

Calendar of Events

2

Q&A with our Chief Scientific Officer

3

FEATURE

Promising Parkinson's Research Studies Underway

4

Top 5 Ways to Engage in Parkinson's Research

5

PD GENERation Expands to Reach New Populations

6

7 Genes Related to Parkinson's and What They Mean

7

Tips for Living Alone with Parkinson's

8

The Parkinson's Journey: Understanding Progression

9

Making Mental Health Care a Priority in Parkinson's

10

Legacy Gift Furthers Parkinson's Foundation Mission

11



Parkinson's
Foundation

Parkinson Report



**Promising Parkinson's
Research Studies Underway
PAGE FOUR**

Event Calendar

SEPTEMBER

- 7 Expert Briefing: Use it or Lose it - The Impact of Physical Activity in Parkinson's**

Register: Parkinson.org/ExpertBriefings

- 17 Moving Day Buffalo**

Register: MovingDayBuffalo.org

- 24 Parkinson's Disease and the African American Community: Part 2**

Learn More: Parkinson.org/Events

Moving Day Memphis

Register: MovingDayMemphis.org



OCTOBER

- 2 Moving Day Columbus**

Register: MovingDayColumbus.org

- 5 Expert Briefing: Understanding Gene and Cell-Based Therapies in Parkinson's**

Register: Parkinson.org/ExpertBriefings

- 8 Moving Day Long Island**

Register: MovingDayLongIsland.org

Moving Day Los Angeles

Register: MovingDayLosAngeles.org

- 9 Chicago Marathon**

Learn More: Parkinson.org/Champions

- 22 Moving Day Atlanta**

Register: MovingDayAtlanta.org

Moving Day @ Home (virtual)

Register: MovingDayatHome.org

- 29 Moving Day Miami**

Register: MovingDayMiami.org

NOVEMBER

- 2 Expert Briefing: Let's Talk About Dementia**

Register: Parkinson.org/ExpertBriefings



- 5 Moving Day NC Triangle**

Register: MovingDayNCTriangle.org

Moving Day Phoenix

Register: MovingDayPhoenix.org

- 6 New York City Marathon**

Learn More: Parkinson.org/Champions

- 12 Moving Day Tucson**

Register: MovingDayTucson.org

- 19 Philadelphia Marathon**

Learn More: Parkinson.org/Champions

Virtual events are open to all and available online. View all upcoming events at Parkinson.org/Events.

Help us invest an additional \$30 million to accelerate Parkinson's research, improve care and increase access to quality-of-life programs.

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Parkinson.org/Podcast



Q&A

with Our Chief Scientific Officer, Dr. Jim Beck



Jim Beck, PhD, Chief Scientific Officer of the Parkinson's Foundation, answers your questions about Parkinson's disease (PD) research and what brings him hope on the horizon.

What is happening right now in Parkinson's research?

We are trying to slow and stop Parkinson's through research. We must understand what causes it and how it progresses in order to end it. It's not an engineering issue — it's not simply building a bridge from here to there. For PD, we are trying to solve the fundamental problems that will allow us to tackle the chasm that is between us and a world without PD. The Parkinson's Foundation works to fill that void through a multi-pronged research approach.

What kind of research does the Parkinson's Foundation fund?

We seek to fund the best science. Some of the ways we do this includes funding research centers with teams working on multiple PD studies together; our genetics initiative; and grants that fund scientists. Research is a human and creative endeavor. It's people who are devoting their lives to analyze and find a solution to Parkinson's. Through everything we fund we make steady progress forward.

Does the Foundation fund "high-risk" and "high-reward" research?

Yes! For researchers, it is nearly impossible to get funding for high-risk studies that test new ideas and are not built off existing data. No one knows exactly what will work, but a PD research breakthrough can happen at any time, at any lab. That is why we fund these ideas.

What will it take to find a cure?

We know a cure to PD will happen as a result of our research efforts along with the community to better understand PD. But there is no shortcut. To one day solve this disease we are taking a multi-prong approach to decipher the underpinnings and fundamentals of PD while also speeding clinical research and trials that test new ideas.

What Parkinson's Foundation study gives you the most hope?

PD GENERation: Mapping the Future of Parkinson's Disease, our genetic study that offers genetic testing and counseling at no cost. Genetics can not only help us uncover potential causes of Parkinson's but results from this study can identify people who can help test and identify likely treatments for those with genetic ties to PD. We hope this can lead to improved treatments and care for everyone with Parkinson's.

To stay up to date on our research efforts, watch our Neuro Talk videos at [Parkinson.org/CSOJamesBeck](https://www.parkinson.org/CSOJamesBeck).



**Follow our Research
Team on Twitter
[@PFResearchTeam](https://twitter.com/PFResearchTeam)**



Promising Parkinson's Research Studies Underway

While working to make life better today for everyone living with Parkinson's disease (PD), the Parkinson's Foundation is focused on the next Parkinson's breakthrough. To change the course of Parkinson's, the Foundation funds three types of research:



Understanding Biology

This research seeks to understand how Parkinson's impacts the brain and body at a cellular and molecular level. Understanding the biological changes caused by PD can help investigators work towards developing new treatments.



Understanding Neural Circuitry

These studies take a big-picture view of how the brain and nervous system work. Both paths help us understand how things should function and where problems arise.



Understanding Symptoms

Parkinson's symptoms can change everything from the way a person moves to the ways they experience the world. Investigating movement, and non-movement symptoms helps researchers create new treatments.

The Parkinson's Foundation invested \$4.3 million across 29 research grants to support the work of promising scientists in the PD field in 2021. We checked in with three of these funded researchers working to make life better for people with Parkinson's.

1) Understanding Biology: Sex Differences in Parkinson's

Biological sex has a strong influence on the symptoms and course of Parkinson's. Ellen Hess, PhD, of Emory University, a Parkinson's Foundation Center of Excellence, received a Parkinson's Foundation George G. Kaufman Impact Award to study sex differences in Parkinson's.

Previous research has established that males are two times more likely than females to develop Parkinson's. Men also develop the disease at an earlier age than females. Women tend to have more PD-related tremors, greater anxiety and depression, and more severe involuntary movements caused by the PD medication levodopa.

"The biological reasons for the differences between the sexes are largely unknown and unexplored but nonetheless very important because understanding these differences could ultimately lead to personalized and more effective treatments that are targeted to males or females," said Dr. Hess. "The Parkinson's Foundation grant

is providing my laboratory the opportunity to expand the focus of our work and, for the first time, to contribute to Parkinson's disease research in a meaningful way."



Ellen Hess, PhD,
Emory University,
Parkinson's Foundation
Research Grantee

2) Understanding Neural Circuitry: Improving Movement

As Parkinson's advances it can weaken cognition, movement and the senses, which often leads to falls. Taraz Lee, PhD, of the University of Michigan, received a Parkinson's Foundation Stanley Fahn Junior Faculty Award to study

the relationship between movement and cognitive systems in the brain known as the Attentional-Motor Interface.



*Taraz Lee, PhD,
University of Michigan,
Parkinson's Foundation
Research Grantee*

"Our research has the potential to deepen our understanding of the progression of PD," said Dr. Lee. "Perhaps, more importantly, our work also has the potential to open a new avenue for a therapeutic target that might improve day-to-day functioning in people with PD in the early stages of the disease."

Dr. Lee will use a non-invasive brain stimulation technique called transcranial magnetic stimulation (TMS) to find out if disrupting activity in a specific area in the brain will worsen motor deficits in people with Parkinson's, and whether enhancing activity in this same brain area may lead to improvements in motor function.

Such a finding would provide a promising avenue for treatment. "I think it is incredibly important to understand the basic mechanisms of the brain to arm us with the knowledge necessary to fight diseases like PD and organizations like the Parkinson's Foundation really make a difference in helping to support researchers trying to do this work," Dr. Lee said.

3) Understanding Symptoms: The Loss of Cognitive Function

Research suggests PD symptoms arise from an imbalance between two key brain chemicals: dopamine and acetylcholine. Scott Owen, PhD, of Stanford University, received a Parkinson's Foundation Stanley Fahn Junior Faculty Award to study, to study where and how acetylcholine acts in the brain to facilitate flexible learning, and how it affects following the loss of dopamine.

"Changes in cognitive function are comparatively poorly understood, but can be life-changing and debilitating," said Dr. Owen.

"By investigating mechanisms underlying these changes using mouse models, and how these mechanisms respond to common treatments including Levodopa and deep brain stimulation, our goal is to build a fundamental understanding of the underlying biology that can be used to modify, develop and innovate future treatments that are tailored to improve cognitive function."



*Scott Owen, PhD,
Stanford University,
Parkinson's Foundation
Research Grantee*

Dr. Owen looks forward to furthering cognitive research beyond this study. "Building on the support from the Parkinson's Foundation, I anticipate that this work will be a core focus of my lab for many years."

Learn more about ongoing research studies at Parkinson.org/ResearchWeFund.

Top 5 Ways to Engage in Parkinson's Research

Parkinson's research is the only way we can improve and develop treatments, and one day a cure. Here are five ways you can engage in research:

- 1. Enroll in PD GENEration:** This study offers genetic testing and counseling at no cost for people with Parkinson's. Parkinson.org/PDGENERation
- 2. Become a research advocate:** This program brings together people who live with PD and those developing new treatments. Parkinson.org/ResearchAdvocate
- 3. Sign up for Parkinson's Foundation Surveys:** Share your PD experience to help us advance Parkinson's care. Parkinson.org/Surveys
- 4. Read Science News:** We sort through the latest published PD research studies and give you the takeaways. Parkinson.org/Blog
- 5. Listen to PD experts discuss the latest in research in our podcast episodes.** Parkinson.org/Podcast





PD GENERation Expands to Reach New Populations

"Diversity is critical when it comes to Parkinson's disease (PD) research," said Anna Naito, PhD, Associate Vice President of Research Programs of the Parkinson's Foundation who helps lead the Foundation's genetics study. "Parkinson's research has long been static and lacked diverse populations. Considering the unique experiences of every person with PD, through PD GENERation we are dedicated to diversifying our data, which will, in turn, accelerate the pace of research to help all people with Parkinson's."

PD GENERation: Mapping the Future of Parkinson's Disease is a soon-to-be global initiative that offers genetic testing for clinically relevant Parkinson's-related genes and genetic counseling at no cost for people with Parkinson's. The goal is to enroll 15,000 participants. The study is currently at 27 percent of its goal and working towards adding more testing sites — while still offering at-home testing and in-person sites in the U.S.

The study is quickly expanding, allowing for more accessibility for participants. Currently, study participants are enrolled from all 50 U.S. states, Puerto Rico, the Dominican Republic and Canada.

Dedicated to Diversity

With inclusivity being one of the study's goals, PD GENERation is engaging the Latino/Hispanic and Black and African American communities as a start. All components of the study, including genetic testing and counseling, is provided in English or Spanish. More than 300 Latino participants have enrolled, with plans to enroll more.

"PD GENERation will soon be a global study," said Dr. Naito. "We are currently in the process of expanding to Israel and several other countries that will bring a new level of diversity and depth, leading to the possibility for greater insights through these data."

The PD GENERation team is also working to reach new populations within the U.S. by collaborating with clinicians and participants in underrepresented communities. One example is the new partnership between the Parkinson's Foundation and Morehouse College to make the study more accessible for the Black and African American community in Atlanta, GA and beyond.

Parkinson's and Genetics

The research community has long used the statistic that 10 to 15 percent of Parkinson's is caused by genetics. Currently, PD GENERation has found that 14 percent of participants have a genetic link to Parkinson's.

PD GENERation is the most comprehensive at-home test available, testing for seven genes related to Parkinson's ([learn more on page 7](#)). Knowing your genetic tie to Parkinson's can help steer treatment options and increase access to participation in more clinical trials.

<div>PD GENERation</div> <div>MAPPING THE FUTURE OF PARKINSON'S DISEASE</div>	<div>By the Numbers</div> <div>Data as of April 2022</div>	3,970
		genetic tests completed
	<div>U.S. Puerto Rico Dominican Republic & Canada offer PD GENERation</div>	14%
		of participants have a genetic link to Parkinson's
		78
		Black & African American participants
		300+
		Latino participants

Learn more and enroll at Parkinson.org/PDGENERation.

7 Genes Related to Parkinson's and What They Mean

PD GENERation: Mapping the Future of Parkinson's uses the most comprehensive genetic test that detects changes (known as variants) in all genes the medical community believes are linked to Parkinson's disease (PD). PD GENERation identifies variants in seven Parkinson's-related genes that include:

1. *GBA*

GBA is the most common PD-related gene, present in five to 10 percent of people with PD. It is also one of the most challenging genes to test. Most *GBA* carriers never develop PD, but those who do may experience PD symptoms at an earlier age compared to those without a genetic form of PD. Pharmaceutical companies are testing drugs that target this gene to help slow or stop the progression of Parkinson's.

2. *LRRK2*

Variants in this gene play a role in about one percent of all people with PD and five percent of those with a family history. Certain ethnic groups have higher prevalence among people with PD, like Ashkenazi Jews (about 15 percent). Many *LRRK2* carriers do not develop PD — those who do often experience milder symptoms of dementia and depression. Pharmaceutical companies are testing drugs that block *LRRK2* variants to treat Parkinson's.

3. *PRKN*

PRKN is the most common genetic mutation associated with young-onset PD, which appears before age 50. *PRKN* carriers may be more likely to experience early symptoms such as bradykinesia (slowness of movement) and rigidity. Drug companies are studying treatments that boost parkin protein activity, which directly impacts dopamine production.

4. *SNCA*

This is the first PD-related gene to be identified. In 1997, Parkinson's Foundation research fellow Roger

Duvoisin, MD, discovered that *SNCA* plays a role in PD. Carriers usually have a parent with Parkinson's, and rarely develop Parkinson's. *SNCA* is often associated with young-onset PD. Researchers are studying this gene to design treatments that can reduce levels of toxic alpha-synuclein in the brain of people with PD.

5. *PINK1*

This is the second most common variant associated with young-onset PD. Carriers experience early symptoms such as bradykinesia and rigidity, and non-motor symptoms may be more common, however, usually experience slow PD progression and respond well to the medication levodopa. Drug companies are studying treatments that could boost *PINK1* activators to help keep cells healthy.

6. *PARK7*

Tied to young-onset PD, this variant leads to a decrease in a protein called DJ-1 that is essential for nerve cell health and interferes with the production of dopamine. Researchers are studying whether treatments focused on DJ-1 could suppress nerve cell death.

7. *VPS35*

Only discovered in 2011, this rare genetic mutation is tied to the onset of PD after age 50. The PD GENERation team is studying *VPS35* to better understand this type of Parkinson's, which can lead to the development of treatment strategies.

Learn more about Parkinson's and genetics at [Parkinson.org/Genetics](https://www.parkinson.org/Genetics).





Tips for Living Alone with Parkinson's

Discussions about Parkinson's disease (PD) often mention a spouse or care partner, but many people with Parkinson's live alone. Living alone with PD comes with its own set of benefits and challenges.

Accepting Your Situation

As a person living alone with Parkinson's, your daily experience is different from someone who lives with a care partner. Each person with PD manages the disease in their own way. Remember that you and your experience are valid.

Social Isolation

Living alone with PD offers independence, but it may also feel isolating. If you experience feelings of apathy or fatigue for more than five days over a two-week period, reach out to a medical professional to discuss treatment for depression.

Staying Connected

Living alone does not mean you are alone. Your network of support may include family, friends, neighbors, coworkers and your medical team. Try out these options to stay connected from home:

- **Join a support group.** Support groups allow you to share your

experiences and engage with the PD community.

- **Participate in an exercise class.** Exercise helps you stay active while managing your PD symptoms.
- **Get involved in your local community.** Volunteering allows you to share your skills while making connections.

Planning for the Future

Living alone adds the responsibility of keeping yourself safe. Starting the planning process early will ensure that you have control over important life decisions. It may be difficult to admit you need assistance after living independently for so long, but safety should always be the priority. If you have trouble moving around your space or accomplishing daily tasks, reach out to someone you trust to adjust your living situation.

Tips for Living Alone with PD

Living alone with PD involves

adapting to your circumstances.

Here are tips for managing everyday tasks:

- **Adjust your living space.** Place essential items where you can easily see and access them.
- **Create a scheduling strategy.** Schedule commitments around the times of day when you typically feel your best. Set timers for your medications.
- **Set out to accomplish one task on the tougher days.** If you are feeling down, try to call one person or achieve one goal for the day.
- **Work towards making new connections or participating in an activity.** This can help boost your motivation and decrease feelings of loneliness.

You may live alone, but that does not mean you are alone. Visit [Parkinson.org/Events](https://parkinson.org/events) for virtual and in-person events and call our Helpline 1-800-4PD-INFO (473-4636) for help finding resources near you.

The Parkinson's Journey: Understanding Progression



Researchers are investigating how to someday slow or stop Parkinson's disease (PD) in its tracks. While scientists are evaluating everything from medications to mindfulness practice for clues, they have discovered some of the biggest benefits start at home.

Healthy Eating

Making nutritious food the mainstay of your meals has countless proven benefits. Studies show targeted nutrition may slow Parkinson's advancement. Eating a whole-food, plant-based, Mediterranean-style diet — including fresh vegetables, fruit and berries, nuts, seeds, fish and more — may be linked to slower PD progression.

Regular Exercise

When you live with PD, exercise is critical to optimal health. The Parkinson's Foundation Parkinson's Outcomes Project shows that people with PD who start exercising earlier and a minimum of 2.5 hours a week, experience a slowed decline in quality of life compared to those who start later. Regular physical activity can slow PD symptom progression, boost balance, improve heart and lung function, increase memory, minimize depression and more. To make exercise work for you:

- Exercise for 150 minutes per week
- Plan a weekly routine that includes aerobic activity, strength training, balance and stretching exercises

- Visit a physical therapist with PD expertise for an evaluation

Exploring Therapy Advances

People with Parkinson's take a variety of medications to manage symptoms. PD researchers have spent decades working to discover therapies to slow or stop Parkinson's.

A 2009 study looked at whether rasagiline — a monoamine oxidase-B (MAO-B) inhibitor that can ease movement symptoms — could put the brakes on disease progression for people in early-stage Parkinson's. The results suggested the possibility that a 1 mg daily dose of rasagiline might hold disease-modifying potential, but a 2mg daily dose did not. Despite the study's uncertainties, it still showed that rasagiline better controlled symptoms for people with PD, which is why it is used in concert with levodopa.

Levodopa is a proven effective therapy. A 2019 study looked at whether starting levodopa earlier or later could change the course of Parkinson's. While research showed levodopa didn't slow PD, it proved starting the medication early on in Parkinson's is effective.

When people who live with PD begin to experience severe motor fluctuations, deep brain stimulation (DBS) can deliver electrical pulses to the brain, easing symptoms and boosting quality of life. Results of a 2020 study proved people with Parkinson's can also get long-term symptom relief with DBS when coupled with optimal medication.

As researchers work to solve Parkinson's, empower yourself by prioritizing your well-being. Wholesome food paired with regular exercise habits and comprehensive team-based treatment are the building blocks of a better life with PD.

This article is based on a Parkinson's Foundation Expert Briefings webinar, Can We Put the Brakes on PD Progression, presented by Joash Lazarus, MD, Multiple Sclerosis Center of Atlanta.

Register for upcoming Expert Briefings webinars at [Parkinson.org/ExpertBriefings](https://parkinson.org/ExpertBriefings).



clinical study of PD, found that apathy and depression are more intrusive and debilitating than movement symptoms for people living with PD.

"Mental health screening should become routine practice in Parkinson's care," Dr. Shah said.

Making Mental Health Care a Priority in Parkinson's

During her training, Hiral G. Shah, MD, observed that a lot of people with Parkinson's disease (PD) had mental health issues that were not being addressed. "Individuals and families felt stigma or hesitation about discussing mental health, but also providers often lacked the sensitivity to be able to recognize these issues," Dr. Shah said.



Hiral G. Shah, MD

Today, Dr. Shah is a movement disorders specialist at Columbia University Medical Center's Multispecialty Neurology Division, a Parkinson's Foundation Center of Excellence. She is driven to improve access to quality care for people who live with mental health conditions and neurodegenerative disorders like Parkinson's.

"I want to be a source of information and comfort to individuals and families who are dealing with PD," said Dr. Shah. "Seeing the way that Parkinson's can impact one's cognitive,

psychological and motor functioning can be really devastating but it also drives me as a physician to take an active role in providing holistic care."

At the outset of her career, Dr. Shah completed specialized training at Columbia, funded through the Parkinson's Foundation Movement Disorders Fellowship Program. This program, which supports medical institutions in providing fellows with a two-year, mentored training, has helped 150 neurologists become certified movement disorders specialists.

"My fellowship training was instrumental in my professional development," said Dr. Shah. "Without the fellowship, I wouldn't be where I am today."

In Dr. Shah's medical experience, unrecognized mental health issues often overshadow movement symptoms in terms of quality-of-life impact. The Parkinson's Outcomes Project, the largest-ever

Increasing access to healthcare and representation among priority populations in Parkinson's care is also paramount to Dr. Shah. In developing educational materials for the PD community, she found that Black people with PD she spoke to felt extremely isolated. "They told me that they have never been in the room with someone else who is Black and has Parkinson's," she said.

This realization led to her latest project: publishing a book, due out this summer, about the Black and African American experience with PD. "My hope is that people might find a piece of themselves in the stories, something that they can relate to, which helps them to see that they're not alone."

Dr. Shah credits the Parkinson's Foundation with being a critical resource for her patients as well as a source of professional connection. "The Foundation has always been really enthusiastic and encouraging of my work," said Dr. Shah. "When people with mutual interests and common concerns come together, it really helps advance the cause."

Read the latest in Parkinson's articles about research and more at [Parkinson.org/Blog](https://www.parkinson.org/Blog).



Legacy Gift Further Parkinson's Foundation Mission

Creating a future without Parkinson's disease (PD) was a high priority to Parkinson's Foundation supporter Leonard Eisenberg. Leonard, who battled Parkinson's for over 20 years, designated an impactful gift from his estate to the Parkinson's Foundation. The recently received bequest will help advance the Foundation's mission in the coming years.

Born in Brooklyn, NY, Leonard spent most of his life in Long Island before retiring with wife Bernice to Boca Raton, FL. He was a decorated World War II Army veteran who served honorably in the South Pacific. He went on to partner with

his brother in their construction and development firm, Eisenberg Sons Carpentry.

"Dad was incredibly hardworking and never one to sit still," said his son Michael Eisenberg. "Parkinson's gradually took everything away: from his ability to move, to his ability to do things with his hands and his ability to speak and express himself. It was very devastating to him."

Michael reflected on his father's intentions in leaving such a significant legacy: "It was important to dad to keep people from having to go through what he went through. It is my hope that this gift will help people with PD enjoy longer, healthier lifespans."

Help us fund research that advances Parkinson's treatments and medications. Contact Kate Nelson, Associate Vice President, Individual Giving, at knelson@parkinson.org to learn more.



Teresa Jackson biked 300 miles across Virginia accompanied by her husband and support team in April. Teresa rode for herself and wore the names of others living with Parkinson's on her cycling shirt. She raised more than \$20,000. "I am not a cyclist, but I am someone that wants to make a difference in the world," she said.

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



In April, the Stonehill College Gaming Club raised funds for the Parkinson's Foundation through a weekend of gaming and livestreaming through their "2022 Stream to Beat Parkinson's" event. They raised more than \$3,000 playing various games while raising funds on campus.

Learn more at Parkinson.org/Stream4PD.

SUPPORT THE FIGHT AGAINST PARKINSON'S

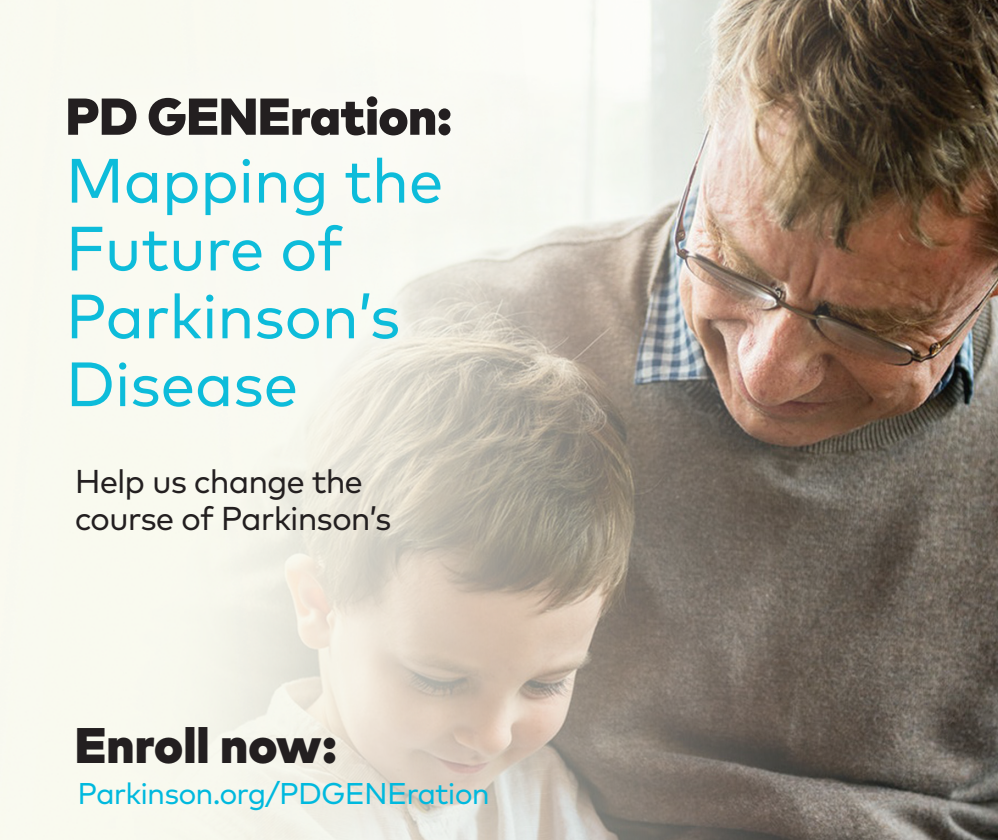
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course of Parkinson's

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