

Research Roundup

This month we reflect on Parkinson's research highlights in 2024 and thank you for the role you play in helping push forward Parkinson's research.

Research news

2024 Research Summary

2024 was a busy year for Parkinson's research, both in research results and in how the community has come together to push for better.

Parkinson's research gathers momentum: making progress to find better tests for Parkinson's

In 2024, Parkinson's UK funded research at University College London (UCL) made headlines after identifying a blood test which may be able to detect Parkinson's earlier, before symptoms appear.

Led by Professor Kevin Mills and Dr Jenny Hällqvist, the work showed that a simple blood test was 100% accurate in identifying Parkinson's in over 130 people with and without the condition, and could also predict the development of Parkinson's in high risk individuals..

"We need to start experimental treatments before patients develop symptoms. We set out to use state-of-the-art technology to find new and better biomarkers for Parkinson's and develop them into a test. Parkinson's UK funding was integral in its development."

- **Professor Kevin Mills**

The news captured the media's attention, with Parkinson's UK featuring on BBC Breakfast and local radio across the UK to highlight how this research could be a vital tool in trialling new treatments, could shape diagnosis in the future, and sparking conversations about what it might mean for the Parkinson's community.

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Exploring growth factors as new Parkinson's treatments

Growth factors are molecules that can help feed, protect and stimulate new growth of brain cells. This has made them of key interest to researchers when looking for new treatments for Parkinson's.

In 2024, we announced we'd no longer be funding research exploring device-delivered GDNF, via complex surgery, as a therapy for Parkinson's. However, we're still interested in the potential of growth factors.

We're now investing in a trial of HER-096, a potential treatment designed to protect and restore brain cells affected by Parkinson's. The drug is based on a growth factor, called CDFN, that is naturally produced in the brain and helps to keep cells healthy.

Unlike GDNF, HER-096 can be administered through injection, avoiding the need for brain surgery. With a £1.55m investment from the Parkinson's Virtual Biotech, the first clinical trial of HER-096 offers new hope for growth factor-based treatments for Parkinson's. The trial is now underway in Finland.

Parkinson's UK funds pioneering research projects towards new treatments

Thanks to our supporters, we continue to fund crucial research projects that aim to bring us closer to better treatments for Parkinson's. In 2024 we've committed over £2.5m towards 11 new projects through our research grants programme, and over £8m to a further 5 projects through our Parkinson's Virtual Biotech partnership. All of our projects are selected based on the insights of people living with Parkinson's.

"Our testimonies really make a difference in helping Parkinson's UK decide what research to fund. It is fascinating and greatly rewarding."

- Ellen, one of our Lay Grant Reviewers

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We were also pleased to launch our pioneering Landmark programme. Applying groundbreaking new scientific approaches to the most precious research resource we have – donated tissue from the world-leading Parkinson's UK Brain Bank – to unlock new treatments.

Our hope is that this powerful collaboration of charities, academia and industry will significantly strengthen our ability to develop potential new treatments for Parkinson's, and bring them to clinical trials.

Bringing the Parkinson's community together

From expert researchers to experts living with Parkinson's, our Parkinson's research community shapes everything we do. In 2024 we were thrilled to bring people together, from meetings of our funded researchers in September to ignite collaborations, to research steering group volunteers who are focusing our priorities for 2025

Connecting people living with Parkinson's at Par-Con

In October, we were delighted to host Par-Con, a 2-day in-person and online event for the Parkinson's community. Taking place in Leeds, the event saw over 1200 people come together, to meet others affected by the condition, hear from expert speakers, and learn about living well with Parkinson's.

"I live with someone newly diagnosed with Parkinson's and I cannot tell you how valuable those 2 days were to me. I have learnt so much. I also met so many people, some of whom I will continue to stay in touch with. I was just buzzing after the event"

- Par-Con attendee

Highlights included a live recording of the podcast '2 Parkies in a Pod' with special guest Professor Bas Bloem and sessions on hidden symptoms and revolutionary research. More to come in 2025.

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Our Research Support Network reaches over 10,000 people

In May we shared the message that “Parkinson’s research needs you” to make sure everyone has the chance to consider how they can stay up to date and get involved in Parkinson’s research and called for people to join our Research Support Network. 10 members of the Research Support Network shared their stories about why they got involved and what difference the network makes to them.

Thanks to the Network sharing these stories far and wide, in 2024 our Research Support Network grew by nearly 2000 to well over 10,000 people! We’re thrilled to have reached such a milestone of people coming together to get the latest research information, opportunities and having their say on research.

Ensuring everyone has a voice in Parkinson’s research

Driving forward race equality in Parkinson’s research

We know it’s vital that Parkinson’s research represents all members of the community. In 2024, Parkinson’s UK came together to work with Equality, health charities, community organisations and people with lived experience to co-produce a film, INVISIBLE, to encourage greater diversity in health research. The film features a powerful spoken word piece about making those who are currently invisible in the healthcare system more visible.

This is just one highlight out of many we’ve made in our Race Equality in Research project. We’re continuing to work closely with volunteers and community members towards our 5 priorities aiming to increase diversity in Parkinson’s research.

In 2024 we:

- established a monthly online support group for people from Black, Asian, Arab and Mixed Heritage backgrounds. Learn more about the group.

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- supported more “Living well with Parkinson’s” events online and in person in Lewisham, South London, and Sheffield, Yorkshire. Read more about our Race Equality in Research events.
- partnered with a company called Equality to hold workshops with people from Black, South Asian and Arab backgrounds to come up with recommendations to improve our research communications to make them more welcoming and accessible
- ran workshops on the importance of increasing diversity in research for our funded researchers and people who are interested in applying for our grants

collaborated with other health charities to produce a film encouraging greater representation in health research. Watch the video on YouTube.

Working with you to shape what we do

Parkinson’s research simply couldn’t move forward without the whole community being involved at every step, from prioritising research questions to taking part in research trials.

In 2024, we supported more than 70 research projects by linking them with people in the Parkinson’s community to make the research as relevant and impactful as possible. And we’ve supported a further 40 by helping them find participants to take part in their research studies.

Studies like those of PhD researcher Hazel Haworth who’s creating a digital resource for Parkinson’s medication management. Hazel first worked with public and patient involvement contributors to help shape her research questionnaire and make it relevant and fit the needs of the community. This meant when we asked Research Support Network members to take part, there was a great response.

“We had a total of 509 participants in the end, all living with Parkinson's, which is fantastic as we were hoping for 150.”

- Hazel Haworth, PhD researcher at Queen's University Belfast



Some of our research highlights in numbers

Ensuring the patient voice is included in research

The power of community voice was also recognised at an international event in 2024. Since 2021, at Parkinson's UK we've been working with pharmaceutical company UCB and the Parkinson's Foundation on an initiative called the Patient Engagement Council for Parkinson's Research (PECPR). The PECPR embeds the voices of people with Parkinson's in clinical research, and aims to ensure that people with Parkinson's are involved at every stage of drug development

In 2024, the PECPR was awarded the Made with Patients award, recognising the outstanding contribution it has made towards improving clinical research for people with Parkinson's.

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Marc van Grieken is a patient advocate and member of the PECPR. He was diagnosed with Parkinson's in 2006. He said:

"The experience with the PECPR demonstrates that patients can make an impactful contribution to prioritisation, planning, and programming of research. PECPR being awarded the Made with Patients award further encourages industry and patient organisations to see us for who we are."

Looking ahead: 2025

There's plenty to look forward to in Parkinson's research in 2025. It will see the launch of a number of new drug trials, including a new platform trial called ACT-PD which rethinks how clinical trials for new Parkinson's drugs are carried out. The study will take a new approach, trialling drugs in parallel to speed up the research process. The study should be ready to start registering interest in early 2025.

We're also looking forward to hosting Par-Con again. We're in the process of putting together a steering group of people with Parkinson's to help shape the event, and look forward to being able to share details about the 2025 event soon.

Take Part 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.

CAN-PDP: Cannabidiol (CBD) for people with Parkinson's who experience hallucinations or delusions

The research

Research teams across the UK aim to investigate whether CBD is an effective treatment for hallucinations and delusions.

Who do the researchers need?

- 120 people with Parkinson's who:
 - are over 40 years old
 - have experienced any symptoms of psychosis for at least one month. This could include seeing, hearing, or feeling things that aren't there and mistaking objects for other things (hallucinations). For example, a pile of clothes might look like a dog. Symptoms could also include unusual thoughts, beliefs, or worries that aren't based on reality (delusions)
 - have been taking any Parkinson's medications for at least one month
 - are not taking clozapine
 - and have someone who can attend study visits with them

What is involved?

- If you are eligible to take part, you will either receive the study treatment (CBD) or a placebo treatment (such as a sugar pill) for 12 weeks.
- You will be asked to attend up to 6 visits. Some of these can take place over the telephone or online, and others will need to take place at your local research centre or at your home. Each visit will last between 1 and 3 hours. During the visits, you may be asked to give blood samples, complete surveys, or physical examinations.
- You can also optionally take part in 2 MRI scans.
- There are sites recruiting across England, Scotland and Wales.

Interested in taking part?

Please contact the Research Team by email at canpdp.trialoffice@kcl.ac.uk or call: **07936 545 178**

The deadline for taking part in this research is **31 July 2025**.