2 June 2025

Parkinson's UK
For every Parkinson's journey

# Research Roundup

This month we share news of a new drug trial that's underway in the UK, a research registry that's launched to help connect people to Parkinson's research, as well as the latest research news, events and opportunities to get involved.

## Research news

### Revolutionising how we test new treatments for Parkinson's

**Clinical trials are a vital part of research, but it's a long process with many hurdles. Can new ways of working change how we carry out clinical trials for Parkinson's and help us find better treatments, faster?**

Current treatments for Parkinson's work to manage symptoms of the condition, but we know they're not good enough. And we still don't have any treatments that can stop Parkinson's from getting worse. Researchers across the globe are working on new ideas, leading us closer to finding a breakthrough treatment that can stop, slow or even reverse the progression of the condition.

**What is a clinical trial?**

Once research in the lab has identified a potential new treatment, an important next step is to trial it in people living with Parkinson's. This is called a clinical trial. They help researchers understand the safety and effectiveness of a treatment, as well as look for any potential side effects.

Currently, there are 153 clinical trials taking place worldwide for Parkinson's. Whilst this offers a lot of hope, setting up and running these trials quickly is a major challenge. However, reimagining this process is possible.

**Traditional way of doing clinical trials**

For a new treatment to be deemed safe and effective, a few different stages of clinical trials must take place: phase 1, phase 2 and phase 3. Research moves onto the next phase once results show that the drug has the desired effect and there are no severe side effects. Read our blog to learn what it’s like to take part in the drug trial.

For each drug, and at every phase, a clinical trial must be set up from scratch. This lengthy process involves:

- **Securing funding** so that there is enough money to run the trial.
- **Developing all study documents**, including the protocol which outlines every detail of how the trial will run.
- **Ensuring that the treatment can be manufactured correctly** and shipped and stored in a safe way to all study sites.
- **Getting approval from regulators** who check that the trial will be carried out in an ethical and responsible way.
- **Setting up the study sites** once approval has been granted to carry out the trial at each site, and training the staff at these sites to be able to carry out the trial safely.
- **Recruiting people** to take part in the study once it has opened.

Following these steps to the end of phase 3 means that it can take over a decade to understand whether a new treatment will work for people with Parkinson’s. And at the end, we only have an answer for the 1 treatment that has been through this process. If a treatment makes it through phase 3, it still then faces a lengthy process of approvals before it's rolled out and available to the public.

“It took a long time to get to where we are, and that's because there is quite a lot involved in setting up a clinical trial.”
**Mairead Cullen, Trial Manager for a phase 3 trial of ambroxol, ASPro-PD**

It’s like funding and building a brand new football stadium each time a football match is played. And then dismantling it once the game is over, ready to do the whole thing again the next time you want to play a match. This is a massive undertaking, and a hugely inefficient use of resources. Wouldn't it be better if we didn't have to rebuild the stadium each time?

**A new way of doing things**

Other medical conditions, including prostate cancer and multiple sclerosis, have adopted a different approach. They're using a new format to run clinical trials, called a multi-arm, multi-stage (MAMS) trial. MAMS trials enable many promising treatments to be tested at the same time, speeding up research and finding new solutions to improve care.

Taking learnings from these success stories, it's now time for Parkinson's research to move towards these faster and more efficient clinical trials.

**Trialing multiple treatments with the same infrastructure**

The Edmond J Safra Accelerating Clinical Trials for Parkinson's Disease study, called EJS ACT-PD, is adopting the MAMS format in a new trial which will speed-up the testing of treatments with the potential to stop or slow Parkinson's. This project is funded by the Efficacy and Mechanism Evaluation (EME) Programme, an MRC and NIHR partnership, Cure Parkinson's, The Michael J Fox Foundation, Parkinson's UK, The John Black Charitable Foundation, The Gatsby Charitable Foundation and Van Andel Institute.

EJS ACT-PD will test multiple new treatments at the same time, in separate treatment groups, within one clinical trial. So using the same sites, recruiting from a central pool of interested participants, and using the same funding. This saves on the lengthy and costly process of setting up and testing treatments in separate trials. In other words, we only have to build the football stadium once.

**Georgia, Research Project Manager for the EJS ACT-PD initiative shares what makes this clinical trial different.**

"In EJS ACT-PD,  we'll be able to test multiple treatments at the same time, against only 1 placebo group.

If a treatment doesn't look promising, we can stop pursuing it and open a new treatment in its place, for as long as we have funding. We don't need to shut down and start again. It's a way of getting lots of answers at once, saving money, and more importantly, time.

**A new Parkinson's research registry**

One of the main reasons for delays in clinical trials is slow participant recruitment. The faster a trial can attract the target number of people to take part, the faster a trial can come to a close and publish results. As many as 1 out of 2 clinical trials are delayed because they can't find the right people to take part fast enough.

Currently, most clinical trials rely on people getting in touch if they are interested in taking part in a study. The new Join Parkinson's Research (JPR) online registry hopes to change this. The registry, called JPR@Research+Me, will enable people to register their interest in taking part in Parkinson's studies. Researchers will then reach out directly to those who are suitable for their study. This will take the onus off individuals to get in touch, and get the right people signed up, faster.

**Kate Hockey and her husband, Phil, who has Parkinson's, have both worked closely with the team to design the registry. They shared:**

"I'm delighted to be involved in the Join Parkinson's Research project. The unique way in which it will match individuals with research projects represents a welcome change.

"The JPR@Research+Me portal will revolutionise the way in which people like me find out about research opportunities. I am excited by this development and look forward to using it in the near future."

You can already join the registry as it continues to develop as an important new tool for research. To join the registry, visit: **https://redcap.link/jpr2**

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Testing treatments in a quicker, more effective way, and speeding up recruitment will get us closer to a major breakthrough in the search for better treatments for Parkinson's.

## Pioneering UK trial underway to tackle early causes of Parkinson's

**A clinical trial for people with a sleep disorder who are at higher risk of developing Parkinson's has begun in Oxfordshire.**

The Parkinson's UK funded trial is part of a global effort with Australian drug discovery company, Syntara. It aims to uncover whether a potential treatment can reduce inflammation in the brain, to hopefully protect brain cells from dying over time.

The trial is investigating a drug, called SNT-4728, in people with isolated rapid eye movement sleep behaviour disorder (iRBD). iRBD is a diagnosed condition where people act out their dreams, sometimes multiple times a night. Research has shown that people with the condition have a higher risk of developing Parkinson's.

With research sites in Australia already active, the UK now joins the partnership to better understand the earliest causes and signs of Parkinson's, trialling a drug that aims to slow down or stop the condition from developing.

Francis, 1 of 40 participants, who is living with iRBD, kicked off the start of the UK part of the trial earlier this week. He received the first dose of either the active medication or the placebo (a dummy medication that looks like the real thing) and will continue to take this over the next 12 weeks.

### Motivation to take part in research

Francis was diagnosed with iRBD 5 years ago and is aware that it could lead to Parkinson's.

“I took part in this research as it felt like time to contribute something back. It is also good to have an understanding of Parkinson’s moving forward, how it progresses, and anything that I could do to slow its progression. The hope is that a cure, or a slowing down of the condition, will be found for the future, and give people hope.

“For now, exercise is extremely beneficial to me. I go to classes twice a week. This is supported locally through Parkinson’s UK with subsidised exercise groups".

### What’s iRBD got to do with Parkinson’s?

Previous research has identified that the development of iRBD increases people’s risk of developing Parkinson’s. A recent study found that over 70% of people with iRBD went on to develop Parkinson’s or a similar neurological condition over 12 years.

Trialling potential new treatments to slow or stop Parkinson’s in people with a high risk of developing the condition enables researchers to better assess how effective a drug might be.

### What’s next?

If this small trial is successful it could pave the way for a larger study to continue to understand the potential of this drug for people with Parkinson’s.

## Get involved in Research

The development of new Parkinson’s treatments is only possible if everyone is part of the research process. We need your help to push promising research forward.

### Shape a pain management toolkit for people with Parkinson’s

Jenni Naisby, a researcher at Northumbria University, is developing a toolkit to help people with Parkinson’s manage pain. Jenni would like to understand people’s experiences of pain, healthcare for pain management and your ideas for the design of the toolkit. Your feedback will help ensure that the toolkit is useful and practical for people with Parkinson's.

**Who do the researchers need?**

- People with Parkinson's who experience pain frequently (for the last 3 months or more)
- People who support people with Parkinson's who experience pain frequently (for the last 3 months or more)

**What is involved?**

- Completing a survey online or over the phone
- The survey will take 20 to 30 minutes to complete
- You can also choose to complete another survey at a later date

**Interested in taking part?**

To take part please contact Jenni Naisby by email at jenni.naisby@northumbria.ac.uk or by phone on **0191 2156434**.

The survey closes on **25 June 2025**

If you are based in or near Newcastle Upon Tyne and you can attend an in person co design workshop. Please contact Jenni for more information by **20 June 2025**.