (DBS) technology could keep people with PD from falling?

Dr. Aasef G. Shaikh, MD, PhD, the recipient of APDA's prestigious three-year George C. Cotzias Fellowship for 2018-2021, is trying to accomplish just that. DBS can help with many symptoms, but doesn't yet address the issues that cause people to fall.

Thanks to your support, Dr. Shaikh and his team are studying how vision, eye movements, the inner ear/vestibular system, and proprioception (perception or awareness of the position and movement of the body) interact.

### The Process

They start by studying patients with PD who have undergone DBS to understand how they navigate the world. Next they modify one source of information about the patient's environment, for example, vision. Then they manipulate the patient's DBS parameters to study how the DBS stimulation affects their function.

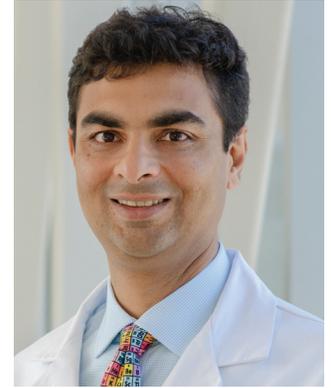
They study connections in the patients' brains using magnetic resonance imaging and bio-electric simulation of their DBS therapy. Finally, they replicate the findings in animal models to learn more about how DBS changes the way the brain cells talk to one another and influences movement.

### Space Age Technology

Dr. Shaikh's team uses different experimental setups in their research including a system normally used by NASA to train astronauts! The researchers have modified it to study postural control and balance function in PD, which are critical to preventing falls. They are the only group utilizing such a state of the art system in combination with DBS to understand how DBS can be used to improve balance function in PD.

### Promising Results

The research is uncovering key pieces of information critical to understanding fall prevention. In a specific program related to gait and postural instability in PD, they found that DBS can affect important connections between the cerebellum and thalamus to influence balance and gait function. This could provide a new way to think about these deficits, and possibly treat them.



Dr. Shaikh says that the support of his patients keeps him passionate about research. He also gets excited when the research leads his team to ask new questions they hadn't thought of before. "Sometimes that question and its answer lead us in a completely new direction. The process continues, with one set of questions leading to the next, fueling the growth of our research program."

To read more about Dr. Shaikh's APDA-funded research, please visit [www.apdaparkinson.org/research/investigators/aasef-shaikh](http://www.apdaparkinson.org/research/investigators/aasef-shaikh)

*Dr. Shaikh in the lab with a post-doctoral fellow, working with a state of art system (normally used by NASA!).*

# Centers for Advance Research Spotlight: Brigham and Women's Hospital, Harvard Medical School

Your support helps APDA fund eight Centers for Advanced Research across the United States, where some of the best scientists in the field are conducting cutting-edge investigations that are helping us understand what causes PD and how best to treat it, and ultimately getting us closer to a cure.

One of these centers is at Brigham and Women's Hospital at Harvard Medical School. The funding of this Center supports a large research program, which includes: basic, translational and clinical research, as well as outreach for building a community of patient-partners and the education and training of the next generation of scientists and clinicians dedicated to solving PD. Dr. Clemens R. Scherzer, MD, directs a team that is:



**Studying genetic mutations that cause PD**



**Seeing approximately 2,200 patients each year**



**Running a biomarker discovery program**



**Utilizing stem cells and big data analytics for a drug discovery program**



## Diversity, Inclusion, and the Future of Parkinson's Helping EVERYONE with PD live life to the fullest



Rosa Peña, APDA Senior Director of Programs and Services Field Operations moderates the patient/care partner panel at APDA's Diversity in Research Conference.

The vast majority of PD research that has been done thus far has not fully represented the people who live with this disease. In general PD research has predominantly reflected older, Caucasian men.

This lack of diversity is not just relevant to PD research. It also applies to access to medical care, programs and services. There are significant disparities when it comes to who is getting the proper care and support they need, and who isn't.

In short, APDA wants to fix this. Our mission is to help *everyone* impacted by Parkinson's disease live life to the fullest. *Everyone*. Are there cultural reasons why a person isn't getting the care they need? Are there genetic differences that influence how PD, or PD treatments, affect certain ethnicities? We are uncovering the gaps so we can figure out how to improve our efforts to make sure PD research, support, and services become accessible to all people.

### New grant to help make important changes

As a big first step, thanks to a grant from the prestigious Patient-Centered Outcomes Research Institute (PCORI), APDA convened the first-ever Diversity in Parkinson's Disease Research Conference in May to address the urgent needs surrounding PD in diverse and under-served communities.

At this groundbreaking conference, experts in the field presented the current facts concerning PD in diverse populations, with the goal of broadening diversity among the PD research that is being done today and in the future. The long-term objective is to understand the unanswered questions in the field of Diversity in PD Research, with the ultimate goal of fostering high-quality PD care for all.

### Funding for future diversity research

Ultimately, APDA plans to create a specific grant that will be awarded each year to support research that is focused on closing the diversity gaps. As our work in this area continues, we look forward to sharing more progress and updates.

“

*I think we can do great things to make both our research and services more inclusive and accessible.*”

– Dr. David Standaert,  
Chair of Neurology, University of Alabama  
Birmingham, Chairman, APDA Scientific  
Advisory Board



— Ask the —  
**DOCTOR**  
**Q&A**

with  
**Dr. Rebecca Gilbert**



## What's happening at APDA



### First Northwest Research Symposium

The APDA Northwest Chapter hosted an event bringing together PD researchers from every major research institution in Washington State to share the latest in PD research and what it's like to be a research participant. Nearly 300 people came and met the scientists and clinicians who are working towards a better understanding of the causes of PD in their quest to find a cure. The event was broadcast live and recorded for later viewing on the APDA Northwest YouTube Channel [www.apdaparkinson.org/events/apda-research-symposium/](http://www.apdaparkinson.org/events/apda-research-symposium/)



### Optimism Walks

April showers (torrential downpours!) didn't stop the dedicated walkers at the APDA Hampton Roads Optimism Walk at Neptune Park on the Virginia Beach boardwalk. Top fundraiser, 14-year-old Julianna Howe was honored for raising \$1,400 in memory of her Papa Bob Hilker and in honor of her grandfather Bob Howe both of whom were diagnosed with PD. Pictured: Grandfather Bob Howe is moved to tears by the love and support of the Howe family.

### A Flash Mob for PD

The APDA Vermont Chapter's Annual Parkinson's Awareness Day took place on April 13 in Burlington, VT, where participants came together for informative sessions about cognitive rehabilitation, health technology for people with neurologic disease, a Movement for Parkinson's and circle singing gathering (and more). The day before, participants from several of Vermont's Movement for Parkinson's classes held a "flash mob" on Church Street, Burlington's pedestrian mall. The event was covered by several news outlets and drew quite a crowd!

#### Q. I am on carbidopa/levodopa 25/100. What do the numbers 25 and 100 mean?

**A.** The numbers correspond to the formulation of the medication. In this case, it means you are taking a combination pill of carbidopa 25 mg and levodopa 100 mg. Without the carbidopa, the levodopa would be broken down in the body before it got a chance to make it into the brain. The carbidopa acts to inhibit the enzyme that breaks down levodopa.

There are various carbidopa/levodopa formulations on the market that differ in the dosage amounts of the two medications (e.g. 10/100, 25/100, 25/250) as well as the physical properties of the pill that may make the dose onset quicker or last longer (e.g. Sinemet, Sinemet CR, Parcopa, Rytary). Your doctor will prescribe a formulation based on your medication requirements.

#### Q. I was advised to take my carbidopa/levodopa at least 30 minutes after a meal. However, this caused a lot of nausea and stomach upset for me, so I now take the medication with meals which I find to work much better for me. Is this OK to do?

**A.** There is no issue with taking levodopa with meals except for possibly reduced absorption — usually only in the presence of dietary protein and even this is only in a subset of patients. If you find that the medication works well for you when you take it with food, then you can continue doing what you are doing. It is always wise to talk to your doctor about any issues you're having with your medication and discuss any potential changes in the dosing or timing.

For more information, visit our website at [www.apdaparkinson.org](http://www.apdaparkinson.org), or call (800) 223-2732. To make a donation online, visit [www.apdaparkinson.org/Renew](http://www.apdaparkinson.org/Renew).

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