

HOPE IN PROGRESS: NEW RESEARCH UNDERWAY

From understanding levodopa induced dyskinesias to exploring environmental risk factors of PD, APDA-funded researchers launch cutting-edge studies

With someone diagnosed with PD every six minutes, scientific research is critical as we push for better treatments and ultimately, a cure. Devoted to our search for answers, APDA recently awarded \$1.975 million to support innovative PD research for the 2023-2024 funding year.

“APDA is steadfast in its research focus – identifying and supporting researchers early in their careers to encourage them to either commence or continue dedicating themselves to PD research, as well as helping established investigators pursue new and novel ideas.”

*— Leslie A. Chambers,
APDA President & CEO*

The funded research projects will delve into key areas of PD biology including RNA regulation in levodopa-induced dyskinesia, cognitive impairment, underutilization of deep brain stimulation, and physical activity among Latino/a PD patients; as well as the clinical subtypes of PD, SARS-CoV-2 induced dopamine neuron damage, and so much more.

Twenty grants have been awarded and include Post- Doctoral Fellowships, Diversity in PD Research grants, the George C. Cotzias Memorial Fellowship (APDA’s most prestigious award), and more.

You can learn more about these grantees and browse all APDA-funded research by visiting apdaparkinson.org/research.

A GLOBAL GATHERING OF INSPIRATION, INNOVATION AND COMMUNITY

This summer, APDA participated in the 6th World Parkinson Congress (WPC) in Barcelona, Spain. We are thankful for the incredible connections we made, the inspiring conversations we had, the compelling presentations we attended, and so much more!



WPC is geared toward both people with PD and medical professionals, which is one of the unique things about this event. With more than 2,500 attendees from 73 countries, we met wonderful people from around the world — many of whom already knew about APDA from our extensive virtual programming! It was incredibly exciting to see the far reach of APDA’s programs.

APDA was an International Partner of the conference, participated in the pre-conference Leadership Forum, and was featured in the Exhibit Hall. Science, activities, and community — there was truly something for everyone. We hope to see you at the next WPC!



A MESSAGE FROM OUR PRESIDENT & CEO

Dear Friend,

As President and CEO at the American Parkinson Disease Association (APDA), I see the many challenges our community is faced with. However, I am encouraged by the progress we're making as we help those affected by PD live life to the fullest.



One of the many reasons for my encouragement is the amazing PD research that is being conducted every day. The groundbreaking progress made by APDA researchers will continue to make an impact for the PD community, thanks to partnerships like yours. Together, we can also make sure we're sharing exceptional resources so that those affected by PD and their loved ones have the confidence to face this disease.

I remain optimistic about our achievements as a community, and I know we will build on the progress we've made. Thank you for your dedication as we advance unique research and inspire hope for those impacted by this disease.

Sincerely,

A handwritten signature in black ink that reads "Leslie A. Chambers". The signature is fluid and cursive.

Leslie A. Chambers
President & CEO

GET IT ON WITH PARKINSEX

Parkinson's disease can make it difficult for partners to maintain a healthy relationship, especially when it comes to intimacy. Symptoms of PD can affect the well-being of your relationship, and a couple may grow apart physically and emotionally because of it.

Although sexual intimacy can be challenging for many people to talk about, we're choosing not to tiptoe around the subject. Instead, we're addressing the topic head-on by creating **ParkinSex** — **an exciting resource** that encourages the conversation. It was developed in partnership with Havas Health & You, to help people with PD rekindle their intimacy and sex life.

*"We work tirelessly to help people impacted by Parkinson's disease **live life to the fullest and we know that intimacy can play a significant role in quality of life.** This is why we created ParkinSex."*

— Leslie A. Chambers, APDA President & CEO

Each kit includes an insightful and beautifully illustrated educational guide designed to help strengthen relationships between partners navigating PD, along with items meant to foster connection and intimacy — including massage stones, candles, a blindfold, and more.

These items, along with the book on how to put them into practice, will help address the physical and emotional needs of people with PD. The ParkinSex booklet is also available in a downloadable PDF version, as well as an audio version of the book.



*"We want to **help couples explore physical connection** — whatever that may mean for them, knowing that it may look different for everyone."*

— Rebecca Gilbert, M.D., Ph.D., Chief Scientific Officer for APDA

PD shouldn't make it difficult for partners to sustain a healthy relationship. If you're wondering how to feel more connected to your partner — and/or are interested in learning more about PD and intimacy — you can get more information and your very own **ParkinSex Booklet & Kit** at apdaparkinson.org/ParkinSex.

PLAYING GOLF AND RAISING PD AWARENESS

The Central New Jersey Chamber of Commerce hosted a nine-hole golf tournament in May to benefit APDA.



Organized by Milton Paris, golfers enjoyed some friendly competition on the course, followed by a celebratory luncheon. APDA representatives were invited to meet the participants and share information about PD.



Milton's dedication to making the event a success is truly inspirational, and his hard work paid off! The event raised \$5,700 for APDA which will help APDA provide even more educational resources, programs, and support services in the NJ area! Thanks to passionate people like Milton, APDA can continue supporting those facing PD. If you'd like to host a fundraising event to benefit APDA, please contact jcolasuonno@apdaparkinson.org.



WHAT'S HAPPENING AT APDA

Tools for daily success



Join us for our brand-new three-part web series, **Thriving**

Through Occupational Therapy, where we will explore the world of occupational therapy (OT) and the many ways it can benefit people living with PD. Hosted by trained OT experts, we will share practical knowledge, and provide tips and tricks to help with daily living. Visit apdaparkinson.org/events to find the next episode and register today!

Advanced PD training course



APDA recently launched **Taking Care of the Person**

with Advanced Parkinson's Disease[®], a free, specialized online training course to help those who care for people with PD — particularly home health aides, nursing home staff, and visiting nurses — better understand the symptoms and challenges that come with advanced stages of the disease. Take any of our professional training courses at apdaparkinson.org/training.



“ASK THE DOCTOR”

with Dr. Rebecca Gilbert



Q. Can travel affect PD symptoms?

A. Yes, in several ways. First, travel can be exhausting, especially when dealing with time changes — and that fatigue can make PD symptoms seem worse. In addition, timing of medication doses can be difficult to manage when you’re changing time zones and out of your regular routine, which can affect symptom management as well. Changes in food, altitude, and climate can all affect general well-being and as a result, impact PD symptoms. However, travel can be very rewarding and enjoyable — and with careful

planning you can get the benefits of travel without the downsides.

Q. I have gastroparesis from my PD, which causes my abdominal pain. I have been told that the gastroparesis causes OFF time. How does that happen?

A. Gastroparesis or delayed gastric emptying is a condition in which the stomach’s normal movements are slow. Gastroparesis can cause nausea, a bothersome sense of fullness, and abdominal pain. It can also cause medication doses to remain in the stomach instead of traveling to

the small intestine where they are absorbed. In this way, gastroparesis can cause dose failures which lead to return of PD symptoms also known as OFF time.

Treatment of gastroparesis includes eating small frequent meals, drinking fluids during meals, avoiding fat in your diet, taking a walk after eating, and avoiding medications that can slow down the gut such as opioids. There are new prescription medications that can be tried to help gastroparesis, so ask your neurologist for a referral to a gastroenterologist.

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 is a biopharmaceutical company fearlessly leading the way to create a world with better brain health. Our mission is to pioneer solutions to deliver life-changing brain health medicines, so every person can thrive. For more information, please visit sagerx.com.

MARK YOUR CALENDARS FOR GIVING TUESDAY NOVEMBER 28!

Join APDA during this global generosity movement and show the PD community you care.

Visit apdaparkinson.org/GivingTuesday to learn more!



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To make a donation online, visit apdaparkinson.org/Renew.