

## APDA's New Diversity-Focused Grant Invigorates Inclusion in Parkinson's Research

As part of our efforts to support novel and innovative research, your generosity has made it possible for the American Parkinson Disease Association (APDA) to grant \$1.4 million to support critical Parkinson's disease (PD) research for the 2020-2021 funding year — one of the grants awarded being the first-of-its-kind *Diversity in Parkinson's Disease Research* grant.

### Shedding new light on research for underrepresented communities

The APDA *Diversity in Parkinson's Disease Research* grant was created to help study the circumstances of PD in diverse and underrepresented communities.

Chantale Branson, MD, was awarded the grant through our annual competitive application process and review by APDA's Scientific Advisory Board (SAB). Dr. Branson will focus on better

understanding the factors that affect the diagnosis of PD in a large African American population and provide additional data on the causes of the disparities and the prevalence of PD in this population. This research is important because people of African descent often have delayed diagnosis, more severe symptoms at the time of diagnosis, inadequate treatment, and worse clinical outcomes compared to their Caucasian counterparts.

### Diversity as a priority for the future of PD research

*"We are proud to encourage and support researchers who are committed to diversity-focused research so we can learn more about how the disease affects different populations and ultimately better serve people with PD*



With APDA's *Diversity in Parkinson's Disease Research* grant, Dr. Chantale Branson hopes to better understand the racial demographics of PD among the African American community.

*from all communities,"* states David G. Standaert, MD, PhD, John N. Whitaker Professor, Chair of Neurology at the University of Alabama at Birmingham School of Medicine, and Chairman of the SAB.

With the steadfast support of our community, we can continue to fund promising scientific research and help develop better treatments and ultimately, a cure. Our work is not possible without you. Visit [apdaparkinson.org/research/what-we-fund/](https://apdaparkinson.org/research/what-we-fund/) to learn more about APDA-funded research.



**"We are proud to encourage and support researchers who are committed to diversity-focused research."**

— David G. Standaert, MD, PhD

## A MESSAGE FROM OUR CEO & PRESIDENT



Dear Friend,

We have all faced uncertainty and unprecedented challenges this past year — and for many who were already facing the challenges of life with Parkinson's disease (PD), it's been particularly tough. But as this new year begins, we look ahead with optimism and know that we can find strength through coming together as a community.

In this issue of *Insights*, you can read about two young men who were inspired to find their own creative ways to fundraise for people with PD, as well as new virtual support programs that supporters like you are making possible — and much more.

As APDA commemorates our 60<sup>th</sup> year, I cannot help but be reminded of how much progress we have made. Although there is still so much left to do, we are more determined than ever and I'm looking forward to the year ahead. There's no telling what we can accomplish together in 2021 — and I hope you know how grateful we are to have you in this fight. Thank you.

Wishing you a happy, healthy year ahead,

Leslie A. Chambers  
President & CEO  
American Parkinson Disease Association

Commemorating our  
**60<sup>th</sup> year**  
of spreading hope  
and optimism for people  
living with PD.

## FIGHTING BACK AGAINST PD IN A WHOLE NEW WAY

Showing your support in the fight against PD can be easier (and more fun!) than you think. Today, more people than ever are fundraising to support the PD community and using their hobbies, passion... and a little creativity to do so. For young men like Alexander Rodriguez and Jaskeerat Gujral, joining the fight against PD was as easy as picking up a video game controller or following a passion for neuroscience.



For **Alex Rodriguez**, a new socially distant hobby, developed during the early months of COVID-19, proved to be a great way to raise money for APDA. Using a video game streaming platform, Alex hosted a 24-hour stream and played his favorite video game for nearly a day straight (with friends taking over so he could nap or eat). He encouraged his followers to donate and by the end of his stream, he had raised \$2,195!

**“Because of my mom having  
Parkinson’s disease, I’m always  
trying to give back.”**

— Alex



**Jaskeerat Gujral's** interest in neuroscience and PD began long before it touched his own family — and then after he lost a family member to the disease, he knew he had to act. While sponsoring his own do-it-yourself fundraiser with the goal of \$2,000 for PD support and research, Jaskeerat also found a mentor in Dr. Sachin Kapur, a clinical neurologist based outside Chicago. Together, the duo has been investigating the effects of an herbal supplement on people with PD since last August.

People around the world are getting involved and using their interests and hobbies to create their own fundraisers to support people affected by PD and drive new scientific research — and you can too. You can make a difference with your passion by visiting [apdaparkinson.org/get-involved/diy-fundraising/](https://www.apdaparkinson.org/get-involved/diy-fundraising/) today.

# SUPPORT CONTINUES FOR THE PD COMMUNITY

Despite the disruption that COVID-19 has caused, APDA was able to make immediate changes and develop extensive online programs and resources for those living with PD, including opportunities for our community to come together safely, connect, and support one another virtually — thanks to the steadfast loyalty and generosity of our supporters.

Here are just some of these events and programs:



Our nationwide **Optimism Walk series\*** transitioned into fun and inspiring online celebrations followed by safe and socially distant walking. Participants were encouraged to walk in their own neighborhoods, rather than in larger, organized events. As a result, virtual walkers could still participate and raise funds for people with PD while staying safe.



APDA's signature **Parkinson's Roadmap for Education and Support Services (PRESS)™** program was also reimaged, and a virtual version of this eight-week psychosocial education and support group became available via Zoom. PRESS is designed for individuals diagnosed with PD within the last five years and is led by a trained clinician. The new online format enables participants to attend from wherever they are and receive uninterrupted support.



APDA's Information & Referral (I&R) Center at the NY Institute of Technology (NYIT) offered the very unique **Young Women's Patient Education Virtual Forum**, a conference for women to help clear up the myths surrounding women diagnosed with Young Onset Parkinson's Disease (YOPD) and provide a wide range of information and resources to patients and caregivers alike. The Forum not only served as an excellent source of dependable information for healthcare experts, but for the 70+ YOPD women, caregivers, friends, and family members in attendance, it also provided a chance to connect.

By continuing to stay active in the PD community, regardless of the circumstances, supporters like you are making a difference. With your loyal generosity, we can continue our work to provide support for the one million people in the U.S. who are living with PD — as well as the 60,000 more who will be diagnosed in the year to come.

*\*The full 2020 **Optimism Walk nationwide event series** was supported by the generosity of our National Sponsors: Adamas Pharmaceuticals, Amneal Pharmaceuticals, Lundbeck, and Sunovion Pharmaceuticals. We are so thankful for their partnership!*

*The Spring 2020 Virtual Optimism Walks were also sponsored by Neurocrine Biosciences and Acadia Pharmaceuticals.*



## CREATING A LEGACY

If you wish to leave a legacy that will touch the lives of so many, please consider including APDA in your planned giving (i.e., your will). There are several easy ways to make an impactful gift that will not only help in the fight against PD, but could help you, your estate, and your heirs. Giving through a will or trust, life insurance policies, a charitable gift annuity, and excess retirement funds are just several options.

To learn more about planned giving and which options are right for you, contact your financial advisor, or reach out to APDA's Office of Planned Giving at [apda@apdaparkinson.org](mailto:apda@apdaparkinson.org) or **718-981-9202**. You can also visit our website at [apdaparkinson.org/legacy](https://apdaparkinson.org/legacy) for more info.





# “ASK THE DOCTOR”

with Dr. Rebecca Gilbert



**Q. My Mom has PD and needs to take brand name Sinemet. When she takes a generic, she does not feel well. My pharmacy has told me that there is a shortage of brand name Sinemet. What should she do?**

A generic and brand name of the same drug are required by the Food and Drug Administration (FDA) to have the same strength, dosage amount, route of administration, and quality. There are, however, two differences that are allowed between a generic and brand name drug:

1. They can have different inactive ingredients and will often look different.

2. A small range in the bioequivalence of the medication is allowed — typically the range is no more than 4%. (That would mean a 100 mg dose could be between 96-104 mg.)

Therefore, a small percentage of people who are extremely sensitive to these small changes may be able to tell the difference between different generics or between brand and generic. (The vast majority of people will not be able to distinguish.) If your mom is among the people who can tell the difference between the different manufacturers, the solution is to try all the different generics. One may be even better for her than the brand name version. You will need to talk to her pharmacist

about how to obtain the different generics. One pharmacy may carry one particular generic but may be able to tell you if there is another pharmacy in the area that typically stocks another one of the generics.

If trying multiple generics is not possible or all have been tried and they all cause the same problem, then she will need to choose one of the generics and work with her doctor to increase or decrease the dose a tiny bit to obtain a good clinical outcome.

*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.*



Sage Therapeutics sponsored trial for Parkinson’s Disease Mild Cognitive Impairment (PD-MCI): research study for adults ages 50 to 75 years old who have been diagnosed with PD-MCI. The purpose of this study is to evaluate the safety and tolerability of an investigational medication. Participants must have a confirmed

diagnosis of PD-MCI and have a study partner who is reliable, competent, at least 18 years of age, and willing to be available to the study center by phone.

The study is currently enrolling at the following sites:

- Long Beach, CA** – Collaborative Neuroscience Network – Long Beach
- Fort Myers, FL** – Neuropsychiatric Research Center of Southwest Florida

**Port Charlotte, FL** – Parkinson’s Disease Treatment Center of Southwest Florida

**West Palm Beach, FL** – Palm Beach Neurology and Premiere Research Institute

For additional information on the PARADIGM STUDY, please visit the trial listing on [clinicaltrials.gov](http://clinicaltrials.gov) or contact [clinicaltrialsinquiry@sagerx.com](mailto:clinicaltrialsinquiry@sagerx.com).



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Chairman of the Board of Directors: Patrick McDermott; 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.

**For more information, or to learn about the many ways you can support APDA, please call (800) 223-2732 or visit [apdaparkinson.org/Renew](http://apdaparkinson.org/Renew).**