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Events

**SEPTEMBER**

9 Parkinson’s Policy Forum
Washington, DC
Learn more: Parkinson.org/Events

14 Nutrition and Parkinson’s
Carol Stream, IL
Learn more: Parkinson.org/Nutrition-Chicago

17 Expert Briefing Webinar:
Communication Strategies for Optimal Success
Register: Parkinson.org/ExpertBriefings

19 Parkinson’s, Sleep & Me
Overland Park, KS
Learn more: Parkinson.org/SleepKC

21 Moving Day Buffalo
Register: MovingDayBuffalo.org

22 Mind, Mood & Motion
Dayton, OH
Learn more: Parkinson.org/DaytonEDU

28 Moving Day New Jersey
Register: MovingDayNewJersey.org

**OCTOBER**

1 Parkinson’s, Sleep & Me
Fargo, ND
Learn more: Parkinson.org/Fargo-Sleep

5 Moving Day Boston
Register: MovingDayBoston.org

Moving Day Dallas Fort Worth
Register: MovingDayDFW.org

6 Moving Day Chicago
Register: MovingDayChicago.org

12 New Frontiers/
Women & PD
Cleveland, OH
Learn more: Parkinson.org/ClevelandEDU

19 Moving Day Atlanta
Register: MovingDayAtlanta.org

20 Parkinson’s, Sleep & Me
Columbus, OH
Learn more: Parkinson.org/ColumbusEDU

23 PD 101-Newly Diagnosed
Eagan, MN
Learn more: Parkinson.org/Events

**NOVEMBER**

2 Moving Day NC Triangle
Register: MovingDayNCTriangle.org

Moving Day Venice
Register: MovingDayVenice.org

5 Expert Briefing Webinar:
Coping with Dementia for Care Partners
Register: Parkinson.org/ExpertBriefings

9 Moving Day Miami
Register: MovingDayMiami.org

Moving Day Phoenix
Register: MovingDayPhoenix.org

16 Moving Day Los Angeles
Register: MovingDayLosAngeles.org

Moving Day Jacksonville
Register: MovingDayJacksonville.org

23 Mind, Mood & Motion
Bay Area, CA
Learn more: Parkinson.org/BayArea

For a full list of events visit Parkinson.org/Events.
Research Update from the Chief Scientific Officer

Every day, potentially groundbreaking Parkinson’s disease (PD) research ideas are explored in labs across the country; labs that are funded by the Parkinson’s Foundation. Over the next three years we will bolster our efforts, investing $50 million in Parkinson’s research and clinical care aimed at improving the lives of the one million Americans living with PD today — and the 60,000 people diagnosed each year.

In this special research issue, we are excited to announce four new Research Centers. These centers will receive Foundation funding dedicated to developing the latest in treatment and better understanding this disease. Read more about these centers on page 4 and find out how we will work together to find the next PD breakthrough.

Scientists play a critical role in advancing Parkinson’s treatments. More than 500 scientists have received funding from the Parkinson’s Foundation, like James Dahlman, PhD (page 9), who conducts thousands of drug delivery tests at the same time.

We are optimistic and excited to fund the most innovative and dedicated research initiatives among those new to our field and experts, alike. It is only a matter of time until we evolve precision treatment, revolutionize therapy options and ultimately, cure Parkinson’s.

James Beck, PhD, can be reached at jbeck@parkinson.org.

Top 5 Ways to Engage in Parkinson’s Research

Use these free resources to be in the know when it comes to the latest in ongoing Parkinson’s research:

1. **Become a Research Advocate:**
   This program brings together people who live with PD and those developing new treatments. [Parkinson.org/PAIR](https://parkinson.org/PAIR)

2. **Listen to our Podcast:**
   With more than 50 episodes, PD experts talk about up-to-date research, treatment and therapies. [Parkinson.org/Podcast](https://parkinson.org/Podcast)

3. **Enroll in a Clinical Trial:**
   Find a clinical trial near you and enroll. [Parkinson.org/ClinicalTrials](https://parkinson.org/ClinicalTrials)

4. **Check out our Research Spotlight:**
   Learn more about the cutting-edge research we’re funding right now. [Parkinson.org/ResearchSpotlight](https://parkinson.org/ResearchSpotlight)

5. **Read Science News:**
   We sort through the latest published PD research studies and give you the takeaways. [Parkinson.org/Blog](https://parkinson.org/Blog)
Parkinson’s is an extremely complex disease. It is likely that no one scientist or laboratory has the capacity to find an answer, which is why the Parkinson’s Foundation is launching a new version of its long-standing Research Center program that will advance the field of Parkinson’s disease (PD) treatment through research.

Research Centers are medical or academic institutions that receive Parkinson’s Foundation funding to strengthen their PD research teams and efforts, while collaborating with other scientists and advancing our understanding of Parkinson’s.

In July 2019, the Parkinson’s Foundation awarded a total of $8 million to institutions that will each design and launch Parkinson’s-specific research studies over the next four years.

Of the 66 institutions around the world that applied to become a Research Center, four were selected: Columbia University Medical Center; University of Florida in collaboration with Emory University; University of Michigan in collaboration with The University of Texas Southwestern Medical Center; and Yale University.

The goal of each newly-designated center is to work together with different fields and institutions in order to find innovative ways to treat and study Parkinson’s.

The newly designated Research Centers will undertake a minimum of three interconnected PD research studies. Studies range from basic science (understanding the disease or how PD affects the brain) to applied science (solving real-life problems associated with PD) to clinical research in humans or a combination of these.

“We hope that fostering creativity and collaboration across multiple disciplines and looking at Parkinson’s from new angles will lead to important breakthroughs,” said James Beck, PhD, Parkinson’s Foundation Chief Scientific Officer. “Not only research breakthroughs but finding new implications for precision care and ways to modify the disease itself.”

Knowing that innovation can arise at any time during the research process, 10 percent of Foundation research funding is reserved to jump-start pilot projects or form new collaborations.

“This support from the Parkinson’s Foundation will help us make a significant contribution to our understanding of Parkinson’s disease,” said Kelly Foote, MD, co-director of the Fixel Institute for Neurological Diseases at
University of Florida Health. “We are thrilled they have chosen the University of Florida to help shape the future for people with Parkinson’s disease with new discoveries and better therapies.”

On an annual basis, each center will meet with and report their research progress to the Foundation. Centers will have the flexibility to more aggressively pursue the most promising studies.

“The Foundation designed this program so that centers have the funding to pursue multiple Parkinson’s studies at the same time,” Dr. Beck said. “We’re excited to see these studies pave the way to Parkinson’s research we have not yet imagined.”

Currently, Roy Alcalay, MD, from Columbia University leads the Parkinson’s Foundation genetics study, “PD GENERation: Mapping the Future of Parkinson’s Disease.”

Research Centers will work collaboratively to find new ways to treat and study Parkinson’s and will receive $500,000 per year for four years, totaling $2 million each. The Parkinson’s Foundation plans to open the application process to designate new Research Centers beginning in the fall of 2021.

Learn more about Parkinson’s research at Parkinson.org/Research.

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**PD GENERation**

**MAPPING THE FUTURE OF PARKINSON’S DISEASE**

**How Does PD GENERation Work?**

People with Parkinson’s disease (PD) can enroll at participating Parkinson’s Foundation Centers of Excellence or Parkinson Study Group sites.

1. **Schedule an appointment** for genetic testing at a participating Center of Excellence or Parkinson Study Group site.

2. **Attend your appointment.** Provide consent, have a clinical evaluation and a simple blood draw.

3. **Genetic testing results** will be analyzed and samples will be stored.

4. **Meet with your healthcare professional** in person or a certified genetic counselor by phone 6–8 weeks after the blood draw to receive and discuss your test results.

5. **Fill out online surveys** that will be sent to you after your clinical visit to share feedback on how genetic testing has impacted your life.

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The Parkinson’s Foundation is recruiting 600 participants to enroll in the pilot phase of this study. For more information, visit Parkinson.org/PDGENErater or call our Helpline at 1-800-4PD-INFO (473-4636) to speak with a Helpline specialist in English or Spanish.
A member in my support group told us about a new study that used spinal cord stimulation to manage Parkinson’s disease (PD) symptoms. What does this study mean for people with PD?

Delivered by a surgically implanted device, spinal cord stimulation alters nerve activity to treat chronic back and nerve pain. The battery-operated device sends a low-voltage electrical current to select spinal cord areas. Settings can be adjusted post-implantation for optimum therapy. Researchers are exploring how this decades-old pain treatment might improve hard-to-treat advanced PD gait symptoms, including levodopa-resistant freezing and balance motor issues.

A recently-published pilot study looked at a group of five people with advanced Parkinson’s who had significant gait and balance symptoms, despite medication. Each participant received a spinal cord stimulator implant. Post-implant, all five participants showed significant improvements in performing activities of daily living, as well as sustained improvements in gait measurements. Freezing of gait episodes dropped to zero just six months after surgery and no adverse effects were reported. A much larger clinical study is needed to explore these promising study results of using spinal cord stimulation to treat PD symptoms.

My father has Parkinson’s. Is it true that drinking coffee can reduce the risk of getting Parkinson’s or help with PD symptoms?

Drinking coffee has been associated with a reduced Parkinson’s risk in epidemiological studies (studies that examine risk of getting PD).

A 2018 study showed coffee does have neuroprotective benefits when it comes to developing the disease in mice. The study looked at the potential benefits of one of the nearly 1,000 different compounds in coffee — a fatty acid called eicosanoyl-5-hydroxytryptamide (EHT) — in combination with caffeine on the brains and behavior of mice with PD.

Researchers treated two different mice groups with caffeine alone, EHT alone or caffeine and EHT together. The caffeine and EHT combination slowed the progression of the neurodegeneration associated with PD in the mice, resulting in better neuron function, less alpha-synuclein clumping in the brain, less brain inflammation, less dopamine neuron loss and decreased movement symptoms.

A 2012 study and several follow-up studies showed consumption of caffeine in moderate doses, twice daily, seemed to mildly benefit PD-related motor symptoms. These and other studies on compounds that may offer protection from neurodegenerative diseases, will help spur the development of new drugs and new targets for the treatment of Parkinson’s disease.
I have Type 1 diabetes and was recently diagnosed with Parkinson's disease. Has research shown that PD could also be an autoimmune disease?

In autoimmune diseases like Type 1 diabetes, the immune system destroys cells mistakenly “flagged” as foreign. An antigen, or molecular “flag,” indicates these cells as foreign; the “flagpole” is major histocompatibility complex (MHC), a group of genes that help the immune system recognize foreign substances.

Scientists once thought PD couldn’t be an autoimmune disease because neurons did not appear to have MHC. But David Sulzer, PhD, and colleagues at the Parkinson’s Foundation Research Center at Columbia University Medical Center, proved human brain cells do have MHC with research published in 2014. In a more recent 2017 study, funded in part by the Parkinson’s Foundation, Sulzer’s team discovered abnormal alpha-synuclein, such as that found in PD, can activate an attack on brain cells by the body’s own immune-system cells, potentially triggering an immune response in the brain.

The researchers suggest that Parkinson’s disease may, in part, be an autoimmune disorder. More studies are needed to better understand how the immune system is involved in PD. This can lead to new insights to prevent the brain cell death that underlies PD.

Parkinson’s disease (PD) research shows exercise — yoga, biking, non-contact boxing and others — can help gait, balance, flexibility, and motor coordination. Research to connect exercise to possible cognition, depression and fatigue improvement is ongoing.

Exercise improves mobility in people with PD. It can improve thinking, memory and reduce fall risks. While any level of physical activity is beneficial, to reap the greatest rewards:

- Ask your doctor for a physical therapist referral for PD-safe exercise tips.
- Exercise safely; know your limits.
- Exercise consistently; researchers think that the more you do, the more you benefit.
- Exercise indoors and outdoors. Changing routines can keep you motivated.

The type of exercise you do depends on your symptoms and challenges. Consider trying:

- PD-specific classes
- Treadmill training with body weight support
- Resistance training
- Aerobic exercise
- Home-based exercise (YouTube videos)

To learn more about Parkinson’s and exercise visit Parkinson.org/Exercise.
While researchers explore potential breakthrough therapies to treat Parkinson’s disease (PD), breakthroughs in PD medications are newly available or quickly approaching.

The gold standard drug levodopa/carbidopa therapy replaces lost dopamine, improving motor symptoms. Newer drugs improve or complement levodopa delivery, tackling “off” periods and involuntary dyskinesia muscle movements.

Carbidopa/levodopa enteral suspension therapy (Duopa™) can benefit those experiencing three-plus daily “off” hours. Delivered in gel form (called enteral suspension) a pump carries Duopa™ through a surgically-placed intestinal tube.

Safinamide tablets (XADAGO®), monoamine oxidase B (MAO-B) inhibitor for people taking carbidopa/levodopa experiencing “off” times, block dopamine breakdown; cutting “off” times by 55 minutes daily, without dyskinesia. Interactions include other MAO-B class drugs, certain antidepressants and dextromethorphan.

On-demand therapies:
• Levodopa inhalation powder (INBRIJA™), with levodopa, can improve “off” symptoms in as soon as 10 minutes and last for 60.
• Amantadine ER capsules (GOCOVRI®), a before-bedtime carbidopa/levodopa add-on, treats dyskinesia and “off” time. It can cause hallucinations and lightheadedness. This differs from the once a day combination extended-release and immediate-release amantadine (OSMOLEX ER™).

Newer treatments:
• Pimavanserin (NUPLAZID®) can improve PD psychosis-related hallucinations, delusions, sleeplessness and sleepiness.
• Droxidopa (NORTHERA®) can treat lightheadedness associated with orthostatic hypotension — a blood pressure drop on rising — but can’t be taken within five hours of bedtime. It can increase blood pressure when lying down.
• IncobotulinumtoxinA (XEOMIN®) facial injections can alleviate drooling.

Potential future therapies:
• Apomorphine, given via injection, can’t be taken in a form requiring swallowing. Sublingual apomorphine dissolves under the tongue, relieving PD “wearing off” episodes in 15 minutes, for up to 90 minutes.
• Rimabotulinumtoxin B (MYOBLOC®), approved for dystonia and used off-label for drooling, is in drooling treatment trials.
• Japanese-approved adenosine A2A receptor antagonist istradefylline shows mild motor symptom fluctuation improvements; it is not FDA approved.
• Available in Europe, subcutaneous apomorphine infusion reduces “off” time and dyskinesia. It’s delivered through a small tube placed under the skin, connected to an external apomorphine pumping device.

In development:
• Nonsurgical, 24-hour subcutaneous carbidopa/levodopa pumps offering continuous, under-skin drug delivery.
• The biodegradable Accordion Pill™ Carbidopa/Levodopa (AP-CD/LD) slowly releases treatment in the stomach for steady absorption.
• IPX203, an extended-release oral carbidopa/levodopa formulation.
• Available in Europe, awaiting FDA review, opicapone stalls an enzyme that breaks down levodopa.

This article is based on a Parkinson’s Foundation Expert Briefings webinar exploring innovative PD treatments by Rajesh Pahwa, MD, from the University of Kansas Medical Center, a Parkinson’s Foundation Center of Excellence.

For more information about Parkinson’s treatments and medications call our Helpline at 1-800-4PD-INFO (473-4636) or email Helpline@Parkinson.org.

Taking a PD medication? Always discuss potential drug interactions with your doctor or pharmacist.
Critical Funding Brings Researcher to Parkinson’s Field

Most people with Parkinson’s disease (PD) rely on medication to help manage their symptoms. These medications only work because of a process called drug delivery — the targeted delivery and/or rate a drug is released.

James Dahlman, PhD, at Georgia Institute of Technology has dedicated his lab to evolve drug delivery when it comes to people with PD.

“The difference between ours and other labs is that we can rapidly perform drug delivery experiments, performing up to 20,000 experiments at once, which allows us to evaluate things more quickly and figure out which drug delivery systems are going to work or fail more quickly,” Dr. Dahlman said.

Dr. Dahlman received the Parkinson’s Foundation Stanley Fahn Junior Faculty Award, allowing his lab to join the PD research field. “We work with a lot of diseases, but Parkinson’s is an important one for us,” Dr. Dahlman said. “Our goal is to find what works best, which would help people with Parkinson’s get better concentrated drugs into the part of the brain that they need it to go.”

The grant Dr. Dahlman and his team received allowed him to launch his first Parkinson’s study — a tough feat in the highly competitive field of Parkinson’s research grant funding.

“There is no way we could be in the field without this grant, zero percent chance,” Dr. Dahlman said.

The Stanley Fahn Junior Faculty Award helps ensure promising early career scientists, like Dr. Dahlman, a bioengineer and molecular engineer, have the chance to join and make an impact on PD research.

As Dr. Dahlman’s lab continues to study and analyze hundreds of thousands of drug delivery systems, they have also simultaneously published their findings, seven in total. “The Parkinson’s Foundation grant allowed us to get started and use a new way of measurement and study different parts of the brain.”

Parkinson’s Foundation research grants enable researchers to stay in the PD research field, helping us solve, treat and end this disease. The Stanley Fahn Junior Faculty Award provides junior investigators with the support to develop their own independent funding source. Award recipients receive $300,000 to cover three years of research.

In 2018 the Foundation awarded $6.2 million across 53 research grants to support the work of promising PD scientists. The Parkinson’s Foundation will announce 2019 awardees this summer.

Learn more about studies we fund at Parkinson.org/ResearchSpotlight.

EXPANDING THE CENTER OF EXCELLENCE NETWORK

This summer, the Parkinson’s Foundation added three new Centers of Excellence to its global network: University of Colorado; Thomas Jefferson University; and Indiana University School of Medicine.

The Center of Excellence network is comprised of 48 leading academic medical centers, 34 of which are in the U.S., that serve more than 145,000 individuals diagnosed with Parkinson’s annually. This sought-after designation identifies hospitals and academic medical centers with specialized teams of neurologists, movement disorders specialists, physical and occupational therapists and mental health professionals, who are at the leading edge of the latest medications, therapies and innovations in Parkinson’s.

Through expanding this network, the Foundation can work more efficiently to find the treatments and best practices every doctor can utilize to help people with PD live better.

To find a Parkinson’s Foundation Center of Excellence near you, visit Parkinson.org/Search.
Women experience Parkinson’s disease (PD) differently than men. They experience unique symptoms and side effects, challenges with access to healthcare and a lack of social support. Research often does not include or account for women with Parkinson’s, which is why the Parkinson’s Foundation Women and PD Initiative is addressing the issue.

“Historically, Parkinson’s care has been based on research that has focused too narrowly on men,” said Allison W. Willis, MD, MS, co-leader of the Women and PD project, from the University of Pennsylvania, a Parkinson’s Foundation Center of Excellence. “The Parkinson’s Foundation is defining gender-specific research and care practices and working with healthcare professionals to improve care provided to women with Parkinson’s.”

“Becoming my own advocate and taking charge of my health care has really helped me to live a better life with Parkinson’s,” said Kelly Weinschreider, Women and PD participant living with Parkinson’s. “I hope to help others do the same through my work with the Parkinson’s Foundation.”

The Foundation led the first national effort to address the long-standing gender disparities in Parkinson’s research and care that ultimately impact quality of life. This initiative furthers the Foundation’s commitment to developing approaches to advance treatment and care for underserved communities.

**Women and PD Research Needs**
The Parkinson’s Foundation developed an agenda, providing patient-centered recommendations identifying women’s research and healthcare priorities, while suggesting ways researchers can include women in future PD studies.

**Care**
4. **Accessibility:** Parkinson’s care must be more accessible to women. Programs should target health, wellness and management of PD and should help women feel comfortable and included.
5. **Personalization:** PD care should be personalized to women. Future programs should address biological and gender/cultural differences.
6. **Communication:** Medical professionals and women with PD should better communicate and work together to identify goals for treatment.

**Education and Empowerment**
7. **Self-management:** Provide women with PD with the knowledge and tools to maintain a desired quality of life early in their diagnosis.
8. **Shared Responsibility:** Care teams should better understand the needs and priorities of women with PD and be more involved in their care.
9. **Advocacy:** Additional education efforts are needed to increase public awareness about PD.

See what the Foundation is doing at Parkinson.org/WomenandPD.
Family Creates Movement Disorders Fellowship to Fight Parkinson’s

After Lourdes Dosal was diagnosed with Parkinson’s disease (PD) in 2014, she and her husband Alberto gave a major gift to the Parkinson’s Foundation. The initial gift launched a deep family commitment to fighting PD, a diagnosis shared by the mother-in-law of one of the Dosals’ sons. Through his involvement in Wines on the Bay fundraisers and Moving Day, Alberto has raised more than $250,000 for the Foundation.

A former Parkinson’s Foundation board member, Alberto helped facilitate the 2016 National Parkinson Foundation and Parkinson’s Disease Foundation merger. The Dosals, who are close with Parkinson’s Foundation National Medical Director, Michael Okun, MD, and board member John Kozyak, wanted to help more doctors focus on PD treatment. To that end, they recently donated another $100,000, establishing the University of Florida Dosal Family Movement Disorders Fellowship. Dr. Okun is the Adelaide Lackner Professor and Chair of Neurology at the Fixel Institute for Neurological Diseases at University of Florida Health.

Though the couple is now committed to traveling the world and enjoying retirement and family together, Alberto said they are “forever grateful” for Dr. Okun’s continued help in treating Lourdes, and for the tireless efforts of the Parkinson’s Foundation board members for serving as ambassadors for all people with PD. “The Foundation’s growth and unwavering commitment to help people with Parkinson’s on a national and local level, has been incredible,” Alberto said.

To learn more about planned giving opportunities, visit Parkinson.org/PlannedGiving.

HELP FIGHT PARKINSON’S ALL YEAR LONG

Become a Parkinson’s Hero. A Parkinson’s Hero is part of a special group of donors who make monthly gifts to the Parkinson’s Foundation. Your regular monthly support will provide critical funds we can rely on to fuel the fight against Parkinson’s year-round.

Commit today at Parkinson.org/Hero.
We have expanded our Helpline hours!
Call our free Helpline at 1-800-4PD-INFO (473-4636) Monday through Friday from 9 a.m. to 8 p.m. ET to get your Parkinson’s questions answered in English or Spanish.

Help is just a click away.
Get the resources and information you need. Our free educational books, hospitalization kit, podcast, fact sheets and webinars are made for everyone in our community.
Parkinson.org/Library

1.800.4PD.INFO
Helpline@Parkinson.org

We’re here for you.