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PAPRIL

- **Moving Day San Antonio** Register: MovingDaySanAntonio.org
- 15 Moving Day San Jose Register: MovingDaySanJose.org
- **29** Moving Day Charleston Register: MovingDayCharleston.org

Moving Day Tampa Bay Register: MovingDayTampaBay.org

Moving Day Ventura County Register: MovingDayVenturaCounty.org

Moving Day Westchester, NY Register: MovingDayWestchesterNY.org

30 Big Sur International Marathon Weekend (26.2, 5K and more) Register: Parkinson.org/Champions

> **Moving Day Palm Beach** Register: MovingDayPalmBeach.org

MAY

Moving Day Washington DC Register: MovingDayDC.org

> **Moving Day Kansas City** Register: MovingDayKansasCity.org

Moving Day San Francisco Register: MovingDaySanFrancisco.org

Moving Day Twin Cities Register: MovingDayTwinCities.org

- **Celebrate Spring New York** Learn More: Parkinson.org/CSNY
- **Expert Briefing: Freezing and Fall** Prevention in Parkinson's Register: Parkinson.org/ExpertBriefings
- **20** Moving Day Central NY (Syracuse) Register: MovingDayCentralNY.org
- **21** Moving Day Orange County

JUNE

Moving Day Baltimore Register: MovingDayBaltimore.org

Moving Day Albuquerque Register: MovingDayAlbuquerque.org

- 10 Moving Day Cleveland Register: MovingDayCleveland.org
- **Moving Day Omaha** Register: MovingDayOmaha.org





View all upcoming events at Parkinson.org/Events.

Learn more: MovingDayOrangeCounty.org

We Hope to See You at the 2023 **World Parkinson Congress**

July 4-7 Barcelona, Spain

Learn more at WPC2023.org





JOHN LEHR, PRESIDENT & CEO

A Note From Our CEO

As I mark my sixth year as President and CEO of the Parkinson's Foundation, I am very hopeful about our new partnership with Parkinson's UK. Through the Parkinson's Virtual Biotech, which currently has eleven new Parkinson's drugs under research and development, we will be able to find new PD medications and therapies in years, not decades. Learn about three of the projects on page 9.

We are thrilled that our global genetics study reached its 50% milestone, providing genetic testing and counseling to 7,500 people with Parkinson's at no cost. This is an incredible feat, and thanks to the work of our investigators, this is one of the most diverse PD genetics studies. Participants can use their results to help guide their care and sign up for new clinical trials, and we are utilizing and sharing the data with the global PD research field in hopes that this can accelerate a breakthrough.

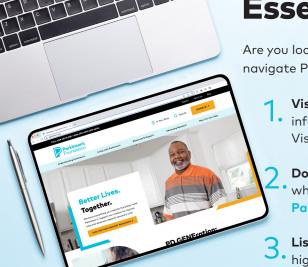
You may have seen that the estimated number of people in the U.S. diagnosed with Parkinson's has increased from 60,000 to 90,000 per year. This year, for Parkinson's Awareness Month we ask that you #Take6forPD. Every six minutes someone is diagnosed with Parkinson's. Take just six minutes to help us raise awareness. Learn more on page 6 and at Parkinson.org/Awareness.



Essential Parkinson's Resources

Are you looking for new tools and information that can help you or a loved one navigate Parkinson's disease (PD)? Explore our top PD resources:

- Visit Parkinson.org. Access unlimited articles highlighting the latest Parkinson's information, from symptoms and research to caregiving and tips. Visit Parkinson.org.
- Download the Hospital Safety Kit. Always be prepared for a hospital stay, whether planned or unplanned. Download or order the kit at Parkinson.org/AwareInCare.
- Listen to our podcast. Substantial Matters: Life and Science of Parkinson's, highlights the most critical PD topics. Visit Parkinson.org/Podcast.
- Participate in a research study. Discover the different opportunities for how you can get involved with PD research. Visit Parkinson.org/JoinAStudy.
- **Start exercising on-demand.** Fitness experts lead PD-tailored workout classes in our Fitness Friday exercise videos. • Visit Parkinson.org/PDHealth.





Sign up for free online CE courses designed to help you provide quality Parkinson's care.

Education.Parkinson.org/ProfCommProviders







Genetics is a key step in solving Parkinson's disease (PD). Understanding how and why Parkinson's and genetics fit together is a mystery the Parkinson's Foundation is looking to solve through our landmark study, PD GENEration: Mapping the Future of Parkinson's Disease. The Parkinson's Foundation is excited to announce that we are accelerating the path to solving the puzzle of genetics and Parkinson's through reaching a significant study milestone of providing genetic testing and counseling to 7,500 participants - 12 months ahead of the study recruitment timeline.

"Ensuring that the entire Parkinson's community — including the 90,000 individuals expected to receive a PD diagnosis this year has access to their genetic status is as critical as ever," said James Beck, PhD, chief scientific officer for the Parkinson's Foundation. "Every PD GENEration participant plays a part not only in their own personal discovery but also in feeding results to researchers which will advance future research."

Half-way to its goal, the study is on track to provide genetic testing and counseling at no cost to 15,000 people with Parkinson's, which will establish the largest Parkinson's genomic dataset in North America. Recognizing the importance of genetic testing to accelerate precision medicine trials, the Foundation is committed to continue PD GENEration recruitment (beyond 15,000 participants) until we reach success with clinical therapies.

"I cannot underscore enough how relevant this landmark study is. Our current and rapidly expanding knowledge of this complex disease highly suggests that the likely 'first cure' to be discovered will be specific to a genetic mutation for PD, which will then serve as a steppingstone for the ultimate cure for the general PD population."

- Hubert Fernandez, MD,
 Head of Movement
 Disorders at Cleveland Clinic
 and co-chair of Parkinson
 Study Group

In 2022, we expanded the study and made access to genetic testing possible for people with Parkinson's in all 50 U.S. states, Puerto Rico, the Dominican Republic and Canada. In the next two years, we will introduce PD GENEration to Israel and other countries, bringing a new level of diversity and depth to Parkinson's genetic research, which can lead to greater insights.

The study continues to expand its reach with the addition of testing sites and collaborations with clinicians in historically excluded communities. This includes a partnership with Morehouse School of Medicine, aiming to make the study more accessible for Black and African American persons in Atlanta, GA.

Similarly, the Foundation extensively engages Hispanics and Latinos and provides genetic counseling in English and Spanish, a first-of-its-kind for a study of this scale. Roughly 22% of PD GENEration participants are of Latino or Hispanic descent, a landmark achievement for any clinical research study of this size.

"Through the expansion of the PD GENEration study to more populations, we are bringing diversity to genetics data," said Carlos Singer, MD, professor of neurology at the University of Miami Miller School of Medicine. "In turn, this will accelerate the pace of research to help all people with Parkinson's, regardless of where they live."

The study's data are analyzed in real-time by the Parkinson's Disease Gene Curation Expert Panel (GCEP), an international working group of genetic experts focused on neurodegenerative diseases formed by the

Foundation within the NIHfunded Clinical Genome (ClinGen) Resources.

Currently, investigators have found that approximately 14% of the overall cohort have a genetic form of PD — a significant observation compared to the long-standing estimate of 10%.

PD GENEration empowers participants to understand their genetic results. This knowledge can help them make more informed decisions about care and take advantage of clinical studies that are newly accessible to them. Genetics can not only help us uncover potential causes of Parkinson's, but results from this study can lead to improved treatments and care for everyone with Parkinson's.

Enroll and help us further PD genetics research at Parkinson.org/PDGENEration.

PD GENEration

IAPPING THE FUTURE OF PARKINSON'S DISEASE

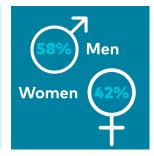
Parkinson's Foundation Global Genetics Study Milestones

7,500

People with Parkinson's disease (PD) have received genetic testing and

50%

Toward PD GENEration goal of 15,000 participants



50 U.S. States
Puerto Rico
Dominican Republic
& Canada
offer PD GENEration



4%

of participants have a genetic form of Parkinson's PD GENEration elevates the **diversity** of the PD genetics field, which accelerates the pace of research that helps all people with Parkinson's.

17%

Hispanic and Latino participants have a genetic link to PD 750+

Hispanic and Latino Participants 160+ Black and African American Participants

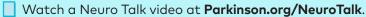
Take 6 Minutes to Help End Parkinson's

April is Parkinson's Awareness Month. Our new incidence study found that every 6 minutes, someone will be diagnosed with Parkinson's disease (PD) in the U.S. To help us create a world without Parkinson's, take 6 minutes to raise PD awareness. Here are some ways you can #Take6forPD:

#Take6forPD to Advance Research

In the U.S., 90,000 people will be diagnosed with PD this year. Take 6 minutes to raise awareness for PD research aimed to improve treatments and find a cure.

Register to participate in our global genetics study, PD GENEration a
Parkinson.org/PDGENEration.



- Sign up for an educational Expert Briefing webinar at Parkinson.org/ExpertBriefings.
- Donate to our Parkinson's Virtual Biotech fund at Parkinson.org/VirtualBiotech.



#Take6forPD to Improve Access to Care

Research shows that seeing a PD specialist leads to better outcomes. Take 6 minutes to raise awareness to help every person living with PD have access to high-quality care.

Call our free Helpline at 1-800-4PD-INFO (1-800-473-4636) to ask a PD question
get a referral or find a nearby exercise class.

Find expert care in your area at Parkinson.org/InYourArea.

- Advocate for your best care when hospitalized. Order or download an Aware in Care hospital safety kit at Parkinson.org/AwareInCare.
- Deep dive into a PD topic that is important to you at **Parkinson.org/Library**.

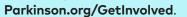


#Take6forPD to Help Empower & Educate

Finding the right information and resources early in the PD journey can make life better for people with PD. Take 6 minutes to help empower yourself or your community through educational resources.

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	Join our e-mail lis	FOI PARKINSON	1.org/Subscribe

- Register for an educational or local event at **Parkinson.org/Events**.
- Subscribe or listen to our podcast at **Parkinson.org/Podcast**.
- Volunteer, run in an endurance event or design your own fundraiser at



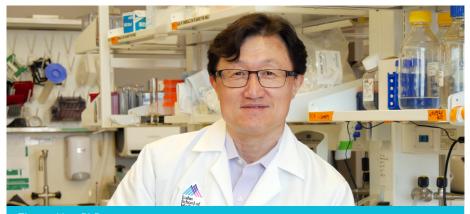


Take 6 minutes to help create a world without Parkinson's at Parkinson.org/Awareness.





New Research Center Explores Dopamine Nerve Cell Diversity in Parkinson's



Zhenyu Yue, PhD

By the time a person is diagnosed with Parkinson's disease (PD), more than 60% of their brain's dopamine nerve cells (neurons) have already died. There are no medications that can preserve the existing dopamine neurons or reverse the disease. However, better understanding how different types of dopamine neurons work, could get us closer to designing more effective treatments. The newest Parkinson's Foundation Research Center, the Icahn School of Medicine at Mount Sinai in New York, is doing just that.

Center director Zhenyu Yue, PhD, and his research team are investigating the diversity of dopamine nerve cells in the brain and their vulnerability. The team recently completed a study profiling more than 300,000 cells from a specific region in the brain vulnerable in Parkinson's. They identified different types

of dopamine neurons in human brains, and found that people with PD have significantly fewer dopamine neurons compared to those without PD.

"I feel privileged to have received this award for our center, as it offers an amazing opportunity to work with a group of outstanding clinical and basic research scientists at Mount Sinai. This award will encourage me to think boldly and attack challenging questions in PD research through collaboration with a diverse team with complementary expertise."

- Zhenyu Yue, PhD

With Parkinson's Foundation funding, the team will now do a deeper dive into the diversity of dopamine nerve cells. Being able to uncover the nuances of the

different types of these nerve cells is essential for the development of new PD medications. In addition, Dr. Yue's team is working to find what leads to the loss of dopamine neurons as PD progresses, and identify ways to help neurons survive, which can ultimately lead to better quality of life for people with PD.

"I thought I could do something to help people," said Dr. Yue, who has dedicated nearly 20 years of his research career to the study of neurodegenerative diseases after the diagnosis of a family member with PD.

Research Centers further the Parkinson's Foundation mission to advance the understanding and treatment of the disease. Centers receive \$2 million each — \$500,000 annually over four years - to fund innovative team science.

Learn more about our critical, research initiatives at Parkinson.org/Research.

Parkinson's Foundation Research Centers are medical or academic centers that advance the understanding and treatment of Parkinson's. Each center investigates three PD research studies. Centers include:

- Columbia University Medical Center
- Icahn School of Medicine
- University of Florida in collaboration with Emory University
- University of Michigan in collaboration with The University of **Texas Southwestern Medical Center**
- Yale School of Medicine



Redefining Intimacy in Parkinson's Disease

With Parkinson's disease (PD), changing relationship roles, stress, medication side effects and PD symptoms can influence sexual health and physical intimacy. Care partners also experience a myriad of health issues that can impact physical connection.

Our new PD Health @ Home Mental Wellness Series highlights mental health conversations. This article complements our virtual event, Redefining Intimacy in Parkinson's Disease & Beyond, featuring certified sex therapist Gila Bronner, MPH. The below tips can help you find new ways to build intimacy with your partner:

Build Connection with Your Partner

Life's pressures and the day-to-day stress of living with PD can cause couples to drift apart. Look for ways to stay connected and continue growing together. Spend quality time together. Go on a date, try a new class, watch a funny movie — anything that unites you and reduces stress. Discussing sex or physical intimacy issues can be uncomfortable and frustrating. Many couples need help navigating these conversations.

Enjoy the Moment

Even just a minute of physical touch can boost "happiness" hormones, such as oxytocin and serotonin, and reduce "stress" hormones that can cause anxiety and restlessness. Having expectations that physical touch will lead to a specific outcome can eliminate the pleasure of the experience, create anxiety or even lead to fear. Put on music, take time to exchange gentle touch and enjoy the experience — without demands or expectations.

Broaden Your Horizons

If you and your partner are experiencing mismatched sexual desire, talk about it. Is it due to stress, fatigue, hormones, PD or another health issue? Staying connected through touch is vital to a healthy, loving relationship. Try to meet each other where you are. You might need to adapt your techniques, explore modifications or even plan out those moments that go beyond sensual touch.

Discuss Intimacy with Your Healthcare Team

Many PD symptoms affect sexual health in men and women, as well as the ability to touch, be close, communicate or even concentrate. Some of these issues can be treated. Talk to a medical professional you feel comfortable with. Your neurologist, primary care doctor or another healthcare professional can offer advice, treatment or refer you to a specialist.

Be Aware of Medication Side Effects

Dopamine agonist medications can lead to impulse control and hypersexuality issues, which can put the person with PD or others in unsafe or unhealthy situations. If you notice these side effects, tell the neurologist right away, as these medications may need to be adjusted. Know that other medications can also impact sexual function.

Discover the PD Health @ Home Mental Wellness series and other weekly live events at Parkinson.org/PDHealth.



Parkinson's Virtual Biotech Drugs in Research & Development

"Parkinson's Virtual Biotech investments can exponentially advance the opportunities for new Parkinson's medications," said James Beck, PhD, Parkinson's Foundation chief scientific officer. "Through this new partnership, we can now broaden our research to support every type of research from basic science to clinical studies."

Parkinson's Virtual Biotech, the international drug discovery and development program of Parkinson's UK, is a groundbreaking global movement working to deliver life-changing new Parkinson's disease (PD) treatments in years, not decades. Today, Parkinson's Virtual Biotech funds 11 new medications and therapies in research and development. Here are three of the programs underway:

1. Exploring the potential of ondansetron for treating hallucinations in people with PD or Lewy body dementia

STAGE: CLINICAL TRIAL

It is estimated that around 75% of people with Parkinson's experience hallucinations, but treatment options remain limited. The drug used to alleviate nausea after chemotherapy called ondansetron (brand name Zofran) is being tested as a treatment for visual hallucinations in people with PD or Lewy body dementia.

Key Takeaway: This study is a phase 2 clinical trial with 306 enrolled

participants. With available safety data, positive results from this study could see this repurposed medication quickly progress to become an available treatment.

2. Molecules that restore the power plants of brain cells

STAGE: IN DEVELOPMENT

University of Sheffield researchers are developing molecules that can boost the function of mitochondria (the power plants of brain cells). Over the next 12 months, the team will develop and test the drug-like molecules in cells from people with PD. If successful, the molecules will move forward into testing, then clinical trials.

Key Takeaway: This research takes important steps toward creating a drug that can protect dopamine-producing brain cells and slow the progression of PD.

3. New treatment aims to relieve PD-like symptoms and target inflammation to slow onset

STAGE: CLINICAL TRIAL

Inflammation is a process that allows the body to fight things like

STAGES OF RESEARCH



In Development: A research team turns promising discoveries into potential new treatments.



Clinical trials: New treatments are carefully tested in study participants.

infection and toxins. If chronically active when it shouldn't be, as might be the case in PD, it can cause harm to healthy cells.

Pharmaxis is investigating if a drug called PXS-4728 can reduce inflammation in the early stages of Parkinson's. This study will enroll 40 people who experience sleep disorder known as isolated rapid eye movement sleep behavior disorder (iRBD). As many as 70% of people with iRBD go on to develop Parkinson's.

Key Takeaway: The hope is that this drug might be able to slow the onset of PD symptoms in this group of high-risk people, ultimately helping find a way to the slow the progression of Parkinson's.

Learn more about Parkinson's Virtual
Biotech projects at

Parkinson.org/VirtualBiotech.

PARKINSON REPORT SPRING 2023 9

Partnering with Morehouse School of **Medicine to Diversify Genetics Data**



masi Kumeh, Parkinson's Foundation rector of research partnerships, and Chantale Branson, MD, at a Morehouse

Chantale Branson, MD, is the firstever movement disorders specialist — a neurologist with specialized training — to work at Morehouse School of Medicine in Atlanta, GA. In addition to treating and helping people with Parkinson's disease (PD), she is committed to improving the health disparities Black and African American individuals face in the PD community.

Under Dr. Branson's direction. Morehouse is the first historically Black institution of medicine to become a PD GENEration: Mapping the Future of Parkinson's Disease research site. Every research site works alongside the Parkinson's Foundation to offer genetic testing and counseling to people with PD, in English or Spanish, at no cost.

"We have a very diverse group of people who are participating," Dr. Branson said. "We want to

encourage more community members to take part in the study so they can improve their disease management, learn more about potential implications for their family, be connected with relevant PD trials and impact the future development of improved treatments — for themselves and future generations."

To date, Morehouse has enrolled the most Black and African American participants for PD GENEration, which is on track to reach its 1,000 participant goal for this demographic.

Today there are numerous regulations in place set to ensure clinical trials follow ethical practices, but this was not always the case. "Due to the historical issues and in regard to race in the United States, research has not been very common within the community, particularly within different diseases such as the Parkinson's disease and neurological disorders," said Dr. Branson.

Openly discussing the historical wrongs of medical research, as well as reminding patients of the safeguards in place that protect them are cornerstones for how Dr. Branson practices medicine. "Having that conversation about understanding the past in order to discuss the present is very important," said Dr. Branson.

No two people with Parkinson's are identical, which is why ensuring diversity and inclusivity

in Parkinson's research, like PD GENEration, is critical to accelerating breakthroughs towards a cure. Diversity in research accelerates the rate that researchers can better understand PD and drives better outcomes for the entire PD community.

Populations of focus — including Black and African Americans, Latinos, women and others — are underrepresented in research often receive less care. Helping populations of focus find quality Parkinson's care is a value shared by the Parkinson's Foundation and Morehouse.

"Everyone has been very excited to participate in this particular study," said Dr. Branson. "I want to encourage community members to take part in PD GENEration, so they can improve their disease management, learn more about their family's risk of Parkinson's disease and potentially be connected to clinical trials."



Enroll and learn more about our global genetics study at Parkinson.org/PDGENEration.

Dr. Kenneth M. Baird: **His Contribution to Science** and Parkinson's



Dr. Kenneth M. Baird was not only a renowned physicist and inventor with visionary ideas who among other achievements helped redefine the length of the meter, and invented an anti-counterfeiting technique adopted universally, he was also a renaissance man who enjoyed languages, travel, music, sports, boating, and even flying a small plane. He had an extraordinarily creative mind and insatiable curiosity, determined to solve any problem, and try any new endeavor, always eager to share his vast knowledge with those around him. His passion was for his family and for science, so when Dr. Baird was diagnosed with Parkinson's later in life, he set out to learn all he could about the disease in hopes of deterring its progression.

"His quest for knowledge was unparalleled," said Heather Galbraith, MD, his doctor who came to be a good friend. "I've never had a patient ask me so much about their disease process, which he did everything in his power to fight."

When Dr. Baird's daughter, Esther, learned about PD GENEration: Mapping the Future of Parkinson's Disease — an initiative to offer genetic testing to people with PD, she approached her 99-year-old father to see if he might be willing to participate. Naturally, he responded "yes," anxious to contribute to clinical research that might lead to

"He was so happy to join the study because advancing science and assisting in future research about Parkinson's was important to him," said Dr. Galbraith. "Even at the end of his journey here on earth, he was so committed to being part of that."

Esther's hope is that her father's story will inspire others to participate in the PD GENEration initiative and to contribute to Parkinson's research so that a cure may be found for this debilitating disease which affects so many.

Help us advance Parkinson's research. Contact Kate Nelson, **Associate Vice President of Individual** Giving, at knelson@parkinson.org.



continents raising more than \$75,000 in honor of his Dad, Rajit. "My father is my hero and my inspiration. In his younger days, prior to his Parkinson's diagnosis, he was an athlete, an adventurer, and an avid mountaineer," he said.

Become a Parkinson's Champion at Parkinson.org/Champions.



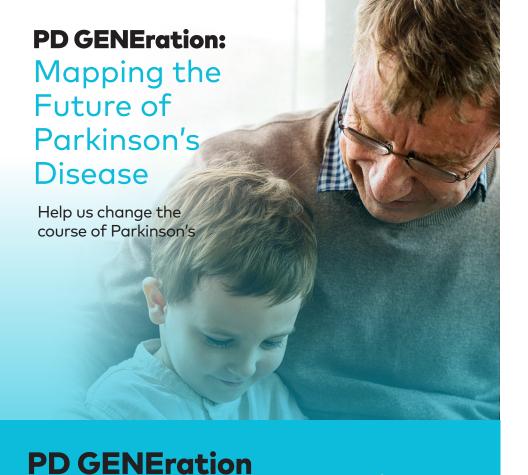
Katie Gorman and her team, "Pauly Dawg's Pack," of 33 riders raised more than \$10,000 at Parkinson's Revolution Buffalo. "May we all handle any struggle we're faced with the same way my dad has handled his Parkinson's diagnosis — with bravery and a sense of humor," she said.

Join the Parkinson's Revolution at Parkinson.org/Revolution.

Our Reach Further campaign will invest \$30 million to accelerate Parkinson's research, improve care and increase access to qualityof-life programs.

Help us Reach Further Parkinson.org/Reach





Parkinson.org/PDGENEration



HELPLINE

1-800-4PD-INFO (473-4636)

Get your PD questions answered. Mon-Fri, 9 a.m. – 7 p.m. ET English / Español

E-NEWSLETTER

Parkinson.org/Register

Get all the latest headlines.

NEW ARTICLES

Parkinson.org/Blog

Stay up to date with Parkinson's news, treatments and research.

NEW EPISODES

Parkinson.org/Podcast

Experts discuss the newest techniques and treatments.

Connect with us on





Let us answer your Parkinson's questions!

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.

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1359 BROADWAY, SUITE 1509 NEW YORK, NEW YORK 10018

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Comments or Questions? Contact us.

contact@parkinson.org Toll-Free: 1-800-4PD-INFO (473-4636) Parkinson.org