

Getting Involved in Research



There is a lot we still don't know about Parkinson's disease (PD). Research is key to unlocking its causes, developing life-changing treatments and ultimately, discovering a cure. One way people with PD can help scientists to better understand the disease is through participating in research. Learn more about the process and how to get involved.

There are two types of clinical studies: an observational study and a clinical trial.

What is an observational study?

An observational study is when researchers observe people and try to figure out what factors affect their health and their likelihood of developing certain diseases, like PD. For example, researchers might look at how different lifestyles affect Parkinson's. Observational studies measure or survey participants rather than applying treatments, like medications.

- **Cohort (or registry) studies.** Follow people with a common characteristic over time.
- **Case-control studies.** Focus on people who have developed a disease and compare them to a group of people who do not have the disease.

What is a clinical trial?

A clinical trial is a research study with human participants that aims to answer specific questions about potential medical treatments. When researchers are developing a new treatment for PD, such as a drug, surgery, therapy or a device, they make sure it works by conducting a clinical trial. These trials help researchers and doctors learn what does and doesn't work in treating diseases like PD.

Types of PD clinical trials

- **Therapeutic.** Test safety and effectiveness (efficacy) of a potential PD therapy — drug or non-drug — or a different way to use an existing therapy.
- **Diagnostic.** Look for biomarkers or a measurable sign in the body that can diagnose PD or track its progression.

Types of PD clinical trials (cont.)

- **Genetic.** Help understand how genes affect PD.
- **Preventive.** Aim to find ways to prevent someone from developing PD.

Phases of clinical trials

Treatments are put through the rigorous process of clinical trials before the U.S. Food and Drug Administration (FDA) can consider approving them.

- **Phase I.** Tests a potential treatment for the first time in a small group of people (with the disease and without) to evaluate safety and dosage and identify side effects.
- **Phase II.** Further evaluates the safety of a treatment in a small group of people from the affected population and provides early evidence of its effectiveness.
- **Phase III.** In a larger group of people, determines if the treatment benefits participants and if its benefits outweigh its risks.
- **Phase IV.** After receiving FDA approval, researchers collect and look over additional information about a treatment, including risks, benefits and how it is best used.

Risks of clinical trial participation

- **The study treatment might not work.** However, unsuccessful studies are important in learning more about PD.
- **Not receiving the study treatment.** You might receive a placebo (like a sugar pill) that lets researchers compare the group that receives the treatment to a group that does not.

Risks of clinical trial participation (cont.)

- **Experiencing unwanted side effects.** These may include known side effects and new ones that might appear during the study. They can be minor or serious in nature.

Informed consent

It is required that you give your informed consent prior to taking part in a study. It ensures that researchers have given you complete information and that you fully understand the trial, risks and your role as a participant.

Why Participate in Clinical Studies?

Your participation in clinical studies can:

- **Advance Parkinson's prevention, treatments and a cure.** Almost all of what we know about Parkinson's is due to research.
- **Give you early access to potentially helpful treatments not yet available.** This does not replace your normal treatment.
- **Contribute to the diversity of research participants.** Individuals can respond differently to therapies.
- **Play a part even if you don't have Parkinson's.** Many trials are looking for "healthy controls" or people who do not have PD.

Which Studies are Right for You?

Some studies are as simple as filling out a survey, while others can involve procedures or treatments. You may want to think about certain requirements, such as the number of times you must visit the study site, the length of each visit, the number and types of tests you will have to do and how long you need to be in the trial. Keep other factors in mind, like commuting to the study site.

Be sure to discuss participating in a trial with:

- **Your neurologist.** Share information about the study. Your neurologist can help you evaluate a specific study and possibly recommend additional studies for you.
- **Your family.** Joining a trial can affect members of your family. Involve your family in your decision-making process. You might go to them for emotional support.

Ongoing Research

In addition to funding research grants, Parkinson's Foundation research initiatives include:

PD GENERation: Mapping the Future of Parkinson's

This national study offers genetic testing for PD-related genes and genetic counseling at no cost for people with Parkinson's. Participation can be either in-person or from home through a telemedicine appointment. For more information and to enroll visit [Parkinson.org/PDGENERation](https://www.parkinson.org/PDGENERation).

Parkinson's Outcomes Project

A clinical study among 13,000+ people with PD conducted at select Parkinson's Foundation Centers of Excellence. Read more findings at [Parkinson.org/Outcomes](https://www.parkinson.org/Outcomes).

Parkinson's Foundation Surveys

This initiative advances Parkinson's care by better understanding the experiences of people living with PD and their care partners and sharing findings with the community. Make your voice heard and sign up at [Parkinson.org/Surveys](https://www.parkinson.org/Surveys).

TOPAZ

This study tests if a medication, called zoledronate, can prevent bone fractures in people with PD. Participation is done from home. To learn more, visit [TopazStudy.org](https://www.TopazStudy.org).

Finding a Parkinson's study

- [Clinicaltrials.gov](https://www.Clinicaltrials.gov) is a database of privately and publicly funded clinical studies conducted around the world.
- National Institutes of Health (NIH) Clinical Research Trials and You is an online resource to help people learn more about clinical trials. Visit [nih.gov/health/clinicaltrials](https://www.nih.gov/health/clinicaltrials).
- Find the latest in Parkinson's research and more information on joining a PD research study. Visit [Parkinson.org/Research](https://www.Parkinson.org/Research).