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For a full list of events visit Parkinson.org/Events.
Find a Moving Day walk in your area! Visit MovingDayWalk.org.

Join us at Moving Day this fall

Help us spread Parkinson’s awareness at in-person events taking place across the country. Let’s celebrate movement, together! Register at MovingDayWalk.org.

SEPTEMBER

5 Expert Briefings Webinar: The Parkinson’s Journey: Understanding Progression
Register: Parkinson.org/ExpertBriefings

10 Fall Volunteer Leadership Call
Register: Parkinson.org/Events

18 Moving Day Buffalo
Register: MovingDayBuffalo.org

OCTOBER

3 Moving Day Columbus
Register: MovingDayColumbus.org

6 Expert Briefings Webinar: PD & Medication: What’s New
Register: Parkinson.org/ExpertBriefings

16 Moving Day Atlanta
Register: MovingDayAtlanta.org

24 Moving Day Chicago
Register: MovingDayChicago.org

30 Moving Day Los Angeles
Register: MovingDayLosAngeles.org

Beyond the Diagnosis:
Managing Mid-Stage Parkinson’s
Register: Parkinson.org/Events

NOVEMBER

6 Moving Day NC Triangle
Register: MovingDayNCTriangle.org

ALWAYS AVAILABLE

PD Health @ Home educational and wellness events are designed for YOU. Check out our exciting new themes and webinars at Parkinson.org/PDHealth.

People with Parkinson’s Disease and parkinsonism have a higher risk of fractures

The TOPAZ study will test if a medicine called zoledronate can prevent fractures and decrease the risk of death in those:
- aged 60 years or older
- with Parkinson’s Disease or parkinsonism

If you are eligible for the study, a nurse will come to your home and you’ll receive a one-time treatment (either zoledronate or placebo).

Want to join or learn more about TOPAZ?
Call: 1-800-4PD INFO (1-800-473-4636)

Join a Parkinson’s Study without ever leaving your home

PARKINSON REPORT
Research Update From Our Chief Scientific Officer

For too long, the causes of and cure for Parkinson’s disease (PD) have remained elusive to people with Parkinson’s, their families and their doctors. Through PD GENEration: Mapping the Future of Parkinson’s Disease, the Parkinson’s Foundation is accelerating the pace of scientific breakthroughs for PD research. We recently reached a milestone of 1,000 participants enrolled in the clinical study. Enroll today and help us improve life for those with PD in generations to come.

On page 8, we highlight the fascinating research of Michael Tadross, MD, PhD, a recent research grantee, who is utilizing his Foundation award to further his Parkinson’s research at Duke University, a Parkinson’s Foundation Center of Excellence. Stay tuned for our next round of 2021 research grant announcements this fall.

Finally, on page 10, we highlight the ways we are reaching further into the underserved Parkinson’s community by expanding our research efforts to improve clinical trial representation within the Latin and Caribbean communities.

To stay up to date on our research efforts, follow us on Twitter @PFResearchTeam and watch our Neuro Talk videos at Parkinson.org/CSOJamesBeck.

How to Enroll in PD GENEration

1. First, visit Parkinson.org/PDGENEration to complete a questionnaire to confirm your eligibility. If eligible, you will complete a phone screening and then schedule your at-home virtual genetic testing appointment. Or, you may choose to complete your assessment in person at a clinic that offers PD GENEration.

2. If you choose to complete the study at home, your genetic testing kit will be mailed to you, which you and your provider will use to collect your genetic sample during your genetic testing appointment. During the appointment you will schedule a follow-up with a genetic counselor to review your test results.

3. Next, return your cheek swab samples for analysis using the pre-paid shipping label. Within six weeks, you will receive your test results through the genetic counseling appointment. Finally, you will be asked to complete an online survey about your experience.

Visit Parkinson.org/PDGENEration to sign up today. For assistance with PD GENEration eligibility and scheduling in English and Spanish, call our Helpline at 1-800-4PD-INFO (473-4636).

Together, we’re mapping the future of Parkinson’s disease. For more information, email us at Genetics@Parkinson.org.
Participant Collaboration Drives PD GENEration Genetic Study Success

The nationwide PD GENEration: Mapping the Future of Parkinson’s Disease study is pushing the boundaries of what we know about Parkinson’s disease (PD). Through their contribution, study participants are helping advance us towards a cure.

PD GENEration participants are enhancing researchers’ understanding of why people experience Parkinson’s differently. The Parkinson’s Foundation is recruiting 15,000 people with Parkinson’s to receive comprehensive genetic testing and genetic counseling at no cost in its landmark PD genetic study, offered in English and Spanish. Unlocking genetic differences among people with PD can revolutionize disease treatment.

“I'm participating in PD GENEration because I know that the more information we can gather about Parkinson’s disease, the closer we can get to finding better treatments and ultimately, a cure.”
— Rick Friedland, a research advocate who has lived with Parkinson’s for 13 years.

Powerful Knowledge
Parkinson’s is one of the fastest-growing neurological diseases, with more than 60,000 people newly diagnosed in the U.S. every year. Current medications cannot stop its progression, and there is no time to waste in finding a cure. PD GENEration participants, such as Rick, directly contribute the data needed to accelerate the pace for global Parkinson’s experts to identify ways to reverse the course of Parkinson’s for future generations. “This is also an opportunity for me to not just deal with symptoms, but also support real progress for the Parkinson’s community,” Rick said.

Genetics are responsible for up to 15 percent of PD cases. Most people living with Parkinson’s, and their doctors, do not know if they carry genes related to the disease. PD GENEration genetic testing has the potential to help discover the unknown drivers of the disease. The study also helps participants identify whether they qualify to enroll in specific clinical trials, which can empower people with PD and speed the development of new treatments.

Superior Study
The PD GENEration at-home and in-person testing panel — created by the Parkinson’s Foundation in partnership with Fulgent Genetics — provides expansive, comprehensive analysis of seven key Parkinson’s genes, including LRRK2 and GBA, the two most common genes linked to PD.

The Foundation collaborated with the Indiana University School of Medicine, a Parkinson’s Foundation Center of Excellence, to develop customized PD-specific genetic test reports. Genetic counselors with experience in Parkinson’s explain report details and answer questions in English or Spanish, all at no cost to participants.
Diverse Data
Participants in this pioneering study have the power to influence the entire PD community. Study participants help grow one of the largest, most diverse collections of North American PD genetic data to fuel research toward a cure.

The unique, expert-led Parkinson's Foundation Hispanic council of advisors work with Hispanic and Latino people with Parkinson's and their caregivers to address their needs and enhance their involvement in Parkinson's Foundation programs, including PD GENEration. “Diversity in genetic data is critical to expanding our understanding of Parkinson's and developing targeted medicines for everyone who lives with the disease,” said Anna Naito, PhD, Associate Vice President of Research Programs and PD GENEration lead.

Global Impact
To increase representation in Parkinson's research and improve care for people living with Parkinson's, the Foundation launched GEN-EP Latino, an initiative that offers PD GENEration genetic testing at no cost to Spanish-speaking PD individuals. This landmark study will launch in the Dominican Republic, led by Movement Disorders Specialist Rossy Cruz, MD, and aims to reach and empower underserved Hispanic people with PD and their families with the knowledge to better understand the disease and help accelerate research.

Recently, the National Institutes of Health (NIH) appointed the Parkinson's Foundation to lead the multidisciplinary international Parkinson's Disease Gene Curation Expert Panel — comprising more than 45 global Parkinson's genetics experts. Under the Foundation's guidance, the Expert Panel is analyzing PD GENEration and other global genetic data with the goal to advance research breakthroughs.

“We uniquely designed PD GENEration to propel Parkinson's research, which is why we anonymously store all genetics samples so that future scientists can access this critical data,” Dr. Naito said. The Foundation teamed with the Aligning Science Across Parkinson's (ASAP)-supported Global Parkinson's Genetics Program (GP2) study, whose goal is to analyze genetic data from 150,000 people with Parkinson's from all races and backgrounds.

Find out if PD GENEration’s genetic test and counseling are right for you. Learn more at Parkinson.org/PDGENEration.

1.800.4PD.INFO (473.4636) Genetics@Parkinson.org

Why PD GENEration genetic testing is the best.
Comparing Your Genetic Testing Options

Why should people with Parkinson's consider genetic testing?
For people with Parkinson’s, genetic testing can uncover gene changes linked to the disease. By better understanding how people with genetic forms of Parkinson's experience symptoms related to the disease and respond to treatment, scientists can begin to develop improved treatments.

PD GENEration

People diagnosed with Parkinson's disease

Commercially Available Genetic Tests

Eligibility

Anyone

Cost

Starting at $100

Tests for 7 Parkinson's-related genes, the most comprehensive test available

Tests are less specific to PD or screen for fewer variants related to the disease

Participants meet with a genetic counselor to review and discuss test results

Not offered

Healthcare providers are involved throughout the process

Not guaranteed

In-person at a participating Parkinson's Center of Excellence or Parkinson Study Group site, or virtually at home

At home

Available in English and Spanish

English only

Participants with genetic mutations are connected with relevant clinical trials for new treatments

No direct access to clinical trials

Parkinson's Foundation maintains database of samples for use in research towards better treatment and a cure

No direct link with future PD research

Find out if PD GENEration’s genetic test and counseling are right for you. Learn more at Parkinson.org/PDGENEration.

1.800.4PD.INFO (473.4636) Genetics@Parkinson.org

SUMMER 2021
Through its national study, *PD GENERation: Mapping the Future of Parkinson’s Disease*, the Parkinson’s Foundation is giving people with Parkinson’s disease (PD) insights into their PD and opportunities to take action, while accelerating PD treatments. Genetic counseling, offered in English and Spanish, is a critical and unique part of this study.

Licensed, board-certified genetic counselors Jeanine Schulze, MS, CGC, and Jennifer Verbrugge, MS, CGC, are with the Department of Medical and Molecular Genetics at the Indiana University School of Medicine, a Parkinson’s Foundation Center of Excellence. Both have taken part in several PD genetic testing research initiatives, including PD GENERation.

**Q: Why is genetic testing important for people with Parkinson’s?**

A: Some people want to better understand why they developed Parkinson’s disease. Others want to learn more about their individual disease or the potential risk to family.

Genetic testing can identify if a gene change, or variant, contributed to PD. Identifying a genetic variant might give us information about family inheritance and the risk of Parkinson’s within a family. Genetic test results might provide information about potential symptoms or future progression, or guide treatment.

Identifying a genetic variant in a person with PD may open the door to participation in research studies, such as clinical trials — giving them an opportunity to help researchers learn more about Parkinson’s causes and potential treatments.

**Q: What does a genetic counselor do?**

A: Genetic counselors empower people with Parkinson’s and their families with information, guidance and emotional support. Counselors help them understand biological history, evaluate genetic testing options and make informed choices based on test results.

**Q: How is PD GENERation setting the bar for Parkinson’s-specific genetic reporting and counseling?**

A: The study puts participants at its center, helping them understand their genetic test results and encourage them to partner in future PD research. PD GENERation provides genetic counseling to every participant. The high-level, comprehensive genetic test is designed to cover all seven of the major PD gene variants, including those important for clinical trials and other research participation.

**Q: How is genetic counseling through PD GENERation unique?**

A: This study enables access to genetic testing and counseling to people with PD across the U.S. at no cost. The new virtual option gives access to people who previously might have been too far from a study site or unable to travel. Participants can have their questions answered by genetic counselors who are highly specialized in Parkinson’s disease and PD genetics. Counseling is offered in Spanish and English.

**Q: What should people know about at-home genetic tests?**
A: There are many kinds of at-home genetic tests. Some direct-to-consumer genetic tests are performed without a physician or a health care provider involved. These tests do not fall under the same guidelines as those ordered through a clinician, and often provide limited or incomplete information.

The PD GENEration at-home genetic testing is ordered through a PD GENEration healthcare provider. Staff mail a collection kit, and coordinators help explain how to collect the genetic sample during the video visit. The sample is mailed to the clinically-certified laboratory running the PD GENEration genetic testing panel. This test was carefully designed and results are carefully analyzed. Each participant’s genetic information is protected by the research study and the lab doing testing. Results are reported to participants by a genetic counselor or clinician who can answer questions and discuss any complexities.

Visit Parkinson.org/PDGENEPodcast to hear podcast episodes that highlight PD GENEration.

6 Facts You Should Know About Parkinson’s and Genetics

Better understanding genetics continuously transforms our knowledge of Parkinson’s disease (PD). Here are six facts about genetics and PD:

1. Most researchers think Parkinson’s is caused by a mixture of environmental and genetic factors.
2. Genetics cause about 15% of all Parkinson’s.
3. Researchers have discovered changes, or variants, in several genes associated with Parkinson’s. The most popular genetic mutations are LRRK2, GBA and SNCA.
4. Some families pass certain gene variants, or mutations, down through generations. Researchers are working to learn why certain ethnic groups, including the Ashkenazi Jews and North African Arab Berbers, have genes associated with PD.
5. Different studies look for people with specific genetic variants — some test new treatments while others observe how genetic variants impact PD symptoms and progression over time.
6. Critical research linking genetics to PD — such as the Parkinson’s Foundation PD GENEration study — is taking place right now, helping us better understand Parkinson’s and improving treatment.

Mel Mitchell
PD GENEration participant and People with Parkinson’s Council member

Learn more at Parkinson.org/Genetics.
Scientist Pinpoints Parkinson’s Brain Changes in Hopes of Advancing Treatment

With a background rooted in electrical engineering, biomedical engineer Michael Tadross, MD, PhD — Duke University’s Tadross Lab director and assistant professor — is reimagining the way science approaches Parkinson’s disease (PD). His groundbreaking DART (Drugs Acutely Restricted by Tethering) medication delivery method might hold the key to a better quality of life with Parkinson’s.

Neurons (brain cells) communicate using electricity and chemicals — sending messages to the nervous system. People with Parkinson’s experience lower or missing levels of the brain chemical messenger dopamine. This impacts the way the brain communicates and sends instructions to the body, leading to PD movement challenges, such as tremors, slowing and stiffening, as well as less visible symptoms. Scientists are working to develop medications that improve Parkinson’s symptoms while minimizing standard side effects.

To do this, they must target specific cells within the striatum — a closely woven cluster in the brain consisting of different cell types. Medications that benefit some of these cells can harm others. Dr. Tadross’ DART system can deliver therapy to a single cell type. Using this technique for several PD medications, his study maps cell types that benefit from specific targeted therapies and those that are responsible for side effects. This method offers possibly the most detailed look yet at how Parkinson’s impacts the cells of the brain. The results will guide development of new Parkinson’s therapies.

A 2017 three-year, $300,000 Parkinson’s Foundation award furthered Dr. Tadross’s “Deconstructing the Behavioral Neuropharmacology of Parkinson’s Disease” research. “The Parkinson’s Foundation was among the first to see the potential of this study,” Dr. Tadross said. Since then, the National Institutes of Health (NIH) recognized him with a five-year New Innovator Award and a BRAIN (Brain Research through Advancing Innovative Neurotechnologies) Initiative Award, for his pioneering research and the potentially revolutionary benefits for everything from Parkinson’s disease to addiction and recovery. Through its National Institute on Neurological Disorders and Stroke division, NIH further awarded Dr. Tadross an R01 Research Project Grant focused on DART’s potentially revolutionary benefits in Parkinson’s.

The Parkinson’s Foundation has invested nearly $370 million since 1957 to advance PD care and research. In 2020, the Foundation invested $3.4 million over 34 research grants, each holding promise to improve the lives of people with Parkinson’s.

Learn more at Parkinson.org/Grants.
Symptom Management: Is it PD, Medication or Aging?

Parkinson’s disease (PD), aging and medications can all impact mental well-being. Identifying thinking change causes and prioritizing wellness can help you live optimally with Parkinson’s.

Parkinson’s and Cognitive Changes
Parkinson’s disease can cause thinking, memory and mood changes for some people. Address any changes with your doctor, especially disorientation, poor judgment, irresponsible behaviors or forgetfulness. Such symptoms can be due to reversible causes or indicate disease progression.

Executive function changes (attention, multitasking and problem-solving declines) can be frequent in PD. Memory can also be impacted. Prompts or clues can be helpful to people with Parkinson’s. Some people with PD may have difficulty with familiar tasks or finding the right word.

Tackle these changes by slowing down, minimizing stress and reducing distractions. Physical therapy can help maintain movement and occupational therapy can help you better navigate your environment.

Staying Well
These research-proven strategies can help keep your mind sharp:
- Engage in exercise — especially aerobic
- Enjoy mentally stimulating activities, such as reading or puzzles
- Connect with friends
- Sleep six or more hours a night

Cognition concerns that include sudden changes over hours, days or weeks are usually not Parkinson’s related. Often due to a medical issue, address acute mental status changes quickly. Abrupt disorientation or confusion requires immediate medical attention. Causes can include infections, dehydration and medication side effects. Depression is also a cognition challenge that may cause sudden cognitive ability changes.

Orthostatic hypotension affects up to 70% of people with PD. Blood pressure drops sharply when someone rises or stands, and side effects can include dizziness and difficulty thinking. Other causes of cognitive change can include aging, medications or other influences.

Aging can impact:
- Multitasking abilities
- Working memory — remembering directions, for example
- The ability to organize, sequence and plan
- Processing speed

Reversible cognitive impairment issues can also impact thinking, including:
- Sleep disturbances, such as obstructive sleep apnea
- Vitamin B12 deficiency
- Hypothyroidism
- Depression

Medications also impact Parkinson’s. Dopamine-producing neurons lost in PD can be further impacted by some medications, worsening cognition and other symptoms. Parkinson’s is also associated with lower acetylcholine brain chemical levels. Acetylcholine is important to cognition. Anticholinergic medications — used in many therapies, including some antihistamines — block acetylcholine.

Other medications can interfere with cognition, including some psychiatric and antipsychotic therapies and certain bowel motility (movement) medications. Your doctor can help you pinpoint the cause of cognitive change, recommend therapies and adjust medications.

This article is based on the Parkinson’s Foundation Expert Briefing “Symptom Management: Is it PD, Medication or Aging?” by Gregory Pontone, MD, MHS, Director, Parkinson’s Neuropsychiatry Clinical Programs, Johns Hopkins University School of Medicine, a Parkinson’s Foundation Center of Excellence, and Lisa Cone, People with Parkinson’s Council member.

Check out and register for our new season of Expert Briefing webinars at Parkinson.org/ExpertBriefings.
Furthering our Reach: Investing in Underserved Parkinson’s Communities

The Parkinson’s Foundation is investing an additional $10 million in 2021 to enhance its research, care and education programs, specifically to reach underserved Parkinson’s disease (PD) communities.

“Our donors and volunteers stood with us throughout the COVID-19 pandemic, and after a record-setting year, we are now accelerating funding to areas that are most important to the PD community,” said John L. Lehr, President and Chief Executive Officer of the Parkinson’s Foundation.

This investment includes expanding PD GENEration: Mapping the Future of Parkinson’s Disease to Hispanic and Caribbean communities that have been historically underrepresented in PD clinical trials. PD GENEration is a global initiative that provides genetic testing and counseling at no cost to people with Parkinson’s in English and Spanish.

This additional investment allows the Parkinson’s Foundation to focus on diversifying the PD population involved in this first-of-its-kind study.

Through PD GENEration, the Parkinson’s Foundation will provide genetic testing and genetic counseling at no cost to 15,000 people with PD, many of whom could become ideal candidates for groundbreaking clinical trials for PD. The Foundation will also expand its research grants by funding additional Impact Awards — designed for new and prominent PD researchers.

“The Parkinson’s Foundation has a longstanding commitment to removing barriers to care, making research more inclusive. Our goal is to diversify the participants in the PD GENEration study so that we can accelerate clinical studies, improve Parkinson’s research and care and empower all people with Parkinson’s — regardless of their background.”

—James Beck, PhD, Chief Scientific Officer of the Parkinson’s Foundation

Part of this funding will support expanded access to improved care in communities and care settings across the U.S. This investment is allowing the Parkinson’s Foundation to partner across its Centers of Excellence Network to advance the role of nurse practitioners in Parkinson’s care; accelerate palliative care as a new standard of wholistic, team-based care; and test new models of hospital care delivery to improve the health and safety of people with PD.

This investment also includes $2 million in funding for Parkinson’s Foundation community grants, more than half of which will serve diverse and underserved, hard-to-reach PD communities. Community grants are awarded each year for health, wellness and education programs that address unmet needs in the PD community. Recently funded local programs include increasing awareness, education and support for the LGBTQ community living with Parkinson’s.

Learn more about the Foundation’s commitment to diversity, equity and inclusion at Parkinson.org/DEI.
George and Mimi’s Gift Supports Innovative Parkinson’s Research

When George Kaufman — an esteemed scholar with a storied international career — was first diagnosed with Parkinson’s disease (PD), his research led him to the Parkinson’s Foundation. As the John F. Smith, Jr. Chair of Economics and Finance at Loyola University Chicago, and an economist who served the administrations of Presidents Gerald Ford and Jimmy Carter, George wanted to put his emphasis and his support behind an organization as committed to research as he was, said Mimi Winter, George’s widow.

Mimi lost George to Parkinson’s last June, but she is carrying forward the couple’s passion to end PD. Mimi is donating $1 million to the Parkinson’s Foundation in memory of George. “We created a charitable trust years ago and the Parkinson’s Foundation was always one of the top organizations on our list,” Mimi said.

The Parkinson’s Foundation’s 2021 Impact Awards will be named after George. The awards fund innovative or unique research exploring Parkinson’s through a new lens. “Outside-the-box research areas are often where the gold is,” said Mimi, a member of the Foundation’s Leaders in Research program that brings together donors eager to invest in novel Parkinson’s research. “I’m very, very excited to be able to contribute.”

Help us fund research that advances Parkinson’s treatments and medications for today. Contact Katherine Griswold, Vice President of Individual Giving, at kgriswold@parkinson.org to learn more.

SUPPORT THE FIGHT AGAINST PARKINSON’S

Make a difference in people’s lives and create a meaningful legacy through planned giving. A bequest is one of the most popular and flexible ways you can make a gift through your will or trust that helps further the work of the Parkinson’s Foundation. We have partnered with FreeWill, which allows you to write your legal will online, at no cost.

FREEWILL.COM/PARKINSON
Get your Parkinson’s questions answered.
Call our free Helpline at 1-800-4PD-INFO (473-4636) for current disease information, health questions, and referrals to local health professionals and resources — in English and Spanish.

PDConversations.org

• Join the conversation in one of our eight discussion groups.
• Find a community with others who share your interests.
• Check out the Top Questions.

We’re here for you.

1.800.4PD.INFO
Helpline@Parkinson.org

Get the latest on social media
/ParkinsonDotOrg

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