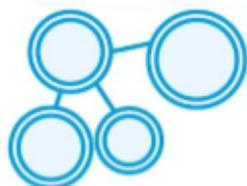




December 2021 Research Roundup

Our Research Support Network (RSN) connects you to Parkinson's research. From finding out more about research to getting involved, there's something for everyone. You can register to receive our research emails directly by visiting www.parkinsons.org.uk/research/get-involved-research and clicking on "Join our Research Support Network."

Here's our **December Research Roundup** with the latest research news and opportunities for you.



GET CONNECTED

The 12 Days of ... Par-Con!

Par-Con was this year's Research Support Network Conference, held 19-21 October 2021, with the theme of 'improving lives through research.'

All 12 sessions (with over 40 speakers!) were recorded, and are now available indefinitely on YouTube for your viewing pleasure. Topics include everything from diet and exercise to the future of clinical trials and what causes Parkinson's.

You can access the recordings with full descriptions online here:

<https://www.youtube.com/playlist?list=PL1ixQpbHed3ZV1AzTWbGM4IVN-ZWaTiVY>

A flurry of Research News

Momentum has gathered this month with news of progress [towards a diagnostic test](#), a trial for dyskinesia [starting recruitment](#) and [new partnerships forming](#) to maximise the impact of research for the Parkinson's community.

Read more research news online here: <https://www.parkinsons.org.uk/news/news-topics/research>

2021 Research Highlights

We continue to work in new and pioneering ways to accelerate the search for better treatments and a cure for Parkinson's. Read on to hear our highlights from the year.

Compared to the hiatus of 2020, for many of us, in 2021 life started moving again. We have adapted and are learning to live in a world that feels a little different than before. And perhaps in doing so have regained a focus for the things that matter most in life.

Along with the world around it, the cogs of research also started to pick up speed. Parkinson's research was able to weather the storm through the worst of the pandemic. And it has also adapted — making some major steps towards being more united and focused on what matters most to the Parkinson's community.

So, in a year that saw so much change, what are our stand out moments?

Uniting to accelerate the research that matters most

We started 2021 by publishing work highlighting the symptoms that matter most to the Parkinson's community. Almost 800 of you took part in the survey that the publication was based on. The major findings of this work were:

- Tremor was the most reported symptom that impacted on people's lives.
- Non-motor symptoms, including problems with psychological health, fatigue, cognitive function and pain were common even in the very early stages of Parkinson's.
- People who'd lived with the condition for 10 years or longer reported problems with walking, balance and falls, speech problems, freezing and dyskinesia.

Read more online: [What symptoms matter most to people with Parkinson's?](#)

Publishing this work is just one way we're making sure that what matters to patients is communicated and at the heart of research to develop better treatments, management strategies and care. This set the theme for the rest of the year, where our achievements were made possible alongside the dedicated work of our volunteers to ensure research is shaped by people affected by Parkinson's every step of the way. One standout moment was our online event for the Parkinson's Community which focused on improving lives through research — Par-Con 2021. The event saw over 2300 people register to watch the talks with special guests spanning the breadth of the research field.

[Catch up on the conference on the Parkinson's UK YouTube channel.](#)

Another triumph was the [launch of our Staying Connected Toolkit](#) that aims to improve communication between researchers and study participants. Something you told us was important.

[You can read more in our blog celebrating our volunteer achievements.](#)

With your help, in 2021 we have also worked with a variety of researchers to shape the planning and design of their studies. And we collaborated with other charities and biopharmaceutical companies to ensure their work is representative of the needs and wants of people living with Parkinson's. Here are just a couple of partnerships where the voice of those with Parkinson's has taken centre stage:

- [UK based pharmaceutical company 4D pharma is working with Parkinson's UK to guide their upcoming trial looking at targeting the gut.](#)
- [Biotech Clexio teamed up with us to better understand sleep problems in Parkinson's ahead of their upcoming trial.](#)

Funding the most promising research

By the end of the year we plan to have spent £8.3 million towards research this year. We continue to accelerate research towards new treatments through our pioneering drug development arm of the charity called the Parkinson's Virtual Biotech — with 8 active projects from drug development to clinical studies. Here were the announcements from this year:



As well as this vital work looking to find better treatments and a cure, we are also investing in research into non-drug approaches that have the potential to transform lives.

Some of the projects that have started this year focus on:

- a weight-shifting strategy that may help overcome freezing
- a speech therapy designed to aid communication
- a wrist worn device to prompt swallowing

Progress towards new treatments

Many different clinical trials for Parkinson's edged forwards this year. Including a number of trials we're supporting through our Virtual Biotech. They will continue into 2022 moving us closer to our ambitious aim to deliver a life changing new treatment by the end of 2024.

Updates:

- Investigating cannabidiol (CBD) for people with Parkinson's associated psychosis. The first stage is almost complete and the researchers hope to take the best dose of CBD forward into the second stage of the study early next year. [You can read more and watch a clip from a short BBC documentary here.](#)
- A trial to understand the potential benefits of ondansetron for people with Parkinson's or Lewy Body Dementia who experience hallucination started recruitment this year, and is still looking for people. [Find out more and take part.](#)
- Just this month the study to assess the drug NLX-112 for dyskinesia started recruitment in Sweden. [Read the news.](#)

Taking steps towards race equality in research

Earlier this year we launched a collaborative project to work with people from underrepresented communities and research professionals to drive real and lasting change to take steps towards making research more representative of the whole Parkinson's population.

Key aims were set out for this project:

- What steps can we take to make research more accessible, engaging and relevant to people from Black, Asian and Mixed race backgrounds?
- What steps can we take to ensure studies and trials we support proactively reach out to people from these backgrounds?
- How can we set clear and measurable objectives to ensure continued focus and resources for this work?

Powered by people

We have now set up a steering group to power this work — made up of people affected by Parkinson's and research professionals from Black, Asian and Mixed race backgrounds, as well as colleagues from Parkinson's UK. We have also got two organisations on board to help ensure we reach and involve as many people as possible from these underrepresented groups.

Read more online: [Ethnicity and Parkinson's: what we know so far](#)

It has been quite a year, and I hope these highlights give you a flavour of the progress we're making. Our network of people dedicated to Parkinson's research is continually growing and we look forward to carrying this momentum into 2022, because together, we can find better treatments and a cure.

Thank you for supporting Research! Wishing you happy holidays and a great new year!

— From the Parkinson's UK Research Team.

Written by Dr Katherine Fletcher, Research Communications Officer at Parkinson's UK

Diet and Parkinson's

This blog explores research into gut health, diet and nutrition for Parkinson's.

We know that diet is important for general health and that everyone should follow the recommendations for a balanced diet. But why is this an important area of research in Parkinson's? In short, it's because diet and gut health have the potential to play a role in understanding the earliest signs and causes of the condition, could offer a way to better manage symptoms and could even pave the way for clues to slow or stop Parkinson's.

The gut and possible ways to boost good bacteria

There's a theory that Parkinson's may start in the gut and spread to the brain via the intricate network of nerves that connects the brain to the rest of the body. You may have heard this theory referred to as the Braak hypothesis, where a research group back in 2003 hypothesised that changes to the bacteria living in our gut may contribute to the loss of vital dopamine producing brain cells and onset of Parkinson's symptoms. Evidence to support this theory is gathering momentum and it's becoming an increasingly hot topic for research. There are a number of ongoing studies — from looking at the potential of transplanting gut bacteria to using probiotics as a way to boost good bacteria — to improve symptoms or slow the progression of the condition.

Some studies to keep an eye on

Probiotic called Symprove — Research is ongoing to understand if a drinkable probiotic, to boost good gut bacteria, is beneficial to motor and non-motor symptoms of Parkinson's. Parkinson's UK funded researchers at King's College London are busy collecting this data in 60 people with Parkinson's. There's a study underway in Sheffield looking to gather evidence too.

Pinpointing good bacteria — Dr Maria Doitsidou's team in Edinburgh have found that a bacteria called *Bacillus subtilis* has the potential to play a protective role in Parkinson's, after publishing research results looking at worms in the lab. [Read more about these results in a previous blog](#). The researchers now hope to move this further towards clinical trials.

Transplanting gut bacteria — This is the idea of taking a sample of gut bacteria from someone who isn't diagnosed with a health condition and putting it into the intestines of people with Parkinson's. It is believed that this could have the potential to quickly alter someone's gut bacteria, to potentially impact the symptoms and even the progression of the condition. But, the evidence so far has been limited to mouse models of Parkinson's and a small clinical trial in [15 people with Parkinson's in China](#). There are more plans on the horizon, including a study happening in Australia by a biotech company called BiomeBank to gather further evidence on this topic for improving motor and non-motor symptoms of

Parkinson's. [You can read more and keep up to date on their website.](#)

Specific diets and Parkinson's

The internet is bursting with information and advice on diets but sometimes it can be tricky to navigate and understand what evidence backs up the claims. Unfortunately, research evidence is limited when thinking about a specific diet or supplement that might help someone with Parkinson's. So, before we look at some research that is underway, let's address some of the main reasons why this area seems so tricky to unpick:

- **Parkinson's is complex.** It's hard to study diet in isolation when so many factors are contributing to the causes and symptoms of the condition, and these will often be unique to the individual.
- **Sticking to specialised diets can be hard!** Clinical trials asking people to follow a specific diet have limitations as not everyone will follow a diet in the same way or with the same commitment. It is also tricky to have a properly controlled trial, as it is evident to the participants and the researchers who's following the specialised diet versus who's in the placebo group.
- **Lab based studies are too far removed to form nutritional advice.** When studying natural ingredients in the lab they are usually being investigated at much higher concentrations than someone would get from their diet. So, while this research is very interesting scientifically and could provide a route to developing new treatments, it's usually too far removed to be a direct source of nutritional advice. An example of this is a recent study showing the potential of an ingredient found in fruit. [Compound found in fruit shows promise for Parkinson's](#)

That being said, there's still research looking for answers and let's hope this is an area that gets more attention in the future. Here's three areas of research to highlight:

Could a high fat diet protect brain cells?

The body is usually powered by a sugar called glucose allowing our cells and organs to function properly. A lot of this energy comes from the body breaking down carbohydrates. Like most things, this process is carefully regulated but sometimes it can result in damaging products being produced and left to cause harm. These damaging side products are thought to contribute to the damage of brain cells in Parkinson's. So what if brain cells could get energy from an alternative source?

A ketogenic diet is high in fats and low in carbohydrates. In theory it forces the body to switch its usual energy source from glucose (sugar) to ketones — products that are made from the breakdown of fats, which are used to power the brain when glucose is less readily available. It is thought that switching the way the brain is powered may have protective effects.

Evidence so far largely comes from studies conducted in cells in the lab and animal models. But there are also results from an early stage clinical trial in 38 people with Parkinson's to show a ketogenic diet [could help to improve non-motor symptoms](#) such as thinking and memory. And there is even evidence that this alternative energy source could help [boost exercise](#) ability for people with Parkinson's. Crucially, more evidence is needed before this diet would be recommended to people with Parkinson's. Larger, long-term studies are now needed to assess whether this diet is practical, safe or effective.

This blog is not medical advice. Getting the right nutrition is vital but it's also individual and will depend on a range of factors including your weight, activity levels, any other health issues you have and the medications you take. So it's really important to speak to your doctor or nurse before making any significant changes.

What's the evidence for sticking to a Mediterranean diet?

Back in 2008 [a study collected and reviewed data from over 1.5 million people](#) to understand how this particular diet might impact life expectancy and incidence of particular health conditions. The results showed that sticking closely to a Mediterranean style diet could be overall beneficial to health and reduce incidence of Parkinson's.

Mediterranean diets are high in vegetables, fruits, legumes, nuts, beans, cereals, grains, fish, and unsaturated fats such as olive oil. They usually include a low intake of meat and dairy foods. There's also evidence that components of a Mediterranean diet may be beneficial to those living with Parkinson's — as highlighted by an ongoing study that tracks diet and lifestyle with Parkinson's symptoms. Read on to find out more.

Uncovering more about diet, supplements and lifestyle in Parkinson's

Research being led by Dr Laurie Mischley at Bastyr University called CAM Care in PD is investigating the influence of diet and lifestyle factors in Parkinson's by collecting a wide range of data from people across the globe. The aim is to generate evidence based guidance related to diet and lifestyle to improve lives for people living with the condition. The team aims to track people over a period of five years using online surveys, where participants input every six months, answering questions about medications, diet, supplements, exercise, medication and an array of other factors. At the same time, they are asked to rate the severity and impact of their Parkinson's symptoms. [You might be interested in finding out more on their website.](#)

This study started in 2012 and is ongoing, but back in 2017 did publish some initial results where some foods seemed to be linked to slower or faster progression. Where foods such as fresh fruit and veg, olive oil and herbs seemed to be on the helpful list and fizzy drinks, beef and ice-cream were on the not so helpful. But it is important to note that the data is still being collected and we have already covered why diet research can be tricky to unpick. [This 'Science of Parkinson's' blog](#) explains the full findings of the study so far.

Written by Dr Katherine Fletcher, Research Communications Officer at Parkinson's UK

Stem Cells - What's the latest?

We discuss the latest research exploring the potential of using stem cells as a treatment and therapy for Parkinson's.

Parkinson's is caused by a decrease in dopamine, a chemical made in the brain. The cells that produce dopamine either stop working properly or are lost over time, leading to the range of symptoms that someone with Parkinson's can experience. Current treatments for Parkinson's work by boosting dopamine levels in the brain, helping to manage some of these symptoms. However they don't slow or stop the progression of the condition, as dopamine producing cells continue to be damaged. But, what if there was

a way to replace the lost and damaged cells with new ones? This is where stem cell therapies might hold the answer. Research into this area has been happening for over a decade and a lot has already been learnt, although most clinical trials are still in the early stages of development.

Currently, there is no approved stem cell therapy or treatment available that has been shown to slow or reverse Parkinson's in clinical trials. A word of caution — there are a number of organisations and agencies from other countries that falsely claim they can deliver stem cell therapy. When in doubt, please get in touch with us at research@parkinsons.org.uk where we can answer any research questions you might have.

This blog explains the science behind the potential of stem cell therapies and highlights some of the latest research.

What are stem cells and how could they help in Parkinson's?

Stem cells are a powerful type of cell. They are the original cells that everything in the body is made from and they are responsible for repairing tissues and organs when they get damaged. This is possible because stem cells have the ability to develop into different types of specialised cells — from muscle cells to brain cells. These properties make them attractive to researchers looking to find new treatments for various health conditions, including for Parkinson's, where they could be used to replace lost brain cells and potentially slow or reverse the condition. Before we look at the current research that's underway, it's important to understand there are different types of stem cells and approaches being investigated for Parkinson's.

Different types of stem cells:

Adult stem cells are found all over the body and they help regenerate old and damaged tissues and cells. However, they are limited in what types of cells they can change into, and the stem cells present in our brains (called neural stem cells) are not able to prevent or repair the damage being done in Parkinson's. This is why adult stem cells are less commonly used in stem cell research.

Embryonic stem cells are found inside developing embryos and they can change into any type of cell in the whole body — the scientific term for this is pluripotent. These cells are a powerful tool for research but they come with additional ethical considerations. In the UK, stem cells from human embryos can be collected from leftover embryos produced as part of in vitro fertilisation (IVF) programmes that would otherwise be destroyed. There are strict legal guidelines for using embryonic cells for research from the Human Fertilisation and Embryology Authority (HFEA).

Induced Pluripotent Stem (iPS) Cells are stem cells that have been made in the lab. Scientists can turn specialised adult cells, such as skin cells, into stem cells which can go on to develop into any type of cell, for instance brain cells. This means that researchers could use cells from a person with Parkinson's to generate new dopamine producing brain cells to study in the lab or for a possible transplant. This reduces the risk of the body rejecting the new cells as they have originated from the recipient. Although iPS cells are slowly becoming the go to stem cell to use in research, they haven't long been discovered so let's take a look back at stem cell research in Parkinson's...

Key breakthroughs in stem cell research and Parkinson's:

1960s — Adult stem cells were first discovered in the bone marrow

1980s — Embryonic stem cells discovered and first fetal cell transplant for Parkinson's

Embryonic stem cells were discovered in mice in 1980. After successful preclinical experiments in rats, researchers in Sweden transplanted the first fetal stem cell into people with Parkinson's. The results were initially positive with the cells replacing lost dopamine producing cells however some participants experienced unwanted side effects as a result so further investigations and research was needed.

2002 — Transplanting stem cells may reverse some Parkinson's symptoms

[In 2002](#), Scientists in the US showed that transplanting stem cells into the brain in rats may indeed be able to reverse some symptoms of Parkinson's.

2006 — Scientists turn adult cells into stem cells — iPS cells

One of the biggest breakthroughs came when researchers in Japan were able to generate iPS cells in the lab. They used human skin cells and turned them back into stem cells.

2010s — Success of iPS cells in animal models

Researchers in the USA showed that Parkinson's symptoms improved after they transplanted dopamine producing brain cells generated from iPS cells in a rat model. Japanese researchers used a similar technique to then show similar results in monkeys in 2017. This showed that the transplanted dopamine producing cells made from iPS cells did successfully produce dopamine.

These breakthroughs have paved the way for ongoing clinical trials using embryonic stem cells and iPS cells to potentially treat Parkinson's. These studies involve either surgically inserting stem cells into the affected parts of the brain, or directly into your bloodstream through a vein in your arm. Due to this research area being fairly new and novel, stem cell trials are usually longer than other research trials because it's important to understand if transplanted cells survive over time amongst other things. We take a look at some of the latest clinical trials...

What's the evidence from clinical trials?

Trial name: [TRANSEURO](#)

Location: Across Europe including the UK

Aim: This trial aims to test the effectiveness and safety of transplanting dopamine producing brain cells from foetal tissue into the brain.

Recruitment status: Trial completed, awaiting results

Update: This phase 1 trial began in 2012 and finished in the first half of 2021; 40 people with Parkinson's participated across Europe. Initial results have shown that this trial had several limitations, including challenges sourcing enough tissue needed for the transplants. The full research trial results are yet to be published.

Based on these difficulties the researchers are now building on their experience to start a new research trial, STEM-PD.

Trial name: STEM-PD

Location: Sweden and UK

Aim: The research aims to see if using embryonic stem cells has benefits for people with Parkinson's. The research will make dopamine producing neurons from embryonic stem cells.

Recruitment status: Pre-recruitment, aiming to start recruiting in 2022

Update: This European collaboration trial is currently waiting for regulatory approval before they can begin recruiting 8 people with Parkinson's to take part.

Trial name: [Human Embryonic Stem Cell Therapy \(MSK-DA01\) For Advanced Parkinson's](#)

Location: USA and Canada

Aim: This study is using dopamine producing nerve cells made from human embryonic stem cells (DA01) to be transplanted into 10 people with Parkinson's. The main aim of this study is to assess the safety and how well tolerated the stem cell transplants are after 1 year. The study will also monitor to see if the transplanted cells survive and if there are any effects on motor symptoms such as walking after 1 and 2 years.

Recruitment status: Recruiting in the US, trial started

Update: This phase 1 trial began in May 2021 with one participant out of 10 having already undergone the cell transplantation. There is an estimated completion date of January 2024, so we have a while to wait before we see any results.

Trial name: [Mesenchymal stem cell trial](#)

Location: USA

Aim: This study will use mesenchymal stem cells, a type of adult stem cell, that are found in the bone marrow. These cells are important for making and repairing tissues so using them may prevent the loss of nerve cells in Parkinson's. This phase 2 research will look at how safe, as well as how many stem cell treatments are potentially needed to slow down the progression of Parkinson's. Participants will receive 2 to 3 stem cell doses through an infusion going into the bloodstream over the course of a year.

Recruitment status: Recruiting 45 people with Parkinson's in Texas

Update: This phase 2 clinical trial follows on from an initial phase 1 trial which has [recently published](#) results. Phase 1, involving 20 people with Parkinson's, found that there were no serious side effects or immune reactions to the stem cells which came from a donor bone marrow. As well as showing that the treatment was safe, it also showed a reduction in Parkinson's motor symptoms such as freezing, tremor etc.

Trial name: [Aspen Neuroscience](#)

Location: California, USA

Aim: Aspen Neuroscience is developing a stem cell therapy using iPS cells made from a participant's own skin that will be turned into dopamine producing nerve cells. This therapy will aim to avoid the risk of cell transplant rejection that can happen if cells do not come from the participant.

Recruitment status: Not yet recruiting

Update: This biotech company is currently seeking ethical approval to then begin clinical trials in 2022.

There have been huge developments over the past 40 years in stem cell research but there are still a

number of questions left to answer. Researchers are busy addressing these for Parkinson's and a collaborative approach has been established with [GFORCE-PD](#) — a global initiative for stem cell based therapies in Parkinson's — being set up in 2014. This involves regular meetings for researchers in this field to share ideas and learnings to make research in this area as efficient as possible.

If you would like to stay up to date with the latest research then you can join the [Research Support Network here](#).

Written by Rachel Lesbirel, Research Communications Officer at Parkinson's UK

For more research articles, please visit <https://medium.com/parkinsons-uk>



TAKE PART

For people who wish to participate in studies, please visit our [Take Part Hub](#), a post code searchable database of studies actively recruiting participants. The Hub is updated weekly with new studies, so please do check it regularly:

<https://www.parkinsons.org.uk/research/take-part-research>

And for those people not online, you can call our free, confidential Helpline on **0808 800 0303** and our trained Advisors will be able to discuss what you are interested in and put you through to the Research team to find studies for you.

1. Participants needed: Testing antiviral drugs to help combat coronavirus

Who is needed: If you test positive for coronavirus, you may be able to take part in a UK-wide trial to find out if antiviral drugs can help people recover faster. Read more to find out what's involved and why we're encouraging people with Parkinson's to take part.

For full information about the research and to take part: Please go to <https://www.parkinsons.org.uk/news/take-part-groundbreaking-research-test-drugs-combat-coronavirus>

2. Participants needed: Online questionnaire - Bringing

outdoor walks indoors

Sarah Montrose, a trainee Clinical Psychologist at the University of Edinburgh, is evaluating the impact of virtual nature walks on people's psychological well-being.

What is involved? Completing a one off 40 minute online survey and watching a short video clip. For more information, please [visit the website](#).

Who do the researchers need? 100+ people with and without Parkinson's over the age of 65.

Questions? Contact Sarah via email (S2007876@sms.ed.ac.uk) or phone (079 2982 2698) before 1 March 2022.

To take part: Please [visit the study website](#).

3. Participants needed: Online questionnaire - Understanding low blood pressure and Parkinson's

Dr Eduardo de Pablo-Fernandez and the research team at UCL are investigating how symptoms of low blood pressure are experienced by people with Parkinson's and what medication is currently used to manage it. They are hoping this information could lead to better management of these symptoms.

Who do the researchers need? 100 people diagnosed with Parkinson's. You do not need to have been diagnosed with blood pressure issues to take part in this research.

What's involved? A one off online questionnaire that should take no longer than 5-10 minutes to complete. The questionnaire will ask you to grade your experience of symptoms. For more information, please [visit the website](#).

Questions? Please contact Eduardo via email (Eduardo.fernandez.13@ucl.ac.uk) or phone (02076794297) before 31 January 2022.

To take part: Please [visit the website](#).

Need to chat to someone? Our helpline and Parkinson's local advisers are here to answer any questions you have about the symptoms of Parkinson's. You can call them on **0808 800 0303**.

Thank you for supporting research!
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