

PROGRESS

The research magazine of Parkinson's UK | Summer 2022

The journey to understanding Parkinson's – so far...

A look back at how far we've come and discover what lies on the road ahead.

P4

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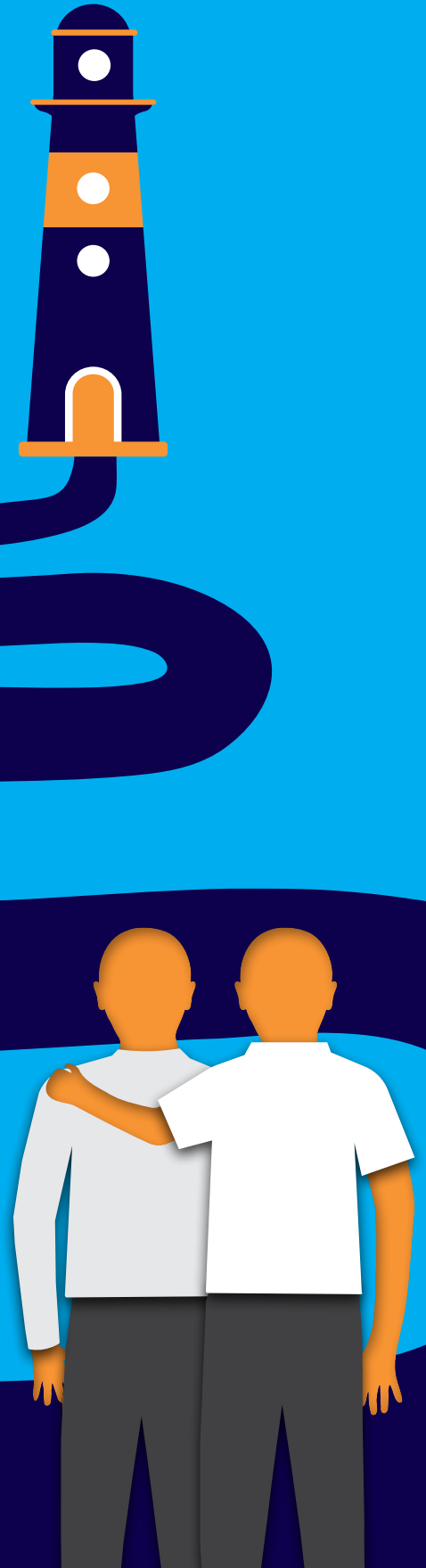
Uncovering new paths to explore
Demystifying lab-based research and the importance of observational studies.

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PARKINSON'S^{UK}
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FIND A CURE.
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WELCOME

Hello and welcome to *Progress* magazine. I'm Caroline Russell and I'm the new Chief Executive of Parkinson's UK. I'm delighted to introduce this issue of our research magazine. The focus is on research into better understanding Parkinson's to get us closer to improved treatments and a cure for the condition.

Over the past few months I've been getting up to speed with Parkinson's research. And I've been astounded at the number of exciting projects happening across the globe and how far research has come to understand what is a hugely complex condition. Page 4 gives an excellent overview of this journey so far.

I'm particularly proud to share that we're celebrating the fifth anniversary of our most ambitious research venture to date: the Parkinson's Virtual Biotech. This is an area of work I'm keen to see us build upon in the coming years. I'm also particularly passionate about us exploring non-drug and technological approaches to find better treatments for the condition. You can read more about the Virtual Biotech on page 17.

I also had the pleasure of recently visiting Oxford with some of our Trustees. We heard what's happening with research in and around the city. We learnt about the importance of large observational studies, such as the Discovery project happening out of the Oxford Parkinson's

Disease Centre. We also met some of the researchers and participants involved in the project and members of the Parkinson's UK local group. It was truly fascinating. I hope you might share this fascination when reading more about how observing people over time is so powerful in our journey to understanding Parkinson's, on page 14.

Thank you for your continued support of research. Every breakthrough is powered by people who care about Parkinson's. People like you. We unite to fund, shape and take part in research to make the biggest possible impact.

I really hope you enjoy this edition of the magazine.

Caroline

PS We're always keen to hear what you want to read about in the future. So, fill in our super quick survey (see page 27) or drop us an email at research@parkinsons.org.uk.

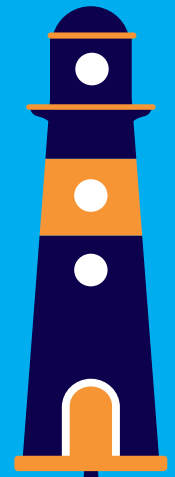
Don't forget:

- If you receive both our *Parkinson* and *Progress* magazines you will need to resubscribe to keep getting these by post.
- You can read this and previous issues of *Progress* online parkinsons.org.uk/progress.

This magazine is produced by Parkinson's UK alongside our *Progress* editorial board, a dedicated group of people affected by Parkinson's, who shape the content and look of the magazine. **Many thanks to:**

- Clive Bartram
- Margaret Emsley
- Kathy French
- Richard Hill
- Emily Kerr
- Iona Lister
- David Wilson

THE JOURNEY TO UNDERSTANDING PARKINSON'S - SO FAR...

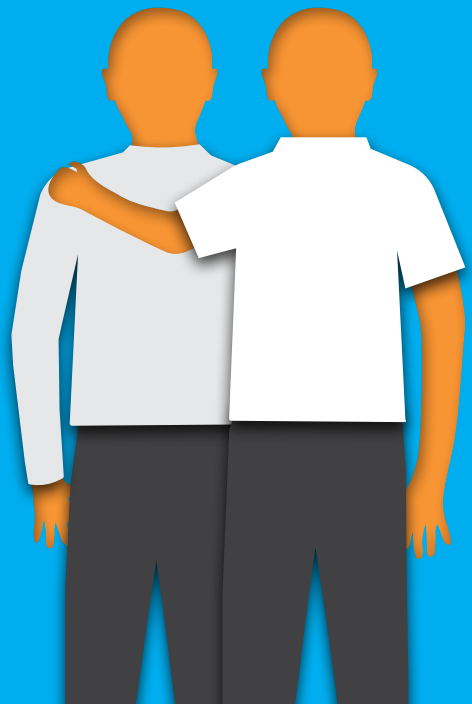


Over the last 60 years, countless scientists from around the world have added to our growing understanding of Parkinson's. In doing so, they have uncovered ways that we might stop its progression. Here we take a look back at how far we've come and discover what lies on the road ahead.



Want to know more about the history of Parkinson's?

Richard, one of our volunteers who helps put together this magazine, recommends the book, *The Enlightened Mr Parkinson*, by Cherry Lewis. He says: "It's an essential read for anyone with Parkinson's or a general interest in history."



When it comes to Parkinson's research, we have a common goal – a cure. It might seem simple enough. If we can find out why brain cells are dying, we can figure out how to stop it happening. Indeed, in 1817, in the essay that first defined the condition, James Parkinson wrote about the need for a treatment with which “the progress of the disease may be stopped”.

Understanding the condition is, and has always been, our best chance of achieving this aim. But the journey towards a cure for Parkinson's has turned out to be more complex than pioneering early researchers once hoped.

It has become evident that a myriad of problems occur inside the cells affected by Parkinson's. There may even be specific subtypes of the condition being driven by different problems and, therefore, needing different solutions.

The fact is, today we don't have an exact map to reach a cure. But the more we understand about the condition and its complexities, the clearer the possible paths become. Parkinson's researchers, guided and supported by the Parkinson's community, are navigating these paths. And with the promise of a better future hanging so tantalisingly close, can we be blamed for wondering, “are we nearly there yet?”

To understand how close we are, let's take a look at some of the current avenues of discovery and how researchers are turning understanding into new treatments.



Replacing dopamine

In the 1960s, scientists knew Parkinson's was caused by a loss of dopamine-producing cells in a part of the brain known as the substantia nigra. The loss of these cells means the brain doesn't make enough of the chemical messenger dopamine to send important signals. With this understanding, early efforts to cure Parkinson's focused on replacing dopamine.

The drug levodopa was first tested in people with Parkinson's in 1961. Once in the brain, levodopa is converted to dopamine, boosting the supply for cells struggling to make their own, which helps to improve symptoms.

Levodopa remains the main treatment to this day, alongside other drugs to reduce the side effects and improve its performance. But it can't slow

down the loss of brain cells and, as the condition progresses, more dopamine is needed.

Other paths are being investigated for replacing and mimicking the dopamine the brain is no longer naturally making. Perhaps the most exciting developments are in the field of stem cell research. Scientists are aiming to replace the lost dopamine-producing brain cells themselves rather than just the dopamine they make.

The first cell transplant trial for Parkinson's happened in the 1980s, an incredible feat when you consider that just 20 years before, researchers were first trialling levodopa. Unfortunately, the results were unclear and highlighted the need to fine tune the potential therapy.

Questions still remain around how long cells may survive after transplantation, if the underlying causes of the condition are not tackled. But new knowledge and technology are allowing scientists to investigate this further than ever before.

Scientists can now grow dopamine-producing brain cells in the lab which opens up the possibility for more large scale cell transplantation. There are a number of active clinical trials of stem cell therapies for people with Parkinson's around the world and this poses a really hopeful avenue.

Go online to read our blog on this subject
[parkinsons.org.uk/
stemcellblog](https://parkinsons.org.uk/stemcellblog)



Targeting problematic proteins

Proteins are the building blocks of the cells that make up our bodies. Like Lego pieces, proteins come in all shapes and sizes. But in Parkinson's, and many other neurodegenerative conditions, some of them seem to misbehave.

Large bundles of proteins (called Lewy bodies) were first seen inside brain cells from people with Parkinson's in 1912 by German scientist Friedrich Lewy. While we knew of their existence, it wasn't until 1997 that researchers started to understand that one protein in particular may play a key role in Parkinson's.

Researchers identified that alpha-synuclein is the main protein found in Lewy bodies. And a separate study found that a change in the gene that holds the instruction to make alpha-synuclein causes a very rare inherited form of Parkinson's.

Further research has revealed that mis-shapen forms of alpha-synuclein buildup inside

the brain cells affected in Parkinson's. These distorted proteins are thought to be toxic, clogging up the cell and stopping it working properly. They may also be responsible for the spread of the condition, as the protein leaks out of affected brain cells and enters neighbouring cells, and is thought to contribute to inflammation. More on that later.

This knowledge has led researchers to develop therapies that target alpha-synuclein, hoping to prevent it building up and spreading to other cells. However, problematic proteins might not be the only reason why Lewy bodies form in Parkinson's. In the early 2000s, scientists discovered that problems with the waste disposal and recycling centres of our cells – known as lysosomes – may also be responsible for the buildup of troublesome proteins.

Today, researchers are exploring multiple routes to remove the

waste and clear up cells. From vaccines that target mis-shapen alpha-synuclein for disposal, to drugs that boost the power of the lysosomes, the discovery of problematic proteins in Parkinson's has yielded a wealth of avenues to explore. Read about a specific Parkinson's UK funded project on page 18.

At the same time, technological advances over the last 40 years have allowed researchers to delve deeper into other genes that might be associated with Parkinson's.

Sequencing all of the genetic instructions from an individual has never been quicker. Although, it is important to note that currently this doesn't necessarily give a clear picture of who will develop Parkinson's. But it has helped to identify a list of Parkinson's-related genes that are allowing researchers to understand more about what's going wrong in Parkinson's.

Boosting energy supply

In the late 1980s, scientists funded by Parkinson's UK started studying brain tissue from people with Parkinson's. They were first to spot problems with the energy producing mitochondria in affected brain cells.

Mitochondria are like tiny batteries that are present inside almost every cell in our bodies. Their job is to convert fuel from our food into energy. When mitochondria don't work properly, they can't produce enough energy and this means cells stop working properly too. Even worse, broken mitochondria actually become toxic to cells and poison them.

Since this initial discovery, scientists have continued to study mitochondria in Parkinson's to understand these problems better and figure out ways to fix them. One of these scientists is Professor Heather Mortiboys, who became a Parkinson's UK Senior Research Fellow in 2013. Since then, Heather has identified molecules that may fix mitochondria function in Parkinson's. Developing these molecules into potential drugs is currently being driven by a £1.3m investment from the Parkinson's Virtual Biotech,

the drug discovery and development arm of Parkinson's UK. You can read more about our latest Virtual Biotech projects on page 18.

As well as designing new drugs from scratch to target the faulty mitochondria, existing drugs are now being tested in clinical trials. One of these is a liver drug called ursodeoxycholic acid (UDCA). Promising results from a Parkinson's UK grant in 2015 saw this drug move into early-stage clinical trials, which finished late last year. We are currently awaiting results.



Dialling down inflammation

Perhaps one of the newest areas of discovery is the role of inflammation. To protect our bodies against infections, injuries and toxins, our cells respond to danger by releasing tiny messenger proteins. These proteins alert the immune system that something is wrong so that the threat can be neutralised. This is inflammation.

In the short term, inflammation protects our cells. But it may become a problem if it is constant or chronic and starts causing damage to healthy cells. Chronic inflammation in other parts of the body has been linked with the development of a range of different conditions including cancer, heart disease and rheumatoid arthritis.

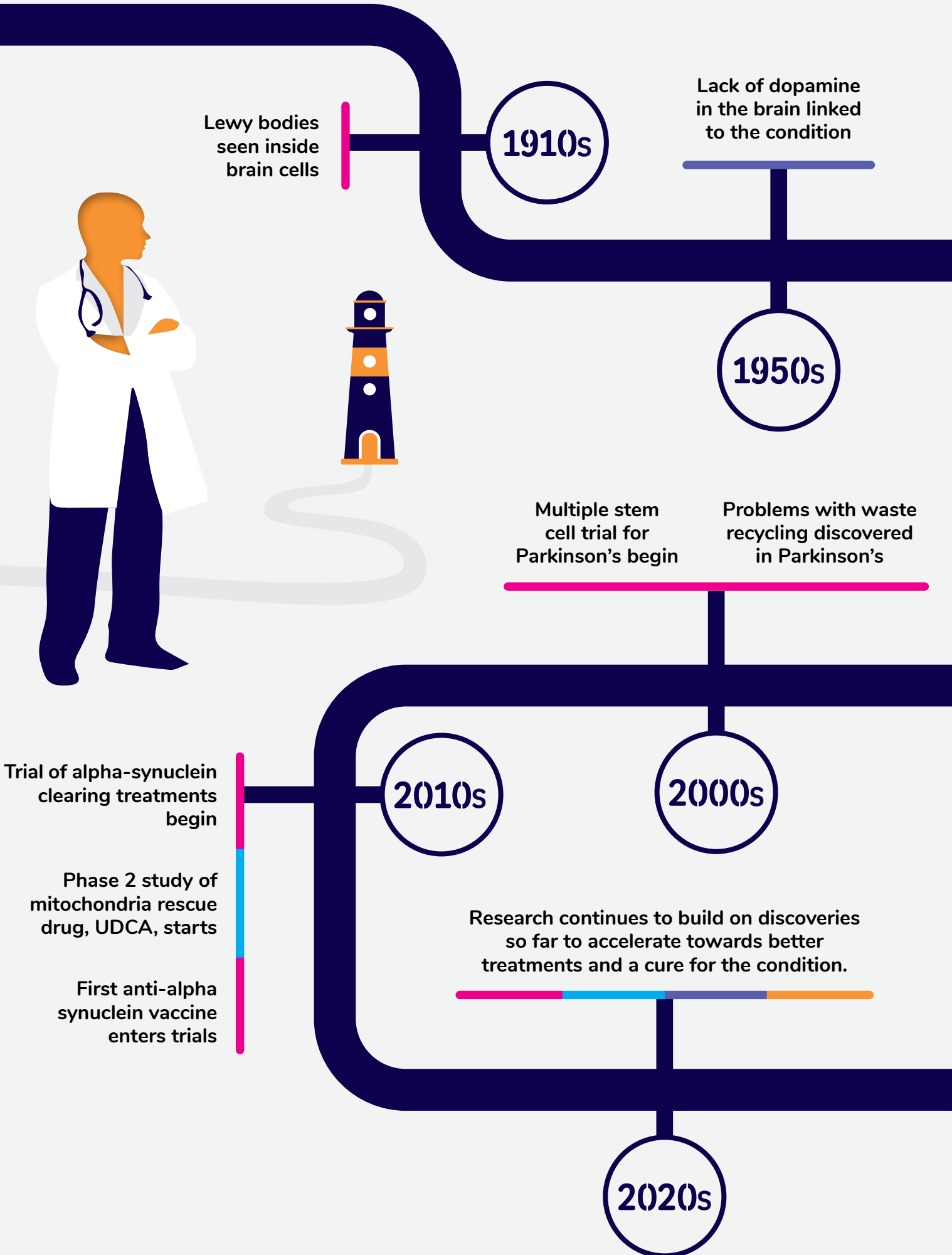
It's now becoming clear that chronic inflammation inside the brain may be involved in neurodegenerative conditions including Parkinson's and Alzheimer's and that stopping it may slow progression. And so, researchers are now starting to develop drugs that may dampen the immune response in Parkinson's, helping to protect remaining cells.

It's still early days in the development of drugs that target inflammation in Parkinson's. However, compounds that target the immune system

are now entering clinical trials for Parkinson's. For instance, there is a clinical trial in Cambridge looking at a drug that suppresses the immune response, Azathioprine.

There is also important work looking to better understand the promise of targeting inflammation in the brain, including a £2.9m investment by Parkinson's UK. Read more on page 18.

**Help fund research to dial down inflammation.
Donate today parkinsons.org.uk/give**



Key

- Targeting protein
- Boosting energy
- Replacing dopamine
- Dialling down inflammation

1960s

Loss of dopamine-producing brain cells in Parkinson's – levodopa given to people with Parkinson's

1980s

Evidence of inflammation found in the brain in Parkinson's

Problems with mitochondria discovered

First cell transplant trial starts in Parkinson's

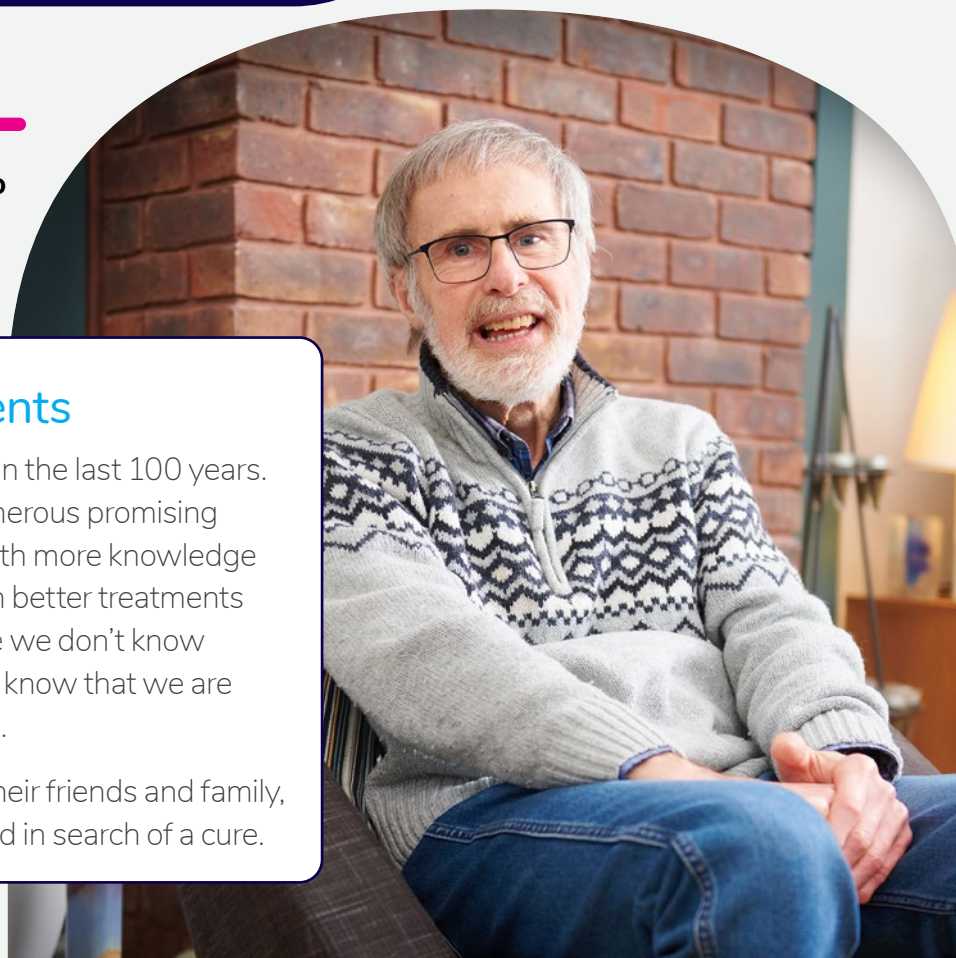
1990s

Alpha-synuclein shown to make up Lewy bodies

Towards better treatments

We've learnt a lot about Parkinson's in the last 100 years. Today researchers are exploring numerous promising paths and illuminating new ones. With more knowledge comes hope that we are closing in on better treatments and a cure for Parkinson's. And while we don't know which paths will find success, we do know that we are closer today than we have ever been.

Driven by people with Parkinson's, their friends and family, together we will travel the road ahead in search of a cure.





UNCOVERING NEW PATHS TO EXPLORE

Let's take a look at some of the ways researchers are building our understanding of Parkinson's. In these next two articles, we'll demystify lab-based research and talk about the importance of observing large groups of people over time.

What is lab-based research?

We've already heard about some of the main discoveries in Parkinson's research so far. These all originated in the lab, and there are new ideas being investigated all of the time. Some will lead to dead ends but some will pave the way for the treatments of tomorrow.

Let's explore what lab-based research involves and what impact this work has for the Parkinson's community.

How do labs identify new theories to explore?



Growing and studying cells.

One of the first ways labs try to learn more about Parkinson's, is by studying cells grown in a plastic petri dish or flask.

Trillions of cells make up the human body. Most have a specific purpose, such as the cells that line our intestines which absorb vital nutrients, or brain cells that send vital signals to power everything that we think and do.

In Parkinson's, researchers are most interested in growing and studying the brain cells that are affected by the condition. Thanks to breakthroughs in the last few years, scientists can transform skin cells to acquire all the key characteristics of brain cells and then study them to get a more accurate view of what is actually happening inside the brains of people with the condition. This amazing feat comes from advances in stem cell technology.

Today researchers are using these cells to:

- Light up individual parts of the cell under the microscope to study them in more detail.
- Measure levels of specific chemicals being released.
- Uncover changes in the DNA and proteins that might be linked to Parkinson's inside the cells by breaking them open



Using donated brain tissue

The Parkinson's UK Brain Bank is a vital resource for Parkinson's research. Thanks to the Brain Bank, we can collect precious tissue from

people with and without the condition who have decided to leave their brains to research. The tissue is then supplied to lab-based researchers studying Parkinson's all over the world, adding to our understanding of what exactly goes wrong in the condition. These insights are crucial to finding ways to treat Parkinson's.

If you're interested in hearing more about our Brain Bank please get in touch or visit parkinsons.org.uk/brainbank.



Using animal models

Studying complete living systems is a vital part of lab-based research.

Researchers can reproduce many aspects of conditions such as Parkinson's in an animal, which makes it an important tool for improving our understanding of what's happening. Animal research is also required when taking discoveries to the next stage and fine-tuning drugs to ultimately test in clinical trials.

It's important to highlight that any work that involves living organisms is tightly regulated. We're currently funding work that involves worms, flies, mice and rats to help develop new treatments and a cure for Parkinson's.

How are new theories turned into new treatments?

By uncovering specific genes and proteins linked to Parkinson's, researchers have discovered how our cell batteries, waste disposal and even the immune system may play a role in the causes of Parkinson's. Now, researchers are using these breakthroughs to develop treatments that might block or remove problematic proteins, or boost protective factors.

New scientific discoveries may be born in the lab, but they need a lot more work to be made into treatments and therapies. This can involve a process of testing and refining ideas in cells, animals, and finally in people. Let's look at the various stages involved in turning ideas into new drugs.

1. Finding and testing the most promising molecules

Making breakthrough drug discoveries often starts with huge libraries of molecules that have the potential to target a problem. The libraries are screened, usually using cells grown in the lab, to identify the most promising molecules to take forward.

The most promising then undergo a series of more complex tests to understand how they are working and what potential they might hold.



2. Turning promising molecules into drugs safe for people

Now the group has been whittled down to molecules with real promise, it's time to start honing and developing them into drugs. This step needs skilled chemists who are specialists in drug design. They'll painstakingly tweak the structure of the molecules to improve their performance and make sure the drug gets to the right place in the body and has the maximum beneficial effect with minimal side effects.

These drugs are then tested in the lab, often in animal models, to understand their safety and effectiveness.

3. Trialling possible treatments in people

Then, lab-based research moves into the clinical research stage. Here, researchers try to understand the potential benefits of a drug in people with Parkinson's through carefully controlled clinical trials.



So, why does lab research matter?



Alison has Parkinson's and is a research volunteer. She helps to decide which research we fund, and shares her reflections on this question:

"Lab-based research is important as it forms the basis of future breakthroughs. It gives me hope that we will see more and more possible treatments coming through to clinical trials in the coming years."

"Being part of the reviewing process is fascinating. I believe it's so important that researchers work alongside people with Parkinson's and their loved ones to ensure their research is relevant to people actually living with the condition.

"Even though the lab-based research applications can be technical and at an early stage, researchers need to have shown they've thought about why their research is important and communicate their plans in a way everyone can understand."

Interested in helping to decide what research we fund?

Turn to page 21 to find out how you can get involved.

Not all discoveries are coming from microscopic cells. Another powerful way we learn more about Parkinson's is by observing people over time. Turn the page to discover more.



Why observe people over time?

For most people, Parkinson's progresses slowly over a number of years. This means understanding the condition takes time. More than a decade's worth of work has provided vital insights into Parkinson's and is helping to develop the treatments of tomorrow.

Dr Alastair Noyce is a Parkinson's UK funded researcher, and a leading expert in studies that involve large groups of people with Parkinson's, known as cohort or observational studies.

We asked Alastair some questions about his work and the importance of large observational studies.



Dr Alastair Noyce,
Reader in Neurology and
Neuroepidemiology and Consultant
Neurologist at Queen Mary
University of London

Q What are observational studies?

"These are studies that don't involve testing the safety and benefits of new interventions or drugs – they are different to clinical trials. Instead they focus on how people change over time. These insights are vital to our understanding of Parkinson's and uncovering new ideas to be tested."

"We are fortunate in the UK to have a number of these types of studies. There are more than 10 actively gathering information related to Parkinson's, each with a different focus, from understanding late stage Parkinson's to investigating the earliest signs of the condition."

"My interest is in the early phase of Parkinson's, before someone receives a diagnosis. I believe early changes may differ from person to person, which could be as a result of different risk factors. Better understanding of this stage is vital to finding treatments that might be able to slow or even prevent Parkinson's."



Alastair is leading the PREDICT-PD study which aims to recruit 10,000 people between the ages of 60 and 80 who don't have Parkinson's. A small number of participants in the study will develop the condition each year. The data from the study will be used to produce a risk calculator that could be used to identify people most likely to develop the condition. Find out more and take part at predictpd.com.

Q What have these observational studies uncovered so far?

“Some of these studies have been observing people for 10 years or more. We have gained tremendous insights already. But these studies aren’t finished. The longer you can follow people, the more valuable the information becomes.”

“What has become apparent is that Parkinson’s is probably an umbrella term that covers a range of different disorders that may have different causes and rates of progression.”

“The Discovery cohort, based in Oxford, and the Tracking Parkinson’s study, in Scotland, have already begun to identify possible subtypes of the condition. They have found groups, so called clusters, of people with Parkinson’s who share certain characteristics and traits. One group, for instance, might be those who experience tremor as their main symptom, another may be those that experience changes in their memory and so on.”

“If we can define these groups more precisely we would have a much better way to recruit people to relevant clinical trials, whilst also aiming to understand how to target symptoms earlier. Making trials more likely to succeed in finding groundbreaking new treatments.”

What’s it like to be part of a cohort study?



Sally Bromley,
a Parkinson’s
UK Trustee
and member
of the

Parkinson’s UK Oxford group,
shares her experience:

“I’ve been involved with the Discovery cohort in Oxford from day one, which must have been over 12 years ago now. This is a study that has over 1,000 people taking part to better understand Parkinson’s. My husband and brother, who don’t have Parkinson’s, are also part of the cohort, as a control and sibling, to provide data to act as a comparison.

When I first heard about this project, from my neurologist, Professor Michele Hu, who is leading the study, I was really excited to be involved.

The tracking of the participants is planned to last 20 years, which would make this study one of, if not the biggest study of its kind in the world. That’s quite something!

Our participation started quite simply, where we were observed walking up and down, doing fine motor control and memory tasks. We were also asked to give our medical history and our family history. I have also been involved in sleep studies and a voice recognition project. It is all truly fascinating.

Every year or two we have a conference where all of the participants can get together and get an update of the study’s progress, and ask the researchers questions.

Being involved in research is a good way to find out a bit more about Parkinson’s, and it makes

you feel your participation counts, and this, in turn, makes you feel good too.

I’d recommend anyone to try to find a research project that they’d be interested in and to take their first step by joining it.”

Uniting to accelerate research

Thousands of people with and without Parkinson’s are making these types of studies possible and building our knowledge of Parkinson’s. It’s estimated that 15,000 people are involved in Parkinson’s specific observational studies in the UK.

Turn to page 20 to find opportunities to get involved in research.

Q How is observational research helping to develop treatments?

“Observational studies are helping researchers understand the causes of Parkinson’s, which in turn aids the development of new drugs, for example:

- Looking at the immune system – data from observational studies will help researchers understand if changes to immune cells are a cause or consequence of Parkinson’s.
- Highlighting risk factors – we know age is a risk factor but these studies uncover other factors that can increase risk. Type 2 diabetes was recently identified as a potential risk factor, where ongoing clinical trials are now investigating the potential of repurposing a diabetes drug.
- Collecting genetic data has led to the identification of changes to the genetic code that may increase risk of Parkinson’s. Previous studies have highlighted changes to LRRK2 and GBA genes, drugs targeting both of these are now in development.”

Q What’s the biggest question we’re yet to answer?

“It depends who you ask, but for me, it’s the absence of a biomarker. This is something that can be quantified and measured, perhaps at diagnosis or as someone’s condition progresses.”

“The good news is, a biomarker could now be on the horizon. There are a few in the running from measuring levels of troublesome proteins to identifying small changes on the surface of the skin. Recent results from Dr Laura Parkkinen’s team, funded by Parkinson’s UK, show promise for a technique in the lab measuring levels of a protein called alpha-synuclein to better diagnose and measure the progression of the condition. This example was made possible thanks to samples from cohort studies.”

Q Are observational studies capturing the whole picture?

“One limitation we have is that Parkinson’s cohorts are not representative of the whole community. We understand very little about the way underrepresented communities experience Parkinson’s. For example, people from diverse ethnic backgrounds, from the LGBTQ+ communities, from different socioeconomic groups, from different professions or from rural vs urban communities.”

“There are ongoing projects that hope to change this, to make sure Parkinson’s is understood across all communities.”

Go to page 19 to read about how Parkinson’s UK is driving forward race equality in research.

Q What’s next?

“One of the things that we are interested in doing is pulling all of this information together.

“Building up a complete picture of Parkinson’s – what is happening from the beginning to the end and everything in between.”

This will benefit Parkinson’s researchers and ultimately the Parkinson’s community worldwide to build up knowledge that powers steps towards better treatments and a cure for the condition.”



OUR RESEARCH PROGRAMME: ACCELERATING SCIENCE INTO NEW TREATMENTS

We interviewed Dr Arthur Roach, Director of Research at Parkinson's UK, who shares some of the latest research news and reflects on five years of the Parkinson's Virtual Biotech.

Q Why did you join Parkinson's UK?

When I joined Parkinson's UK in 2014, the mission was clear – we needed to take some bold steps to speed up the delivery of the next generation of Parkinson's treatments.

Parkinson's UK was in a unique position to ignite collaboration between researchers, companies, doctors and people with Parkinson's across the globe. The time was right to use this potential to fast-track the most promising scientific discoveries to rapidly develop and test promising Parkinson's treatments.

Q What's the main aim of the Parkinson's Virtual Biotech?

In 2017, we launched the Parkinson's Virtual Biotech, the drug discovery arm of our research programme. Unlike traditional charity-funded grants, we were putting ourselves in the driving seat for the first time. Driven by a team of in-house experts and working alongside people with Parkinson's, we would assess the need for particular drugs and identify the projects that hold the most promise.

Q What progress has been made so far?

Now, as we celebrate its fifth anniversary, the Virtual Biotech has more active projects than ever and spans the pipeline from drug discovery all the way to early clinical trials. Without the constraints of our funding being tied up in bricks or people, we have adopted a flexible and fast-paced approach to accelerate new treatments.



We've transformed Parkinson's research, investing over £13m to plug the critical funding gap that stops promising projects from progressing. We've backed carefully selected research with the greatest potential to transform life for people with Parkinson's.

Every penny donated to our Virtual Biotech can drive further investment. We've provided vital early funding and expertise to fast-track projects through the research pipeline, demonstrating their value and encouraging others to back them.

Our Virtual Biotech updates

A drug optimisation study to restore mitochondria in Parkinson's

Mitochondria, the batteries of the cell, play an important role in Parkinson's. Earlier work at the University of Sheffield identified drug-like molecules that can boost mitochondrial function in dopamine-producing brain cells. As part of the previous pilot study in partnership with researchers in Sheffield, these molecules were successfully modified to reduce potential side effects and increase their suitability for use in people with Parkinson's.

In this new stage of the project, the aim is to refine and test the most promising molecules to create a drug that can move towards clinical trials.

Developing drugs to reduce inflammation and protect brain cells

Parkinson's UK is leading a project to develop molecules that can dampen inflammation within the brain. Drugs that can reduce inflammation hold exciting potential to slow the progression of the condition – something no current drug can do.

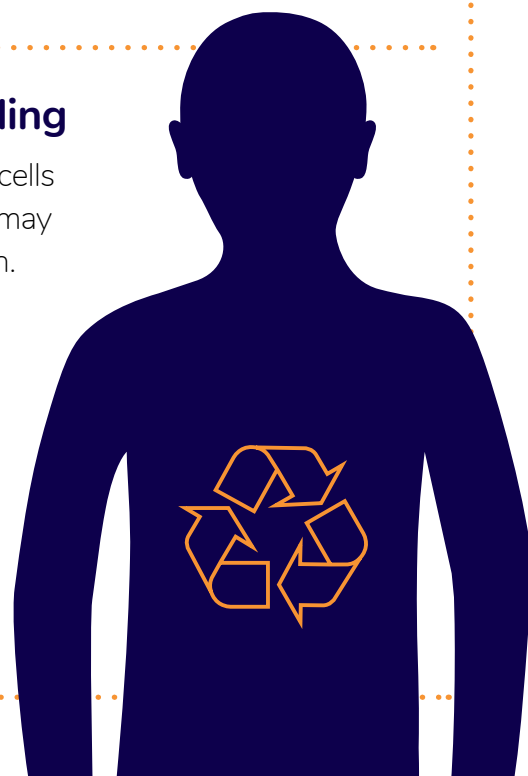
In 2020, Parkinson's UK invested £150,000 in early stage work to identify new molecules to target a protein on the surface of microglial cells believed to be a key driver of inflammation in the condition. During this pilot phase, a new family of molecules was discovered which look extremely promising.

Now, Parkinson's UK is investing £2.9m to drive forward and further develop these molecules and turn them into drugs that can be tested in people with Parkinson's.

Creating pioneering drugs that boost cell recycling

Lysosomes form a key part of the body's recycling system – ridding cells of unwanted proteins. In Parkinson's, problems with the lysosomes may contribute to the build-up of proteins, including toxic alpha-synuclein.

Through newly-formed company Endlyz, Parkinson's UK is partnering with the Dementia Discovery Fund and researchers at the University of Oxford. The project aims to design new drugs that can protect brain cells by boosting the lysosomes and helping cells to clear unwanted proteins.



Driving forward race equality in research

We believe Parkinson's research should involve, include and represent all members of the community. But research has often not included the voices of people from Black, Asian and mixed heritage backgrounds. This means our understanding of the condition does not reflect the experience of everyone.

These groups represent up to 13% of the population in the UK but are currently underrepresented in UK research.

This lack of representation is a problem for a number of reasons. Societal, cultural, and possibly even genetic differences are not being taken into account at the early stages of research. Which means that a potential treatment might not be appropriate for everyone.

That's why, last year, we kicked off the Race Equality in Research project. We started by setting up a steering group, which includes people connected to Parkinson's, researchers and healthcare professionals. This group is helping us to shape what comes next. We are learning from conversations with leaders from organisations who work within different ethnic communities. We are also listening to individuals with Parkinson's from Black and Asian and mixed heritage backgrounds who are not connected to Parkinson's UK.

Get in touch if you are interested in hearing more about this work or getting involved
rsn@parkinsons.org.uk
 or give us a call on
020 7963 3964.



Shafaq Hussain-Ali is a member of the steering group. She said of her experience:

“Being involved in the Race Equality in Research steering group has been a fantastic opportunity to partake in trying to change the diversity of research participants. Through monthly meetings and brainstorming sessions, we are putting into place an action plan to increase the awareness and participation amongst different ethnic groups in research.

I strongly feel that research is key to making further progress in the treatment of Parkinson's, which is why I feel the work of this group is so important.”





OPPORTUNITIES TO GET INVOLVED IN RESEARCH

Join us as a lay grant reviewer to help decide what research we should fund

Our research grant applications are reviewed by both scientific experts and people with Parkinson's or their loved ones – our lay grant reviewers.

Our volunteer reviewers help make sure the research we fund reflects the priorities of the Parkinson's community. We heard from Alison, one of our volunteer reviewers, earlier in the magazine on page 13.

Interested?

Find out more and apply by visiting parkinsons.org.uk/laygrantreviewer or ring our friendly team on 020 7963 3964.

What's involved?

Every research application we receive has a section where researchers describe their plans in a way that doesn't require any scientific understanding. Our lay grant reviewers are asked to feedback on this section in short listed applications to help select what projects we should fund and to give researchers a chance to improve their application.

Who are we looking for?

People with Parkinson's or a loved one of someone with the condition.

No other experience is needed. You'll use your personal experience of Parkinson's to help us decide which grant applications to fund. You will also need access to a device connected to the internet as we use email to communicate with our volunteers.

“The voice of people with Parkinson's should guide real life research. As a Parkinson's UK funded researcher and a champion for Parkinson's expert patient groups, I know first hand how useful comments are from lay grant reviewers to improve our research plans.”

Professor K. Ray Chaudhuri



Help test a wrist worn device for managing symptoms including drooling

In the last edition of *Progress*, we announced that we had awarded funding to a project looking to better monitor symptoms and help manage drooling. You can now take part in this research!

Professor Richard Walker and his research team from the Northumbria Healthcare NHS Foundation Trust are working in conjunction with researchers at Northumbria University and Newcastle University. Together they have designed a wrist worn device that aims to send vibration prompts for swallowing as well as being able to help monitor symptoms for people with Parkinson's.

They have two opportunities for people to take part:

1. They are looking for 300 people with Parkinson's who experience drooling to take part in an 8-week study to trial the wrist worn device.
2. They also want to give the device to 2,700 people with Parkinson's to receive feedback and suggestions for improvements. People will need to have a smartphone. For this part of the study people don't need to experience drooling.



Interested?

Visit the study website cue.band.

If you have any questions, please email Kyle Montague kyle.montague@northumbria.ac.uk

If you haven't already, take part in PD Frontline

The study wants to identify individuals with Parkinson's who have changes in specific genes that might help researchers personalise and improve future treatments.

Interested?

Visit parkinsons.org.uk/PD-Frontline to find out what's involved and take part.

If you have any questions, please email pdf frontline@ucl.ac.uk or phone **0208 016 8413**.

Quick online questionnaire to help understand time perception in Parkinson's

OBJECTIVE: To see if the brain mechanism behind timekeeping may be linked to disrupting walking rhythms.

The study is being conducted by the NeuroMetrology group in the Nuffield Department of Clinical Neurosciences at the University of Oxford. The aim of the research is to understand if time perception is altered in Parkinson's, to ultimately understand how this might affect balance and walking.

Who do they need?

The study needs 4,000 people who are affected by Parkinson's, either diagnosed with or connected to someone who's been diagnosed. You must be over 18, although primarily they are looking for people over 50 years of age. You also need to have access to a computer, tablet or smartphone with a speaker.

What's involved?

Completing a one-off online questionnaire which will include images and sounds. It shouldn't take more than 30 minutes to complete.



Interested?

Visit parkinsons.org.uk/timeperception to find out more. If you have any questions, please contact Lily Su via email zi.su@ndcn.ox.ac.uk or phone **01865 234728**.

“I am currently a PhD student at the University of Oxford and I am excited to lead this project that is looking to better understand motor symptoms of Parkinson's. I look forward to hearing from you if you are interested in taking part!”

Lily Su

Find other opportunities

Browse our Take Part Hub with over 30 studies looking for participants parkinsons.org.uk/takepartresearch.

Not online?

Ring the Parkinson's UK Research team on **020 7963 3964** to get in touch about any of the opportunities featured. We can also help you find out what research is happening near you.

QUESTION TIME

Answering some of the common questions from you, our readers



Q Is there a link between inflammatory bowel diseases, arthritis and Parkinson's?



Dr Julia Greenland, Clinical Research Fellow at the University of Cambridge, said:

“Over active inflammation is thought to play a role in all of these conditions. Immune cells attack healthy cells in the gut in inflammatory bowel disease, cells in the lining of the joints in rheumatoid arthritis and now there is evidence that they contribute to the death of dopamine producing brain cells in Parkinson's.

“However, what triggers the inflammation in these conditions is likely distinct and is still being unraveled by researchers. There is some evidence to suggest that inflammatory bowel disease could increase the risk of Parkinson's. However, more work is needed to understand if this is definitely the case, and if so, why.

“Immunosuppressant medication is used in the treatment of rheumatoid arthritis and inflammatory bowel diseases but not yet in Parkinson's. We have an ongoing research project that is looking into the safety and effectiveness of a medication that suppresses the immune response in people with Parkinson's to see if it can slow the progression of the condition.”

Got a question about research?

Email research@parkinsons.org.uk with the word “Progress” in the subject line.

Q What is MRI-guided focused ultrasound and is it a treatment option for people with Parkinson's?



Dr Tom Gilbertson, Clinical Senior Lecturer/Honorary Consultant at the University of Dundee, said:

“This is a technique that combines MRI imaging with ultrasound technology which can be targeted at brain circuits which cause tremor. The high-powered nature of the sound waves allows them to pass through the skull, without the need for open brain surgery.”

“This technique is being used in the UK to help treat essential tremor and this has led to some interest in its potential for treating Parkinson's. Especially as it could be possible to undertake in patients who would otherwise be ineligible for alternative forms of surgery such as deep brain stimulation (DBS) due to risk from undertaking a general anaesthetic.”

“However, this doesn't mean there aren't associated risks. This is a lesion-based treatment and a minority of patients can develop permanent side effects such as impaired balance or speech. The treatment is performed awake and can be uncomfortable, making it a significant undertaking for patients.”

“At present, more research is needed to fully understand which people with Parkinson's might benefit from this potential procedure. We are hopeful that a UK-based trial may be possible in the next few years, which will help answer some of these questions. It will most likely be for people whose tremor is their most troublesome symptom.”

Q How do I know whether to trust a medical device being sold online?



Dr Katherine Fletcher, Research Communications Manager at Parkinson's UK, said:

“In order for us to recommend or comment on medical devices – ones that might be able to help manage symptoms – we would need to review data from clinical studies. This data is essential for us to know if a device is safe and widely beneficial to people with Parkinson's. This is very important as a lot of devices being sold online are costly and we would always be wary of basing too much on testimonials, as often these are marketing strategies rather than based on sound evidence. When in doubt please get in touch with us at research@parkinsons.org.uk or phone **020 7963 3964**.”

GET INVOLVED WITH RESEARCH AT A LOCAL LEVEL

We have 13 Research Interest Groups dotted around the UK. They are made up of people with Parkinson's and the people who love and care for them. They help increase awareness and understanding of research at a regional level, particularly by delivering research events to keep people up to date with the latest information.

“These groups are for everyone, not just for scientists or those familiar with research. All are welcome to attend and to contribute as much or as little as they feel happy to. Researchers are urged to give plain English summaries of any research so that everyone can get involved.”

Iona, member of the North of Scotland Research Interest Group



Interested in hearing more about your local Research Interest Group and staying up to date?

- Browse a full list of our groups parkinsons.org.uk/research-interest-group
- Get in touch with us at rsn@parkinsons.org.uk or phone 020 7963 9398
- Join online research events organised by our groups. You can browse upcoming events and recordings at parkinsons.org.uk/researchevents
- Join our Research Support Network to receive research news, events and opportunities directly to your inbox parkinsons.org.uk/join-rsn.

WE WANT TO KNOW WHAT YOU THINK

Our magazine is produced in partnership with our volunteer editorial board. To help us also take our reader's feedback on board, please complete this short survey: Online parkinsons.org.uk/summerprogress-2022

Or

Return this page by post to:

Research team, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 15J

1. On a scale of 1 to 5, how interesting do you find Progress magazine?
(please mark one option)

(Not interesting)

(Extremely interesting)

PLEASE MARK 1 2 3 4 5

2. How do you feel after reading Progress? (please tick all that apply)

- Hopeful Inspired Frustrated
 Confused Informed Disheartened

Other (please specify):

3. How could we improve Progress magazine and what would you like to read about in the future?

4. After reading our magazine, how likely are you to get involved in research? For example, take part in a study, join an event or volunteer. (please mark one option)

(Not likely)

(Extremely likely)

PLEASE MARK 1 2 3 4 5

5. Are you signed up to receive our regular research emails through our Research Support Network?

- Yes No I am going to sign up now at parkinsons.org.uk/rsn I don't know



We are Parkinson's UK.
Powered by people.
Funded by you.
Improving life for everyone
affected by Parkinson's.
Together we'll find a cure.

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