

PD GENERation: Mapping the Future of Parkinson's Disease



PD GENERation is a flagship initiative that offers free genetic testing and genetic counseling for people with Parkinson's disease (PD).

Participating and contributing your genetic data, DNA and blood gives you the opportunity to better manage your disease in the future, help scientists in their journey to advance understanding of PD, improve PD care and research, accelerate enrollment in clinical trials and aid in the development of improved Parkinson's treatments and personalized medicine.

About Genetic Testing

Genetic testing, which involves a simple blood draw, is a type of medical test that identifies changes, or variants, in genes. Some of these changes may increase the chances of developing a particular disease or predict which treatment may be more beneficial.

For people with PD, genetic testing can let us know if you carry known gene changes linked to the disease. It's estimated that 10-15% of people with PD have a genetic form of the disease, so by better understanding how those with genetic forms of PD experience symptoms related to Parkinson's and respond to treatment, scientists can begin to develop improved treatments and personalized medicine.

About Genetic Counseling

A genetic counselor is a specialist who advises on risk assessments, provides an education about genetics, analyzes test results and can offer emotional support. PD GENERation provides free genetic counseling to help participants better understand their results, providing people with PD with detailed knowledge of their genetic status for important Parkinson's-related genes,

ultimately empowering them to know more about their own disease.

What are the goals of PD GENERation?

This flagship study aims to provide free genetic testing and genetic counselling that will empower people with PD and their care team, improve Parkinson's care and research and accelerate enrollment in clinical trials. In addition to a blood sample, participants will be asked to provide their family history of PD, current medication dosage and other relevant medical data.

Through PD GENERation we hope to ultimately offer free genetic testing and genetic counseling to 15,000 people with PD in the U.S., beginning with our goal of enrolling 600 participants during the pilot period.

How Does PD GENERation Work?

PD GENERation will provide people with Parkinson's and their physicians with detailed knowledge of their genetic status for important Parkinson's-related genes. In addition, participants will be asked to provide their family history of PD, current medication dosage and other relevant medical data.

People with PD can enroll at participating Parkinson's Foundation Centers of Excellence or Parkinson Study Group Sites. Steps to follow:

- Schedule an appointment for genetic testing at a participating Center of Excellence or Parkinson Study Group site.
- Attend your appointment. Provide consent, have a clinical evaluation and a simple blood draw.

- Genetic testing results will be analyzed and samples will be stored.
- Meet with your healthcare professional in person or a certified genetic counselor by phone 6-8 weeks after the blood draw to receive and discuss your test results.
- Fill out online surveys that will be sent to you after your clinical visit to share feedback on how genetic testing has impacted your life.

Who can participate in PD GENERation?

PD GENERation is available to people with a confirmed diagnosis of PD, regardless of age, through participating COEs and Parkinson Study Group sites. To find out if your Center or site is participating, visit [Parkinson.org/PDGENERation](https://www.parkinson.org/PDGENERation).

Learn more at [Parkinson.org/PDGENERation](https://www.parkinson.org/PDGENERation) or contact us at Genetics@Parkinson.org

You can also call the Parkinson's Foundation Helpline at 1-800-4PD-INFO (1-800-473-4636).