Get involved with research

Parkinson's UK
For every Parkinson's journey

Parkinson's research is powered by people like you

Parkinson's can impact people in different ways. There are medications and therapies that can help manage some of the symptoms. But currently there are no treatments that can slow or stop Parkinson's getting worse.

Thanks to more than 50 years of research, we know more about Parkinson's than ever before. But researchers are still piecing together the clues to understand what is causing Parkinson's, and the best ways to measure how it changes over time. The only way we can find new treatments, devices and therapies sooner, is through research.

We need everyone to be part of Parkinson's research. The more people who get involved, the faster we'll make progress.

What's the first step?

Join our Research Support Network (RSN). You'll receive regular emails with the latest research news and information, events and opportunities to shape and take part in research. Whether you are someone with Parkinson's, a friend or loved one or a healthcare professional, these emails are for you.

Sign up online today by visiting
parkinsons.org.uk/rsn

> **I probably wouldn't have taken part if I hadn't found the Research Support Network, but it's made me feel a lot more comfortable.**
>
> Nicky

Not online?

Find out more about Parkinson's research by calling the Research team at Parkinson's UK on **020 7963 3606**, or call our Helpline

Taking part in research

What does it involve?

Research studies can come in many forms, from questionnaires to trialling new treatments. You can do some research from home, while other opportunities will involve visiting a hospital or research centre.

You could make a difference by:

- answering online or paper questionnaires and surveys about your experiences or symptoms
- talking about your role as a partner or carer of someone with Parkinson's
- trialling new treatments, therapies and medical devices
- undergoing assessments to look at things like movement, thinking and memory
- providing samples of blood and saliva for researchers to study.

> **I think the only way to move forward is by having as many people as possible involved in research. Research is the key to it. And it makes you feel so powerful in the end.**
>
> Winston

What can I expect?

All research studies looking for people to take part have gone through a review process. Your data will remain confidential and used in line with the latest data protection requirements. We make sure that every study we share is checked and has the right ethical approval before we share it.

You'll always get an information sheet to read and a consent form to sign before any research activity happens. This will include information on whether you can expect to receive payment for things like travel.

You can choose to stop taking part at any point.

If you have any questions, you can get in touch with the researchers leading the particular study or with us at **research@parkinsons.org.uk**

> “**If there is something I can do to help others, and potentially even myself, I'm going to be a part of it. We need this research to improve the condition for us all.**
>
> Phil and Kate”

What's in it for me?

Many people who take part in research tell us they benefit from:

- a feeling of control over the condition and symptoms
- feeling part of a community making a positive impact
- more time spent with healthcare professionals and researchers
- sharing experiences with others living with Parkinson's
- being part of research helping find better treatments and improving care

It's important that everyone is represented in Parkinson's research. Only then will we know how to improve living with Parkinson's for everyone. We need people of every age, gender, race and ethnicity to take part.

How to take part

The Take Part Hub is our online tool to help you find out about opportunities to take part in research. Type in your postcode to find a list of studies looking for people to take part: **parkinsons.org.uk/takeparthub**

We're working to make research more inclusive for people from Black, Asian, Arab and Mixed heritage backgrounds. We're working alongside dedicated volunteers who are helping improve representation of people from minority ethnic backgrounds in research. Get in touch if you'd like to join us.

> “**Being part of initiatives that are specific for people who look like me is so important. It offers a sense of community as a Parkinson's diagnosis can sometimes leave you feeling isolated and alone.**
>
> Toussaint”

Help make Parkinson's research better

There are ways you can contribute to Parkinson's research beyond taking part in a study. Your experience as someone living with Parkinson's is essential in helping improve the impact of future Parkinson's research.

You don't need any kind of scientific knowledge. Your personal experience is what counts. You could:

- help improve diversity in research
- help decide what research we fund
- work alongside researchers to shape the design and aims of research studies
- help us to share research with your community.

For a full list of ways you can get involved, visit our website: **parkinsons.org.uk/research-volunteering**

> **I set an aim to help as much as I can to find a cure for Parkinson's, not only for myself but for future generations. Just knowing that I am involved and doing something.**
>
> Shah

Got questions?

Email the Research team at **research@parkinsons.org.uk** or call our friendly team on **020 7963 3606** (please leave a message if we don't answer right away and we will get back to you).

Take the first step by signing up to the RSN today:

RESCH

RESCH

We’re Parkinson’s UK, the charity that’s here to support every Parkinson’s journey. Every step of the way.

Free confidential helpline **0808 800 0303**
Monday to Friday 9am to 6pm,
Saturday 10am to 2pm (interpreting available)
Now Relay UK **18001 0808 800 0303** (for textphone users only)
hello@parkinsons.org.uk | parkinsons.org.uk

Parkinson’s UK, 50 Broadway, London SW1H 0DB

Parkinson’s UK