

# Getting Involved in Research



## Thinking about getting involved in research?

### Why research matters:

- Advance prevention, treatments and a cure.
- Get early access to potentially helpful treatments.
- Benefit from expert medical evaluation and guidance.
- Help scientists understand how people respond differently to treatments.
- Contribute to research, even if you do not have Parkinson's.

### What to consider:

- Side effects, including unknown ones, may occur.
- Some studies include a placebo, like a sugar pill, to compare and test the treatment.
- Treatment may prove ineffective.

Research is key to understanding the complex causes of Parkinson's disease (PD), developing treatments, improving care and ultimately finding a cure. Learn more about the research process and how to get involved.

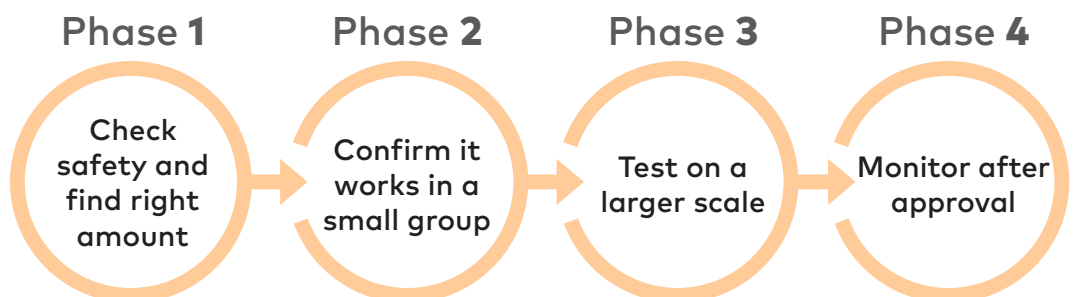
## What is a clinical trial?

Clinical trials are research studies that involve humans. There are two main types: observational studies and interventional trials.

- **Observational studies** analyze real-life situations to uncover patterns and connections. Instead of focusing on treatments, observational studies ask questions about human behavior or take measurements. Examples include:
  - **Diagnostic trials** to search for disease biomarkers (measurable signs) for diagnosing or tracking disease progression.
  - **Genetic trials** to explore the role of genes in disease development and help people identify treatments or trials specific to their genetic makeup.
- **Interventional trials** test new treatments such as medications, surgeries, therapies or devices to ensure they are safe and effective. Examples include:
  - **Therapeutic trials** to test a treatment's safety and effectiveness – both drug and non-drug.
  - **Preventive trials** to explore methods to prevent diseases, such as exercise.

## How are new treatments approved?

Treatments must pass four phases of clinical trial testing before the U.S. Food and Drug Administration (FDA) will consider approval. Clinical trial research phases include:



## Resources

Learn more about our ongoing research, join a clinical trial or explore how to become a research advocate. Visit [Parkinson.org/Research](https://www.parkinson.org/Research).

Find a clinical trial by searching a database of clinical research around the world. Visit [Clinicaltrials.gov](https://www.clinicaltrials.gov).

## Helpline

Get answers to your PD questions and referrals when you contact our Helpline at [1-800-4PD-INFO](tel:1-800-4PD-INFO) and [Helpline@Parkinson.org](mailto:Helpline@Parkinson.org).

We are here to help.



## How can I get involved in research?

Your participation in research can help scientists and doctors discover new treatments, improve care and find a cure. Explore the different opportunities to get involved in Parkinson's research. Visit [Parkinson.org/JoinAStudy](https://www.parkinson.org/JoinAStudy).

The Parkinson's Foundation is committed to supporting ground-breaking research initiatives, including these priority programs:



### PD GENERation: Mapping the Future of Parkinson's

This global study offers genetic testing for PD-related genes and genetic counseling at no cost for people with Parkinson's. Participate in-person or virtually from home. Learn more and enroll at [Parkinson.org/PDGENERation](https://www.parkinson.org/PDGENERation).



### 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 Trial

People with PD have a higher risk of fractures. This study is testing if a medicine called zoledronate can prevent fractures in people with PD. Learn more at [Parkinson.org/TOPAZ](https://www.parkinson.org/TOPAZ).

## Become a Research Advocate

The Parkinson's Foundation pairs people with PD and care partners with researchers to ensure more efficient and effective clinical trials. To learn more about how to become a Research Advocate, visit [Parkinson.org/ResearchAdvocate](https://www.parkinson.org/ResearchAdvocate).

## Tips for Finding the Right Study for You

- ✓ Talk to your doctor for help weighing possible risks and benefits.
- ✓ Check eligibility: Some studies have specific age, disease progression or genetic requirements.
- ✓ Consider time and travel commitments.
- ✓ Discuss the study with your family to understand how participation might impact everyone involved.

