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Learn more: Parkinson.org/Events

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27 Expert Briefing: Young Onset Parkinson’s Series
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NOVEMBER
3 Managing Impulse Control Disorders
Listen at: Parkinson.org/Podcast

10 Expert Briefing: Young Onset Parkinson’s Series
Partnering: The Dance of Relationships and Romance
Register: Parkinson.org/ExpertBriefings

JOIN US THIS FALL AT

We hope to see you at a fall Moving Day, A Walk for Parkinson’s, taking place across the country. Help us fight Parkinson’s and celebrate movement — proven to help manage Parkinson’s symptoms.

View all upcoming events and register at MovingDayWalk.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.

Stay up to date on COVID-19 and Parkinson’s at Parkinson.org/Coronavirus.

Virtual events are open to all and available online. For a full list of events visit Parkinson.org/Events.
Research Update From Our Chief Scientific Officer

We hope our Parkinson’s disease (PD) community continues to stay safe and healthy as we all focus on rebounding from the COVID-19 pandemic. Nearly every facet of life was impacted by the virus and the research community is no exception. Parkinson’s Foundation research continues to move forward, while supporting the work of more than 40 new research studies this year alone.

In this special research issue, we are excited to share what we have learned in the first year of our genetics study, *PD GENERation: Mapping the Future of Parkinson’s Disease* (page 4). We also check in with Anne-Marie Wills, MD, a lead PD GENERation researcher.

A researcher funded by the Foundation may already be working on the next Parkinson’s breakthrough. The Foundation has supported the research of more than 550 scientists, like Erdem Gültekin Tamgüney, PhD, who is developing a new kind of test to establish a PD indicator, known as a biomarker (page 10).

As we learn more about the genetics and brain functions that play integral roles in Parkinson’s, we will be able to design precision treatments for the one million Americans living with PD today — and the 60,000 people diagnosed each year.

How Research Advocates Make a Difference

The Parkinson’s Foundation prepares people with Parkinson’s disease (PD) and care partners to work with researchers to make research more efficient and effective. Below are ways Parkinson’s Foundation Research Advocates have recently made an impact in PD research:

- A Research Advocate leads the team for a $250,000 Patient-Centered Outcomes Research Institute grant to establish patient advisory boards at five Parkinson’s Foundation Centers of Excellence to guide research.
- Research Advocates worked alongside scientists to direct more than $10 million in Foundation research funding.
- A Research Advocate serves on the Patient Engagement Collaborative, created by the U.S. Food and Drug Administration (FDA) and the Clinical Trials Transformation Initiative, to guide how the FDA integrates the patient perspective in drug development.
- Research Advocates partnered in a training of the “Promotores” Hispanic outreach program that increased interest in genetic testing in Hispanic communities by 37%.
- Research Advocates changed a major pharmaceutical company’s approach to clinical trial design through an interactive discussion on how studies are run.

To learn more about becoming a research advocate or working with research advocates visit Parkinson.org/PAIR.
The goal of PD GENEration is to leverage genetics as a powerful tool to help us uncover what is responsible for slowing or stopping the progression of Parkinson’s, which will ultimately improve care and speed the development of new treatments. Study results will advance how we design clinical trials, for instance, testing a new medication based on what type of PD gene a person carries.

As the first national Parkinson’s study to offer bilingual genetic testing in a clinical setting with counseling, the Parkinson’s Foundation flagship study has unearthed exciting preliminary findings.

**Higher Detection Rate**

Of the 291 people who have been tested as part of the study, 51 tested positive with a genetic mutation that is linked to PD. This amounts to 17% of all PD GENEration participants.

This percentage is higher than the current reported estimates of one to 10% of people with PD who have a genetic connection to the disease — a range that is not representative of the entire PD population since not everyone with Parkinson’s has been genetically tested. PD GENEration researchers theorize that as more people with PD get genetically tested, the rate of detection will most likely rise.

**Discovering Rare Mutations**

Genetic test results have led researchers to identify extremely rare genetic mutations linked to PD. Some study participants carry multiple mutations, meaning one person can carry two or three different genetic mutations associated with PD.

These multiple genetic mutation carriers have not been extensively studied — thus, we do not know how living with multiple genetic mutations affects PD symptoms or progression. This finding will significantly contribute to the biological understanding of the disease, helping us assess the impact of each mutation and which ones are more influential towards causing the disease, which will lead to better treatments.

**Creating an International PD Panel**

PD GENEration is working to finalize the development of a global leadership council on genetics and PD. The international expert PD panel convenes leading clinicians, molecular biologists and geneticists who will develop global consensus to decide which genes and mutations are important for PD and will accelerate research efforts towards better PD treatments.

“This panel welcomes anyone and everyone who is significant in genetics and PD,” said James Beck, PhD, Parkinson’s Foundation Chief Scientific Officer. “It will be a platform for experts from around the world to assess PD GENEration data in real time — data that has already led us to new findings.”
A Community Dedicated to Research
As evidence that the study’s outreach to the PD community goes far beyond the Foundation’s immediate network, 33% of the PD GENEration participants came from outside of the Parkinson’s Foundation Centers of Excellence network. Participants traveled from 21 states to six pilot sites.

“This community is determined and resilient to do what it takes to contribute to Parkinson’s research, a great indication that we will be able to successfully complete our goal of enrolling 15,000 participants who want to know if they have a genetic link to this disease,” Dr. Beck said.

The Next Phase
The PD GENEration study will expand to more testing sites. In response to the current climate, PD GENEration leaders are designing a telemedicine-based approach, where participants can submit their test using an at-home kit and complete virtual, bilingual genetic counseling.

PD GENEration recently partnered with Biogen to accelerate the study. Looking ahead, once PD GENEration is complete, the partnership will help drug development companies, like Biogen and others, recruit for clinical trials faster. This will help speed up the development of better PD medications and recruitment for PD clinical trials.

Learn more about PD GENEration and sign up for email updates at Parkinson.org/PDGENEration.

Meet PD GENEration Investigator: Dr. Anne-Marie Wills

Neurologist Anne-Marie Wills, MD, is director of the CurePSP Center of Care at Massachusetts General Hospital, a Parkinson’s Foundation Center of Excellence and a PD GENEration study site investigator. Her groundbreaking research brings hope to people with Parkinson’s disease (PD).

Q: How does PD GENEration: Mapping the Future of Parkinson’s Disease build on your previous research of neurodegenerative disease progression?
A: I trained in both movement disorders and ALS (amyotrophic lateral sclerosis, also known as Lou Gehrig’s disease) genetics at the same time. It is interesting to be involved in both fields and watch them move in parallel. As we discover genes that are common causes of Parkinson’s, it means that we can finally come up with treatments that target those genes.

Q: Why is PD GENEration important?
A: The beauty of genetics is that you can say “OK, this gene mutation really, truly causes the disease.” It’s not just an increased risk, it’s the underlying cause. Cancer genetics has led the way in terms of targeted therapy for different mutations, which are more effective and tolerable than historic chemotherapy. It’s miraculous. It is like the early days of targeted cancer research when my colleagues, led by Daniel A. Haber, MD, PhD, and John Iafrate, MD, (at Massachusetts General Hospital) began sequencing every tumor for every known cancer gene. That is similar to where we are at now in PD GENEration.
Several things will most likely change for good following the COVID-19 pandemic, one of them being the need to provide medical treatment through telehealth services. “I would say that telemedicine is going to be a ‘silver lining’ from this crisis,” said Michael Okun, MD, Parkinson’s Foundation National Medical Director. “We at the Parkinson’s Foundation have been working around the clock for a decade on this.”

Telemedicine is the distribution of health-related services and information using technology. Appointments can be completed using a device with a camera, often through an app or program using an internet connection.

“There are advantages to telemedicine, and throughout the COVID-19 pandemic, telemedicine remains an excellent way to connect to your physician and avoid the spread of the virus while social distancing,” said Roy N. Alcalay, MD, from Columbia University Irving Medical Center, a Parkinson’s Foundation Center of Excellence and PD GENEration pilot site.

COVID-19 led insurance companies and Centers for Medicare and Medicaid Services to relax telemedicine regulations. This provided expanded coverage to more hospitals, physicians and other healthcare organizations — including emergency department visits, physical therapy and occupational therapy appointments. View the full list at CMS.gov.

The relaxed regulations allowed patients to seek treatment from doctors and specialists who are located out of state. “A lot of the doctors opened up our clinics to keep patients at home and avoid exposure,” said Dr. Alcalay. “Find out if your specialist is accepting telemedicine appointments and use this opportunity to find a new specialist, occupational or physical therapist.”

Telemedicine benefits include easy access to healthcare professionals and no transportation hassle or waiting rooms. Additional benefits can include more one-on-one time with your doctor and the ability for family members to join virtually. Telemedicine visits can also provide an elevated level of care, allowing professionals to see your environment. This can prove beneficial for an occupational therapist to provide input on home layout to optimize safety.
“You will see that telemedicine appointments can be a good experience with your doctor,” said Dr. Alcalay. “There are usually much less interruptions on telemedicine than in clinic visits. In some ways, it can be more personal.”

A drawback to telemedicine for people with Parkinson’s is that a doctor cannot perform physical exams, such as tests for rigidity and postural reflex, nor can they administer Botox injections or make deep brain stimulation adjustments. “In treating Parkinson’s, telemedicine has been used mostly for research, but we’ll probably be using it more after COVID-19 and I look forward to being able to treat more patients and have access to current patients, even if they are temporarily out of state,” said Dr. Alcalay.

Learn more about telemedicine at Parkinson.org/Telemedicine.

Tips for Daily Living: Preparing for a Telemedicine Appointment

1. **Get ready.** Prepare as you would for an in-person visit. Check to see if you need any medication refills, have your medication list handy and write down your questions.

2. **Prepare your device.** Choose a location with a good internet connection and remember to charge your device or keep it plugged in. Your provider will let you know which program to download.

3. **Leave room to move.** Try to position yourself near a space where you can perform typical tasks your doctor or specialist may ask you to complete.

4. **Final touches.** Have a paper and pen nearby, along with any items your healthcare specialist may have asked you to bring (for instance, a thermometer).

5. **Video Tips:**
   - Limit any clutter between you and the camera.
   - Avoid backlighting.
   - Limit background noise, like a TV or radio.
   - Speak in your normal voice.

6. **Take notes.** Add them to your medical file.

7. **Provide updates.** Let the doctor’s office know if your pharmacy, insurance or contact information has changed.
Establishing New Parkinson’s-Tailored Exercise Standards

Exercise is known to be a critical tool to treat Parkinson’s disease (PD) symptoms and is associated with slower declines in mobility and improved quality of life.

In March 2020, the Parkinson’s Foundation hosted an Exercise Convening to take the first step in developing National Competencies in Physical Activity for Exercise Professionals Working with People with Parkinson’s disease that will establish PD-related exercise recommendations and exercise guidelines to inform safe and effective exercise for people with PD.

Even though there are many PD-tailored exercise options, there is currently no practice in place to ensure that an exercise professional is trained to help a person with Parkinson’s. “As a physical therapist, knowing which programs or exercise professionals adhere to a nationally recognized competency in exercise for PD would give us greater confidence when referring our patients to exercise classes,” said Terry Ellis, PT, PhD, NCS, from Boston University.

Six primary takeaways established during the Exercise Convening include:

1. People with PD should find ways to participate in regular exercise that includes aerobic, strengthening, flexibility, along with exercises that address balance, agility and dual tasking.

2. Skilled and knowledgeable non-licensed exercise professionals provide personal training and/or group exercise instruction for people with PD, along with social support and motivation. They also have a wide range of backgrounds — from high school diplomas up to a doctorate.

3. Exercise recommendations should be established and based on guidelines developed through rigorous research review on the frequency, intensity, time and types of exercise performed.

4. People with PD participate in exercise through grants, nonprofit organizations, and/or paid programs. However, opportunities toward insurance reimbursement for exercise classes for people with PD could be enhanced with evidence-based guidelines and competencies.

5. Exercise competencies should be created and based on knowledge, skills and abilities considered to be essential entry-level performance by non-licensed exercise professionals.

6. Convening participants collaborated to define common words used in PD physical activity and exercise competencies.

Next, the experts who attended the convening — the American Council on Exercise, American College of Sports Medicine, Parkinson Wellness Recovery (PWR!), Brian Grant Foundation, Rock Steady Boxing and many more — have embarked on an 18 month-long process to develop new exercise competencies.

Ultimately, establishing exercise competencies will provide people with Parkinson’s the peace of mind knowing their exercise instructor understands the personalized needs of helping people with Parkinson’s, which will lead to a better life with Parkinson’s.

Learn more about Parkinson’s and exercise at Parkinson.org/Exercise.
After serving his country for nearly three decades as a U.S. Navy Surface Warfare Officer, veteran Jerry Boster now gives his time and energy to his fellow Parkinson’s disease (PD) community. Jerry is a Parkinson’s Foundation Aware in Care Ambassador who teaches others about the lifesaving hospitalization kit to ensure people living with PD receive the best care possible during a hospital stay.

The U.S. Department of Veterans Affairs (VA) announced a partnership with the Parkinson’s Foundation to benefit veterans like Jerry, who live with Parkinson’s. The collaboration will improve the health, well-being and quality of life of veterans.

“The Parkinson’s Foundation is honored to work alongside the VA to support our veterans and provide the resources and tools veterans need to live better with Parkinson’s,” said John L. Lehr, CEO and President of the Parkinson’s Foundation.

Jerry was diagnosed with PD in 2013 by a movement disorder specialist — a neurologist with additional training to treat people with Parkinson’s at every stage of the disease. He began working through his feelings about the diagnosis, educating himself about the disease, figuring out his medications and joining PD clinical studies. “The impact Parkinson’s had on my life to ‘make things happen’ was immediate and considerable,” Jerry said.

The VA partnership with the Parkinson’s Foundation will increase access to information about Parkinson’s disease and relevant resources for veterans and health care providers — educating and training VA staff on disease management and therapies, and improving access to Parkinson’s-related services for veterans living with the disease. Such resources have been key to Jerry living well with PD.

One million Americans live with Parkinson’s. Of this number, it is estimated that 110,000 are veterans with Parkinson’s (according to research from C. Tanner and S. Goldman). Due to our aging population, this number is on the rise. An accurate and early diagnosis gives people living with PD access to treatments and resources to live better lives.

Working together, the Parkinson’s Foundation and VA will be able to reach even more veterans with Parkinson’s and those newly diagnosed. In 2001, the VA developed the Parkinson’s Disease Research, Education & Clinical Centers (PADRECCs) to serve veterans enrolled in the VA Healthcare System with PD through state-of-the-art clinical care, education, research and national outreach and advocacy. Learn more at www.parkinsons.va.gov or 1-800-949-1001 ext. 5769. Check eligibility for VA Care and apply at www.va.gov/health-care.

The Parkinson’s Foundation honors Jerry, and all veterans who served and continue to serve our country. If you are a veteran with Parkinson’s or care for one, learn more at Parkinson.org/Veterans.
Could Body Fluid Analysis Help Predict Parkinson’s?

At its height, COVID-19 kept millions of people at home, including researchers. As labs begin to open again, many researchers will double their efforts to get back to where they left off. That is why the Parkinson’s Foundation is supporting scientists, providing extra time to get their critical research up and going, like biochemist Erdem Gültekin Tamgüney, PhD.

People who are diagnosed with Parkinson’s disease (PD) can show early signs up to 20 years before primary symptoms, such as non-motor problems. Those can include loss of smell, difficulty sleeping and constipation. However, making a diagnosis before the onset of non-motor symptoms can be challenging. There is no single test for Parkinson’s disease — doctors rely on a combination of various symptoms and diagnostic tests.

Discovering a Parkinson’s biomarker — or disease indicator — and developing early screening could be a major step in implementing any future targeted early treatments.

In people with Parkinson’s, a protein found in the brain called alpha-synuclein misfolds, forming irregular clumps that disrupt brain function. In recent years, scientists have discovered these clumps in the gut of people who later develop PD. New research suggests these clumps may travel — through nerve cells — from the intestines to the brain.

Biochemist Erdem Gültekin Tamgüney, PhD, Research Group Leader at Germany’s University of Düsseldorf, received a Parkinson’s Foundation Impact Award to investigate whether these alpha-synuclein clumps can be detected in bodily fluids. This could be the first step toward developing a new test for early signs of Parkinson’s disease.

“I’m really grateful to the Parkinson’s Foundation for their support,” Dr. Tamgüney said. “It’s so important to have a diagnostic test or a biomarker that can tell us very early that a person may be in the process of developing Parkinson’s disease, allowing them to find help early on.”

Impact Awards of up to $150,000 for one year fund creative research like Dr. Tamgüney’s, aimed at testing novel therapeutic ideas or offering new insight into PD biology. The nearby University of Cologne neurology department will collaborate with Dr. Tamgüney, collecting samples from volunteers living with Parkinson’s. These will be analyzed and compared to samples from volunteers living with other neurodegenerative diseases to help Dr. Tamgüney establish these biomarkers.

The Parkinson’s Foundation invests more than $10 million every year in Parkinson’s research and clinical care. The researchers who receive Foundation awards are key to improving understanding of the disease and ultimately, discovering a cure.

Learn more about funded grants at Parkinson.org/Research.
Leaders in Research Help Change the Course of Parkinson’s

The Parkinson’s Foundation makes life better for people living with Parkinson’s disease (PD) by enhancing care and advancing research toward a cure. The Leaders in Research program unites donors with an enthusiasm for investing in revolutionary PD research.

Members and longtime Parkinson’s Foundation supporters Shelley and Rick Friedland are committed to improving life for everyone with Parkinson’s. “Getting involved gives us some control and empowerment over this disease,” Shelley said. “We are on a fast-paced train, moving forward to find a cure. We MUST make sure that the train’s fuel gauge is always full. Running out of steam is just not an option.”

Rick lives with PD, and Shelley, his wife and care partner who is also a physical therapist, championed the creation of the Parkinson’s Foundation Physical Therapy Faculty Program and the online accredited physical therapy course. Shelley is also the President of the Foundation’s Florida Chapter Advisory Board and served on the Caregiver and Carepartner Symposium Committee. Together, they have also lobbied U.S. Congress on behalf of people with PD, joined clinical trials, started a PD support group and hosted a symposium in their area.

As Leaders in Research members, the Friedlands are helping to change the course of the disease. “Parkinson’s Foundation funding is critical to drawing young, talented scientists into the Parkinson’s research field,” Rick said.

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.

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
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.

1.800.4PD.INFO
Helpline@Parkinson.org

We're here for you.

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PDCConversations.org

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