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### April

4. **New Jersey Uncorked**  
   Closter, NJ  
   Learn more: Parkinson.org/NJuncorked

6. **Moving Day Tampa Bay**  
   Register: MovingDayTampa.org

   Register: Parkinson.org/ExpertBriefings

13. **Parkinson’s in the Light of Day: An Event for the Newly Diagnosed and Their Families**  
    Edison, NJ  
    Learn more: Parkinson.org/NewlyDiagnosedNJ

23. **Women and PD**  
    Omaha, NE  
    Learn more: Parkinson.org/WomenNE

27. **Parkinson’s Unity Walk**  
    New York, NY  
    Learn more: UnityWalk.org

### May

5. **Mind, Mood and Motion**  
   Independence, OH  
   Learn more: Parkinson.org/ClevelandMMM

5. **Moving Day San Francisco**  
   Register: MovingDaySanFrancisco.org

7. **New York Gala**  
   New York, NY  
   Learn More: Parkinson.org/Gala

17. **Celebrate Spring Boston**  
   Learn more: Parkinson.org/CSBOS

18. **Moving Day Albuquerque**  
    Register: MovingDayAlbuquerque.org

19. **Moving Day Nashville**  
    Register: MovingDayNashville.org

21. **New Frontiers in Research and Care**  
    Golden Valley, MN  
    Register: Parkinson.org/MN-Spring

### June

8. **Moving Day Baltimore**  
   Register: MovingDayBaltimore.org

11. **Expert Briefings Webinar: When Care Comes to You: Tips for Using Home Health Aides, PTs and OTs**  
    Register: Parkinson.org/ExpertBriefings

22. **Moving Day Cleveland**  
    Register: MovingDayCleveland.org

23. **Parkinson’s Foundation and University of Minnesota Learning Institute**  
    Minneapolis, MN  
    Learn More: Parkinson.org/PAIRtraining

29. **New Frontiers in Research and Care**  
    Chicago, IL  
    Learn More: Parkinson.org/Events

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FOR A FULL LIST OF EVENTS VISIT PARKINSON.ORG/EVENTS.
A Note From the CEO

Every April, during Parkinson’s Awareness Month, we get excited by the opportunity to amplify Parkinson’s awareness, to remind and educate people that there are 1 million Americans fighting to live better lives with Parkinson’s disease (PD). However, not all of them get the care they need, which is why we’re here to empower the PD community, bring expert care to more people and strengthen our research efforts as we look for a cure.

Together, we made lives better in 2018. Your support allowed us to help even more people with Parkinson’s. Because of YOU, we were able to:

• Expand our global Centers of Excellence network to 45 Parkinson’s expert care centers.
• Help more people through our extended Helpline hours — open weekdays from 9 a.m. to 8 p.m. ET at 1-800-4PD-INFO (473-4636) in English and Spanish.
• Increase research funding to $6.2 million, funding 53 research grants that support the work of promising scientists in the PD field.
• Host a summit for caregivers. Caregiver Summit | Cumbre Para Cuidadores sessions are now available at Parkinson.org/Summit to help even more caregivers in our community.

This year, we’re excited to launch #KeyToPD, highlighting keys to living well with Parkinson’s. We want to hear your tips to live well with PD so we can share them with our community (find out how on page 10).

Top 5 Keys to PD

This Parkinson’s Awareness Month, we want to hear your #KeyToPD. Here are the Foundation’s top five keys to living a better life with Parkinson’s.

1. Find a neurologist. Regular neurologist care can save the lives of thousands of people each year. Neurologist care saves about 4,600 lives each year in the U.S. alone.

2. Get answers. Call our 1-800-4PD-INFO (473-4636) Helpline or visit Parkinson.org to get your Parkinson’s questions answered — at any stage of PD.

3. Put together a care team. People living with PD who seek expert care have better outcomes — complication risks are lower, they enjoy better quality and longer lives.

4. Establish an exercise routine. Increasing physical activity to at least 2.5 hours a week can slow decline in quality of life for people with PD.


Visit Parkinson.org/Awareness to learn more.
Understanding the connection between Parkinson’s disease (PD) and genetics can help us understand how the disease develops and ultimately how it can be treated or cured.

The Parkinson’s Foundation Genetics Initiative, PD GENEration, is the first national Parkinson’s study to offer genetic testing in a clinical setting with counseling for Parkinson’s-related genes.

“The study is groundbreaking in Parkinson’s research because it provides a genetics map to people with Parkinson’s through their clinicians,” said Roy Alcalay, MD, MS, Columbia University Department of Neurology and Lead Principal Investigator. “This study offers people with Parkinson’s clinically meaningful results through a comprehensive mechanism including a certified lab and genetic counseling.”

PD GENEration will officially launch in six pilot sites, all medical centers that provide expert PD care and are designated as Parkinson’s Foundation Centers of Excellence, that will be announced later this year.

Genetics and Parkinson’s
Genetics can be a powerful tool used to help us uncover key mechanisms responsible for slowing or stopping the progression of Parkinson’s, ultimately improving care and speeding development of new treatments.

Scientists believe a combination of genetic and environmental factors cause Parkinson’s disease — with genetics causing about 10% to 15% of all Parkinson’s. In some families, changes (or mutations) in certain genes are inherited or passed down from generation to generation.

Over the years, scientists have studied DNA from people with Parkinson’s, comparing their genes. They discovered dozens of gene mutations linked to Parkinson’s that are now being researched and studied for what role they play in Parkinson’s.

Genetic Testing
Researchers believe that understanding genetic differences across people with Parkinson’s can uncover important clues about how and why every person experiences PD differently. Genetic testing may help improve Parkinson’s care. However, genetic tests are either not available or not affordable, not covered by health insurance or not
offered with genetic counseling. Most people with Parkinson’s and their clinicians do not know if they carry genetic mutations linked to Parkinson’s.

The Parkinson’s Foundation is addressing these unmet needs through a five-year initiative, offering genetic testing coupled with counseling services to people with Parkinson’s through Centers of Excellence and Parkinson Study Group sites. The study’s goal is to track the genetic makeup of 15,000 people with Parkinson’s across approximately 50 U.S. sites. The study will ultimately lead to improving care, expanding research and accelerating enrollment in clinical trials.

More precisely, the genetic test done through the study will identify all possible changes in LRRK2 and GBA genes that are relevant to PD. LRRK2 and GBA are the genes most commonly associated with PD. Common at-home tests with a genetic component only look for one of many possible changes in these genes.

“This study not only furthers Parkinson’s research, but will empower every participant,” said James Beck, PhD, Chief Scientific Officer at the Parkinson’s Foundation. “When people with Parkinson’s know their genetic data, they will be able to work with their health team to better manage their disease and qualify for more clinical studies.”

PD GENEration will ultimately give participants more information about their own disease, allowing them to work alongside their healthcare professional to capitalize on this new information while receiving genetic counseling. When it comes to care, clinicians will be better informed about their patients and can provide better treatment plans.

“The Parkinson’s Foundation is always looking for the best leads in research to help people with Parkinson’s live their most active lives, while also looking for a cure,” Dr. Beck said. “Analyzing and assessing genetics through this comprehensive study can play a crucial piece in this complex puzzle.”

The Parkinson’s Foundation is currently recruiting 600 participants to enroll in this study. Email Genetics@Parkinson.org to learn more.

With the popularity of at-home genetics tests, we’ve highlighted seven key facts you should know about Parkinson’s and genetics:

1. About 10% to 15% of people with Parkinson’s have a genetic link to PD. Their children will likely never develop Parkinson’s.
2. Genetic tests are not a substitute for a diagnosis. Testing positive for a Parkinson’s-related gene is not a guarantee that PD will develop.
3. Genetic counselors discuss and interpret genetic test results and provide emotional support.
4. Researchers believe Parkinson’s is caused by a complex interaction between environmental factors, genetics and lifestyle choices.
5. People who know their PD genetic makeup can enroll in genetics clinical trials.
6. LRRK2 and GBA are the most common PD-associated genes.
7. Genetics can help researchers learn what slows or stops the progression of PD. Ongoing work, like the Parkinson’s Foundation PD GENEration study, can shed light on how genetic factors play a role in Parkinson’s.

Visit Parkinson.org/Genetics to learn more.
My father has Parkinson’s disease (PD). What is my risk of developing the disease?

Around 85 percent of people with PD have no known genetic link and their children will likely never develop Parkinson’s. Some known genetic variations increase the risk of getting PD, but many people with these variations do not develop Parkinson’s. Parkinson’s — like many other diseases — is a result of the complex interaction between genes and environmental factors.

Exposure to certain environmental risks (pesticides and herbicides) and lifestyle choices (exercise, smoking, caffeine) can influence the risk for developing Parkinson’s in a person who is genetically predisposed. But in most people with PD, it is difficult to sort out the environmental factors from the genetic components. Parkinson’s is inherited in a small number of people (from 10 to 20 percent) and can affect multiple family members. Their children may have a higher risk of developing Parkinson’s. However, there is no guarantee they will develop PD.

I have one sibling with Parkinson’s, and my paternal aunt also lived with PD. I have no symptoms, but should I get a genetic test?

We recommend you consult a genetic counselor first if Parkinson’s runs in your family and you want to get tested. Discuss your reasons for being tested and how it may affect you and your family. Genetic testing helps estimate your Parkinson’s risk, but is not a diagnosis and cannot provide your probability for developing PD. A genetic counselor is a specialist on a healthcare team who provides risk assessments and education about genetics and reading test results. They can shed light on gene-related issues and offer emotional support. About half of people with PD and family members will choose not to be tested after meeting with a genetic counselor.

While commercial companies offer at-home genetic testing to find PD-associated genes, if you suspect you or a loved one has Parkinson’s, consult with a neurologist and a genetic specialist before proceeding with genetic testing. Call the Parkinson’s Foundation Helpline 1-800-4PD-INFO (473-4636) to find a genetic counselor.

Substantial Matters: Life & Science of Parkinson’s

Listen to our special edition podcast episodes about genetics and Parkinson’s. New episodes every two weeks.

Parkinson.org/Podcast
My recent genetic test was positive for a Parkinson’s gene mutation. Will I develop the disease?

Though you tested positive for a mutation in a Parkinson’s gene, it does not necessarily mean that you will develop PD. While scientists have identified several genetic mutations that can increase a person’s risk of developing Parkinson’s, some people who have mutations in the genes associated with Parkinson’s (LRRK2 and GBA) never develop PD. A person may inherit a hereditary genetic mutation that increases their risk for Parkinson’s; however, they may also inherit other genes, be exposed to environmental factors or have lifestyle choices that may affect or offset the risk.

It’s important to discuss your test results with your doctor and a genetic counselor. Knowing and understanding your genetic mutations can also help you determine if you are eligible to enroll in certain clinical trials. Several ongoing clinical trials are already testing treatments for people who carry PD gene mutations in LRRK2 and GBA.

People who are living with PD may not have access to comprehensive genetic testing. Those people may qualify for genetic testing for the GBA and LRRK2 genes and genetic counseling through the Parkinson’s Foundation PD GENEration study. Learn more at Parkinson.org/GeneticsInitiative.

Talking to Children about Parkinson’s

Parkinson’s disease (PD) affects the whole family. Empowering children with information can help them better understand PD. Explain that Parkinson’s symptoms can include:

- Shaking
- Stiffness
- Slow movement
- Quieter voice
- Smaller handwriting
- Body pain
- Feeling tired
- Mood and motivation changes
- Difficulty thinking clearly

Doctors and other medical professionals help people with Parkinson’s live well. Medications can make it easier for people with Parkinson’s to walk, stand up and sit down and do other every-day activities. Those medications sometimes make people dizzy, tired or have an upset stomach.

As PD progresses, family plans, finances and responsibilities may change. It’s important for families to share concerns and work toward solutions. It’s also important to find activities that keep the family connected. Reassure children their feelings about the disease — whether anger, sadness, resentment, frustration, embarrassment or guilt — are OK.

Give children an outlet to express how PD affects them; through weekly family chats, or talks with a friend, relative, teacher, counselor or online support group.

For more resources about talking to children about Parkinson’s download our fact sheet about “Parkinson’s and Your Children and Teenagers” at Parkinson.org/Library.
Do you often feel off-balance, dizzy or like the room is spinning? You may be experiencing vertigo. People with Parkinson’s disease (PD) commonly report dizziness or vertigo, which are often associated with balance problems and become more frequent in later stages of Parkinson’s.

Doctors can misdiagnose these common non-motor symptoms. “Learning to identify vertigo or dizziness and relaying the symptoms to your care team can optimize your treatment,” said Michael S. Okun, MD, Parkinson’s Foundation National Medical Director.

Causes and treatments of PD-related dizziness and vertigo include:

- **Orthostatic hypotension**: more than half of people with PD experience a significant blood pressure drop upon standing that can cause lightheadedness, fainting, vision and thinking issues, head and body aches or fatigue. “Orthostatic hypotension, which can also be associated with syncope or ‘passing out,’ is the most commonly overlooked cause of dizziness in people with Parkinson’s,” Dr. Okun said.
  - **Treatment**: Drink six to eight glasses of water daily, wear waist-high compression stockings and add salt to the diet to improve this condition. Medications can also help.

- **Medication-induced dizziness or vertigo**: dopamine agonists, used to improve PD symptoms, are the most common drugs associated with vertigo and dizziness in Parkinson’s. Anticonvulsants, antihypertensives, antibiotics, antidepressants, antipsychotics, pain medications and anti-inflammatory drugs are commonly associated with dizziness.
  - **Treatment**: Your doctor can slowly wean the dosage of the side-effect causing drug.

- **Deep Brain Stimulation (DBS)**: this surgical procedure can be associated with dizziness or vertigo. Symptoms can emerge soon after surgery. Your doctor can determine if the device is causing dizziness by turning it off and observing reactions.
  - **Treatment**: Your healthcare team may need to check the location of the electrodes (usually by brain imaging) and possibly re-program the device.

- **Benign Paroxysmal Positional Vertigo (BPPV)**: sudden dizziness when turning in bed or dizziness lasting a few seconds. It can be diagnosed using an in-office, non-invasive test.
  - **Treatment**: A physical therapist who is an expert in vestibular (inner ear and balance) rehabilitation can treat this or teach you simple movements to do at home, such as the Semont maneuver, which uses seated and reclined positions to clear the inner ear.

- **Migraine headaches**: these can potentially cause dizziness or vertigo; sometimes referred to as migraine-induced vertigo.
  - **Treatment**: Treating the headache or migraine usually ends dizziness.

- **Transient ischemic attack or stroke**: this sudden-onset dizziness, usually present with other neurological signs, could possibly be a brief stroke-like attack or stroke.
  - **Treatment**: If a stroke is suspected, seek medical attention immediately and undergo appropriate imaging and potentially stroke-related therapies.

Dizziness or vertigo can be tied to many causes and is not unique to Parkinson’s. Medications, low blood pressure, anxiety, cold and flu, dehydration, heart conditions and more can provoke these symptoms. Tell your doctor immediately if you regularly experience dizziness or vertigo.

For the latest articles about Parkinson’s symptoms, treatments and research visit Parkinson.org/Blog.
“Through his Parkinson’s, Dad has shown me that there is nothing naïve about hope,” said Jackson Ribler about his father, Larry, who is fighting Parkinson’s disease (PD).

After Larry closed his legal practice due to his advancing Parkinson’s, he and Jackson took on new adventures — like moving from Miami, FL, to Leesburg, VA. “We have spent a lot of time together, traveled and made every effort to not let Parkinson’s define who he is,” Jackson said.

For his December 4 birthday last year, Jackson wanted to do something to help not only his father, but the one million people in the U.S. living with Parkinson’s. So he started a Facebook fundraiser to support the Foundation’s efforts to provide expert PD care and ultimately find a cure.

How to start a Facebook fundraiser:
1. Go to Parkinson.org/FB
2. Fill in a title, fundraising goal and upload a photo
3. Share with your friends

Jackson was moved by those who donated. “My friends and my father’s friends ended up donating $2,000 to the Foundation as a testament to the man my father is, and the importance of the research being done today to improve our lives,” Jackson said. “We are immensely grateful for the work done by the Foundation.”

Become a Parkinson’s Champion on Facebook!

Using Facebook, these Parkinson’s Champions raised money to help us make life better for people with Parkinson’s:

**Cassie** raised $1,044 in her father’s honor on Facebook. “It’s been almost a year since my dad’s passing and there’s not a day that I haven’t missed his smile, his voice and his genuine kindness for everyone,” Cassie said.

**Amy** fundraised in honor of her Mom’s fierce battle to hold on to her clarity of mind and physical independence. She raised $850 for Dolly, ultimately helping the Foundation raise $50,000 on Giving Tuesday.

**Becca** hosted her 21st birthday fundraiser from England in memory of her grandfather, Keith, who fought PD for 19 years. “It means so much to raise money for the Foundation to aid research and support for others,” Becca said.
Your Keys to Living Well with Parkinson’s

April is Parkinson’s Awareness Month and this year we asked people in the Parkinson’s disease (PD) community to share their keys to living better with the disease. Below they share how they modify and use everyday items to help manage PD symptoms. #KeyToPD

“My Fitbit helps monitor my activity level and reminds me to take my medications. I sometimes feel like I’ve walked for miles, but the Fitbit tells me I’ve barely moved all day. It is a good reality check.”
- Andree

“For constipation, try the Squatty Potty. It really works! It elevates the feet when on the toilet, which straightens out the colon and makes it much easier to go.”
- Smitty

“Getting into the right position to sit down safely on the toilet requires walking, turning, backing up and sitting down. We use blue tape to delineate the exact space my dad needs to stand in to sit down safely.”
- Dana

“Get a handicapped placard for your car. I used to think I didn’t really need it, but I have found the less energy I have to expend at the beginning of running an errand the more I have in reserve at the end.”
- Andree

“If you need help falling asleep, try listening to a boring book or meditation app, like Calm, that offers daily sleep stories.”
- Gretchen

“I use hot packs on my eyes in dry climates, which have really helped my dry eyes.”
- Sandy

“If it is difficult to hold a pen or pencil, go to a home improvement store and buy foam pipe wrap (used to insulate pipes). The tube splits open and the pencil fits inside.”
- Mary

“Place colored tape lines in a doorway to make it easier for people who experience freezing episodes. The tape provides a visual cue for where to place each foot when moving through the door.”
- Rose and Joan

“I use a jogging baby stroller with big wheels when I’m walking on the gravel roads by our home. I weighted it with a gym bag and it has really helped my walking.”
- Karen and Rob

“People with PD may have difficulty if the color of the food is the same color as the dish. Consider using dark dishes when serving light colored foods and light dishes when serving dark foods.”
- Joan

Opinions and products listed below belong to the authors and are not endorsed or do not reflect the official policy or position of the Parkinson’s Foundation. 

Tell us your #KeyToPD at Parkinson.org/Awareness.

For the latest in Parkinson’s news and treatments read Parkinson’s Today.

Now featuring Science News, our latest series dedicated to research and current studies.

Parkinson.org/Blog
Leaving a Legacy for Parkinson’s Research

Former educator and avid golfer Pat Mulhollen spent more than 40 years married to the love of her life and golf partner, Chuck. After Chuck received a Parkinson’s disease (PD) diagnosis in the late 1990s, the South Carolina resident retired to provide Chuck with limitless support — and many years later, devoted care.

“My husband’s diagnosis of Parkinson’s was a life-altering experience for the both of us,” Pat said. During the course of his illness, Chuck was able to receive care at Emory University, a Parkinson’s Foundation Center of Excellence. Emory is one of 45 centers nationwide offering a specialized movement disorders medical treatment team. “We were both validated by going there and seeing somebody who understood what my husband was going through,” Pat said.

Pat’s years in education and passion for Parkinson’s research inspired her decision to include the Parkinson’s Foundation in her estate plan. It’s important to Pat that she give to an organization that makes “the most use of every dollar contributed. I’m really happy that I took the step to get involved,” she added.

For more information on including the Parkinson’s Foundation in your estate plans, please contact Sean Kramer at SKramer@Parkinson.org or 305-537-9904.

A Free Gift for You From the Parkinson’s Foundation

To make it straightforward and easy for you to begin writing your will, we’ve partnered with FreeWill. This tool is free to you whether you choose to include a gift to Parkinson’s Foundation or not, and can be used to create a fully valid legal will or guide you through planning your will before finding a lawyer near you. Visit FreeWill.com/Parkinson to get started.
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.