

**PARKINSON'S<sup>UK</sup> CHANGE ATTITUDES. FIND A CURE. JOIN US.**

# PROGRESS

The research magazine of Parkinson's UK  
Issue 17 Autumn 2015

New and better treatments,  
in years not decades

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# WELCOME

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This issue our welcome comes from our Director of Research, Dr Arthur Roach, who explains his vision for research and how we can deliver new treatments for Parkinson's in years, not decades.

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I've now been at Parkinson's UK for a year which has flown by and I'm delighted to say that we've set the stage for our mission to bring new treatments to people with Parkinson's faster.

To achieve this ambition, we need to work with partners at every stage of the research pathway – from funding the early-stage work in labs and hospitals to turning these discoveries into new treatment approaches and supporting and driving clinical trials – and making sure that new therapies are approved and available to patients as soon as possible.

Working with the very best scientific minds, and the most powerful partners will be key to our success.

One of my first priorities on joining the charity was to put together a Research Strategy Board to guide and support our work. The Board includes leading scientific and industry experts, and of course, people living with Parkinson's.

Everyone needs to play a part if we're going to succeed in our mission, and people affected by Parkinson's remain right at the heart of everything we do.

An important part of this is keeping you informed. So, as you rush to your mailbox to devour this and all future editions of *Progress*, you will learn about specific aspects of our new approach and see for



yourself how they will work together to accelerate the discovery and delivery of new treatments.

Research cannot happen without the participation and support of people with Parkinson's, so please join us by becoming part of our Research Support Network and help us get there faster.

[parkinsons.org.uk/rsn](https://parkinsons.org.uk/rsn)

# INTERNATIONAL NEWS ROUNDUP

We keep a close eye on all the latest developments in Parkinson's research. Here are some highlights from the last few months.

## International foetal cell trial begins for Parkinson's

May marked an important milestone of a groundbreaking trial as the first person with Parkinson's in the UK received a transplant of donated foetal cells.

Foetal cells are collected from donated human foetal tissue. This treatment aims to replace the cells lost in Parkinson's with new, healthy, developing cells from foetal brains.

The trial is being led by a team of world-leading researchers across Europe and has been funded by a €12million grant from the European Commission.

The research team have recruited 150 people with Parkinson's from across Europe. 40 randomly selected from this group will be offered the chance to have a cell transplant.

This will involve having foetal cells injected into the brain.

If we can replace the nerve cells lost in Parkinson's it may be possible to slow, stop or even reverse the effects of the condition.

The research team hope to have results available by 2018.

[parkinsons.org.uk/researchnews28may2015](http://parkinsons.org.uk/researchnews28may2015)

## Early stage trial of new growth factor shows promise for Parkinson's

Results from the first clinical trial of the growth factor PDGF in people with Parkinson's suggest the treatment is safe and should go forward to be tested in larger, longer studies.

Platelet-Derived Growth Factor (or PDGF) is a naturally occurring protein found in the body which plays a key role in the growth of nerve cells.

This small trial was carried out by a team of researchers in Sweden. 12 people with moderate Parkinson's had surgery to implant a tube into the brain so that the PDGF could be delivered directly to the area of the brain affected in Parkinson's

Three people received an inactive treatment. The other nine received varying concentrations of PDGF over a 12-day period.

The treatment produced no serious side effects and appeared safe.

Although there were no improvements in symptoms in this short trial, brain scans showed signs that PDGF may boost levels of dopamine inside the brain.

It's still early days, but this research does take us a step closer to a new treatment that ultimately could help to support the nerve cells lost in Parkinson's.

The next phase of trials is already under way across Europe and in the UK.

[parkinsons.org.uk/researchnews20feb2015](http://parkinsons.org.uk/researchnews20feb2015)

## New evidence Parkinson's originates in the gut

New research from Aarhus University in Denmark provided some of the strongest evidence to date that Parkinson's may start in the gut and spread upwards through the nervous system to the brain.

The Danish team studied the medical records of 15,000 patients who had undergone a procedure to sever the vagus nerve in their stomach. The vagus nerve is the main pathway of communication between the gut and the brain.

Up until the mid-'90s, this procedure was a very common method of ulcer treatment. The team found that in the group that had their entire vagus nerve severed, fewer people developed Parkinson's.

We are still in the very early stages of understanding how Parkinson's may spread throughout the body but this research adds important evidence to the theory that Parkinson's may begin in the gut.

[parkinsons.org.uk/researchnews24jun2015](http://parkinsons.org.uk/researchnews24jun2015)

## News in brief

### Depression – an early warning sign?

A new study suggests that people with depression are three times more likely to develop Parkinson's than people without. This study adds to the growing evidence that depression may be one of the very early symptoms that can occur before a tremor or movement problems.

### Vaccine trial shows promise

Results from the first small clinical trial of a new vaccine for Parkinson's carried out in healthy people suggest the treatment is safe and should go forward to be tested in larger, longer studies. Recruitment of people with Parkinson's is now underway for the next stage of testing in the US.

### Solving a sticky problem

Scientists have developed a way that might one day mean we could stop toxic build-up of a protein in Parkinson's. The researchers have highlighted a new way to stop a protein called alpha-synuclein from sticking together which could be an important route to developing new treatments.

### Can beer have benefits?

An intriguing new finding suggests that a chemical in hops – a key ingredient in beer – could slow or even prevent conditions like Parkinson's. Unfortunately there's no evidence that drinking a pint a day could prevent Parkinson's, but this interesting finding could lead to new ideas for treatments.

### Tech giant join research effort

Technology company Apple have created new software which revolutionises the way we collect medical data for research. The new tool is called ResearchKit and is already being used by some teams to study dexterity, memory, balance and gait in people with Parkinson's.

Keep up with all the latest research news as it happens by following us at

[www.twitter.com/parkinsonsuk](https://www.twitter.com/parkinsonsuk) and [parkinsons.org.uk/researchnews](http://parkinsons.org.uk/researchnews)



# NEW AND BETTER TREATMENTS IN YEARS, NOT DECADES

Despite huge scientific progress, there have been no major advances in Parkinson's treatments in the last decade. There isn't enough investment and developing new treatments is taking too long.

**And that's where we come in.** Because everything we do is driven by people with Parkinson's we are striving for new and better treatments that will reach people in years, rather than decades. To do it, we're adopting a radical new approach – tackling the critical roadblocks, filling in the gaps and investing in big ideas that will speed up the whole process and deliver treatments to the people who need them, faster.

## Where do new treatments come from?

Here is a breakdown of the main steps:



### Scientific discoveries

Finding out what goes wrong in Parkinson's and coming up with ideas for how to fix it.

Like detectives, scientists investigate leads and theories based on the best available evidence to understand why people get Parkinson's. Every new piece of the puzzle gives us new ideas for developing treatments.



### Developing treatments

Dedicated teams turn the most promising scientific discoveries into potential new treatments.

This stage is usually led by drug companies with expertise in designing, refining and early testing of new drugs and treatments. It's a lengthy and painstaking process, and only the very best treatments will make it through.

## Why is it taking so long?

The path to develop a new treatment is full of obstacles and challenges. Each step along the way is risky and of the thousand potential projects you start with, on average, only one drug will make it on to pharmacy shelves.

For a new treatment to make it from the lab and into the clinic, many players – universities, hospitals, people with Parkinson’s, drug companies and regulatory authorities – must all work together.

This makes the whole process phenomenally expensive and even the big drug companies are starting to feel the pinch. As a result, companies are becoming more cautious and less likely to invest in the earlier stages of drug discovery and testing, preferring to step in at the later stages where their investment is nearer to producing a financial return.



New treatments that have been proven safe and effective by all other methods are carefully tested in people.

Clinical trials need to be done very thoroughly over a number of years to prove that the treatment is safe and effective. Many treatments fail at this stage because the trial does not demonstrate the hoped-for benefits for people with Parkinson’s.



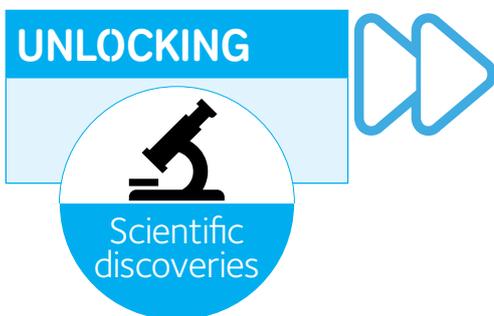
All treatments need to be officially approved before they can be made available.

Approving new treatments is the job of regulatory authorities. They are responsible for checking that all the necessary testing has been done, scrutinising the results and judging which treatments are effective and safe for use.

## What we're doing to speed things up

Despite the challenges we believe that better treatments for Parkinson's are possible within years rather than decades.

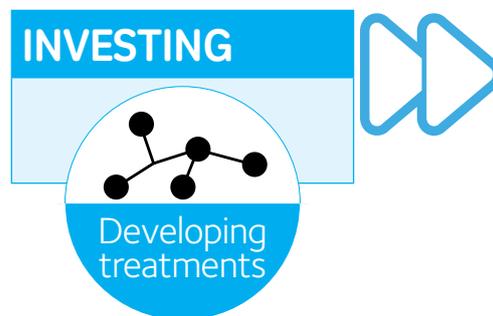
But if we want treatments for Parkinson's now we cannot wait for others to do it for us. We have to invest in research at every step of the way, and work smarter to push new treatments forwards.



We're backing the best and brightest minds to unlock the ideas that will lead to new treatments, and one day a cure.

We support the most promising scientists working in labs and hospitals across the UK and beyond to unravel the mysteries of Parkinson's.

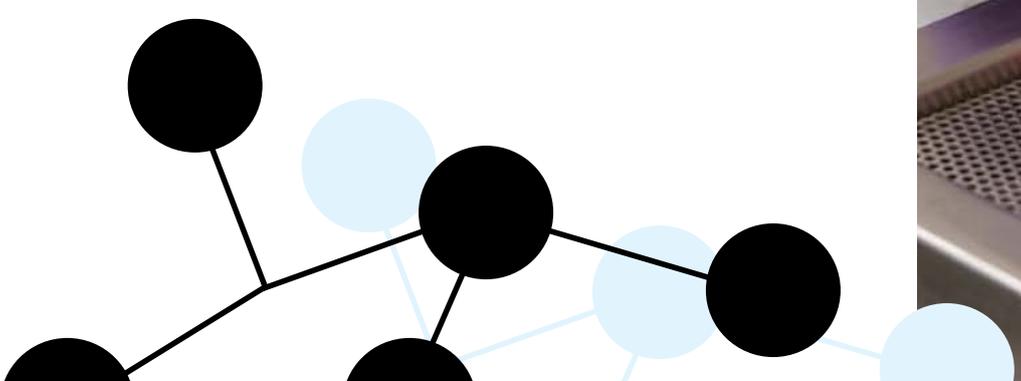
It's only by truly understanding the complex causes and how it progresses that we'll be able to come up with strategies that can stop, reverse and prevent Parkinson's.



We invest in the best ideas, wherever they come from, and rapidly turn them into treatments that can be tested and progressed.

Scientists are uncovering insights with exciting potential for treating Parkinson's but there's not enough investment from industry to drive these discoveries forwards. This is a major roadblock in our mission to develop better treatments and a cure.

So we're filling this gap by working with researchers, companies and other charities to invest in ideas with potential and develop new treatments as quickly as possible.





We believe clinical trials can work better so we're bringing the right people together to make trials faster, cheaper and more likely to succeed.

This is the most costly and lengthy part of the whole process and in recent years, several promising new treatments for Parkinson's have failed to show benefit in clinical trials.

We, and many others in the research community, believe the problem may not be that the drugs don't work, but that we're testing them in the wrong way.

So we are doing two things. We're joining up with researchers, drug companies and regulators to change clinical trials so they're smarter, more likely to succeed and meet regulatory approvals. And we're making sure that trials find the participants they need.



We're taking the fastest route to better treatments by tracking down drugs that are already approved and in use for other conditions, which have untapped potential for Parkinson's.

Developing a drug from scratch is a long, slow and expensive process. But people with Parkinson's need better treatments now, so we're looking for shortcuts.

We're convinced there are already drugs available on pharmacy shelves with hidden benefits for Parkinson's. Aspirin for example, one of our oldest drugs for treating fever and pain, has recently been shown to have other powerful effects – such as reducing risk of heart attacks and stroke.

By finding these drugs and moving them rapidly into clinical trials we can make them available for people with Parkinson's much more quickly, easily and cheaply.

## Join us!

As the world's largest patient-led Parkinson's charity, everything we do is driven by people affected by Parkinson's. This means that when it comes to research, people with the condition and their families are setting the agenda, helping us make decisions about the projects we fund and working in partnership with researchers at every stage. Join our Research Support Network and get involved: [parkinsons.org.uk/rsn](https://parkinsons.org.uk/rsn)

# Over to you...

It's always great to hear your thoughts on Parkinson's research and *Progress* magazine. Please do keep your ideas coming and help us shape the style and content of each issue.

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## A LASTING LEGACY

My husband David recently donated his brain to the Parkinson's UK Brain Bank for research. I want to let people know the process was so easy that we were very glad we went through it. Six months later we received a report about his condition which was useful as it showed the family had taken the right actions. The report confirmed that David did have Parkinson's. For 20 years we went to Professor Roger Barker at Addenbrooke's hospital and took part in research, giving tissue and blood. My husband really enjoyed taking the tests as it made him feel useful. I hope the Brain Bank will find his tissue useful. I have also pledged to donate my brain as for 53 years we both lived in the same environment. I hope this will help to drive research forward.

**Laura Lawrence**

Anyone can make a vital gift to research by pledging their brain to Parkinson's research. Find out more at [parkinsons.org.uk/brainbank](http://parkinsons.org.uk/brainbank)

## WHY SUPPORT RESEARCH?

Pathfinders are supporters who have signed up to give a regular monthly donation to support our research.

Here's why some of our Pathfinders have chosen to support our work in this way.

"My husband John was diagnosed with Parkinson's four years ago, so obviously this has motivated me to become a Pathfinder – anything to help him and others is a must. As a talented saxophonist, John continues to play with his quartet and has recently made £900 from the proceeds of his concerts." **Margaret**

"I was motivated to become a Parkinson's Pathfinder in the hope that the research studies could help find new and better treatments for people living with Parkinson's, and ultimately find a cure as soon as possible." **Mrs Rekha Shah**

If you would like to find out more about becoming a Pathfinder, call our Supporter Services Team on 020 7932 1303

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## PRAISE FOR OUR EVENTS

We work with researchers, local groups and individuals to arrange visits to labs, events, open days and talks all over the UK on Parkinson's research.

"Hurrah for @ParkinsonsUK wonderful lecture @John Rylands Library tonight. Wonderful. Can use the word 'mitochondrial' in conversation."

**@JonathanMayor on Twitter**

"Thanks for a really interesting and informative research lecture in Manchester. Thanks to everyone concerned and keep up the research ... we're getting close to amazing breakthroughs."

**Sylvia on Facebook**

"May I also add my thanks for an informative, positive and moving research lecture."

**Alison on Facebook**

Find out what's coming up at [parkinsons.org.uk/researchevents](http://parkinsons.org.uk/researchevents)

# GENES DON'T HOLD ALL THE ANSWERS

I had my DNA tested by 23andMe about two years ago. It was free because I have been diagnosed with Parkinson's.

You get access to an enormous amount of data which will suggest that you have a higher than average chance of developing disease X and a lower than average chance of developing disease Y.

You also get a lot of data about your ancestry which may or may not interest you. For example they tell me that I am 2.8% Neanderthal.

Probably the most famous example of someone acting on genetic information is Angelina Jolie who had a double mastectomy when she discovered that she had a specific genetic mutation which meant she had a more than 80% probability of developing breast cancer. But I'm sure she discussed this with medical people first!

But this is unusual. Usually the tests say that your probability of getting 'Cancer A' has increased from 1.25% to 1.8%. To which your

first response should be "Don't panic" and your second response should be "OK, are there any lifestyle changes I can make to reduce the other factors which lead to this condition?"

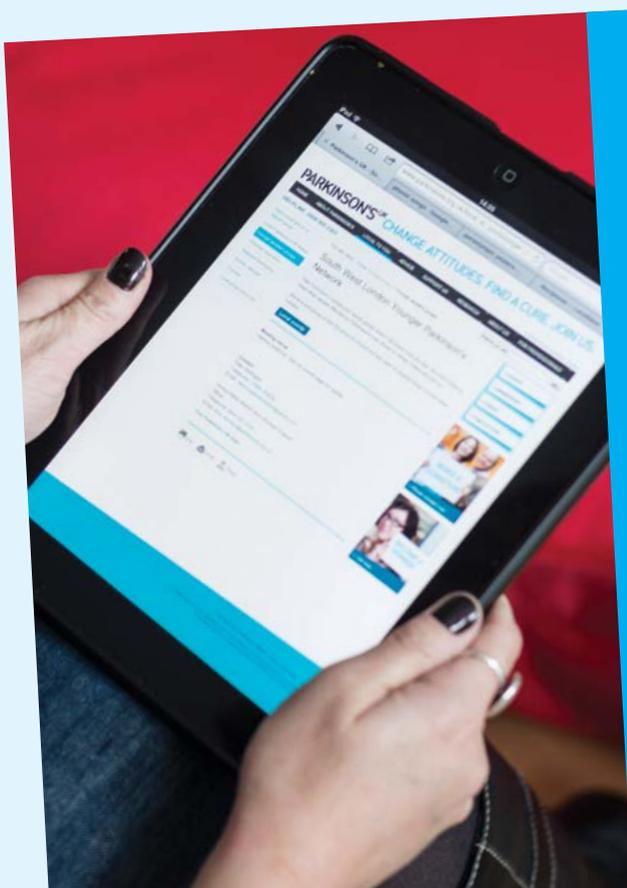
**A post by Andrew John on our online discussion forum: [parkinsons.org.uk/forum](https://parkinsons.org.uk/forum)**

A personal DNA testing kit from US company, 23 and me, went on sale in the UK earlier this year.

The 23andMe Personal Genome Service (PGS) provides genetic information about a person's health, ancestry and family traits. It also tests for genes that may reveal risk factors for Parkinson's.

We estimate that only 5% of Parkinson's is inherited – meaning a genetic test will only have limited use. It's also hugely important that any genetic testing is carried out with appropriate access to counselling and advice.

If you're interested in finding out more, check out our *Inherited Parkinson's and genetic testing* information sheet which is available online at [parkinsons.org.uk/publications](https://parkinsons.org.uk/publications). Or you can order a copy by calling 0845 121 2354.



## Tell us what you think of *Progress* magazine

We'd love to hear your feedback to help us make *Progress* magazine better. We'd especially like to know:

- how easy you find *Progress* magazine to read
- what you most enjoy reading about in the magazine
- what you least enjoy reading about in the magazine
- what topics you'd like to read about in future issues

There are lots of ways to tell us what you think:

Complete our quick and easy online survey at [parkinsons.org.uk/progressfeedback](https://parkinsons.org.uk/progressfeedback)

Email us at [research@parkinsons.org.uk](mailto:research@parkinsons.org.uk)

Call us on 020 7963 9326

Write to: Research team, Parkinson's UK,  
215 Vauxhall Bridge Road, London SW1V 1EJ

# NEW RESEARCH PROJECTS

We fund the best and brightest researchers to help us unravel the mysteries of Parkinson's and pioneer new ideas for better treatments. You can find details of all our projects at [parkinsons.org.uk/currentresearch](https://parkinsons.org.uk/currentresearch)

## Learning new movements with rewards



**Who?** Dr Ned Jenkinson  
**Where?** University of Birmingham  
**What?** £83,919 over 36 months

We may not realise it, but we are all constantly learning new movements to adapt to changes in our environment – for example, learning a new dance step or to use a new device like a mobile phone. Learning and adapting movement is also vital to the success of interventions such as physiotherapy or speech and language therapy. Although people with Parkinson's can learn new movements perfectly well, they can find it more difficult to retain these newly-learnt skills. This may mean the benefits of therapies that involve motor learning, such as physiotherapy, may be more short-lived in people with Parkinson's.

“We will combine reward learning and brain stimulation to see if these techniques can help people with Parkinson's overcome difficulties with learning new movements. This project could find ways to improve the long-term benefit of therapies and help people with the condition lead more active and independent lives – improving quality of life for both the individual and their family.”

## Understanding the causes of pain in Parkinson's

**Who?** Dr Monty Silverdale  
**Where?** University of Manchester  
**What?** £88,090 over three years

More than half of people with Parkinson's experience chronic pain. Despite this, there has been little research into pain in Parkinson's until now. Monty and his PhD student aim to understand whether the area of the brain responding to pain is overactive in people with Parkinson's by looking at brainwave activity.

They are particularly interested to see what happens in the brain when a person is expecting to feel pain. They hope to find out if people with Parkinson's expect to experience more pain because of a chemical change in the brain which causes the area responding to pain to become overactive.



“This project will help us understand a great deal more about why some people with Parkinson’s experience pain. If we prove that the area of the brain responding to pain is overactive then we may be able to use new treatments to manage pain in Parkinson’s such as meditation training. This has been successfully used in other conditions.”

### Looking for biomarkers in the breath

**Who?** Professor Roger Barker and Professor Hossam Kaick

**Where?** University of Cambridge and Israel Institute of Technology

**What?** £400,000 over three years  
This project is co-funded equally by Parkinson’s UK and the British Council.

Biomarkers are tiny changes in the body that can be measured to diagnose or monitor a condition. But no biomarkers have been found for Parkinson’s yet.

The team aim to find out if the breath test can be used to diagnose and monitor the progression of Parkinson’s over time. They will analyse the molecules they find in the breath samples from people with Parkinson’s, which could give us new clues to what causes the condition.

“We hope to develop a reliable and simple test that can be used not only to diagnose and monitor Parkinson’s but also identify different subtypes of the condition. This research could also shed

new light on different molecules that play a role in the development of Parkinson’s. This information has the potential to provide us with new targets for therapies that could slow down or even stop the progression of Parkinson’s.”

### Mindfulness to tackle anxiety and depression in Parkinson’s



**Who?** Dr Angeliki Bogosian

**Where?** City University London

**What?** £32,795 over 12 months

People with Parkinson’s can be affected by a range of non-motor symptoms from sleep problems through to depression, anxiety and other psychological problems. Mindfulness is a type of talking therapy that aims to help people adjust to living with a long term conditions such as Parkinson’s and cope with challenging symptoms. But as yet there haven’t been any studies looking at the effects of mindfulness in treating anxiety and depression in Parkinson’s. Angeliki and her team aim to test this talking therapy in people with Parkinson’s. Firstly they will adapt the mindfulness course previously developed for people with multiple sclerosis, using the input of people living with Parkinson’s. The next step will be to test this course with 40 people with the condition to assess how helpful it is and the affect it has on mood, sleep, pain, fatigue and everyday life.

“We hope that at the end of the study we will have a well-adapted version of a mindfulness course that addresses the needs of people affected by Parkinson’s.”

# CAN CELL TRANSPLANTS IMPROVE NON-MOTOR SYMPTOMS?

Dr Mariah Lelos at Cardiff University has been awarded a **Career Development Award** to find out if stem cell treatments can help with non-motor symptoms in Parkinson's. We talk to Mariah about the inspiration behind her new project.

## NEW RESEARCHER



### Who?

Dr Mariah Lelos

### Where?

Cardiff University

### What?

£250,000 over 36 months

### Why did you decide on a career in Parkinson's research?

When I was an undergraduate at university, I became interested in neurodegenerative conditions. I worked in different laboratories researching Alzheimer's, Parkinson's and Huntington's and meeting people who had been diagnosed with these conditions. After joining the Brain Repair Group at Cardiff University, I became very excited about the prospect of repairing the brain to reverse the symptoms that people with Parkinson's experience.

### What do you think are the most exciting avenues for Parkinson's research at the moment?

I'm clearly a bit biased here, so you won't be surprised to hear that I think the recent advances in stem cell therapies are incredibly exciting. The

basic idea is to transplant dopamine-producing brain cells into the brain to replace the cells that have been lost in the condition. Studies carried out more than 20 years ago using fetal tissue transplants in people with Parkinson's have shown promise.

Some participants responded extremely well and experienced improvements in motor symptoms. However, using fetal tissue comes with ethical and logistical issues so we need to find other sources of cells to develop future treatments.

Recent advances in research mean we can now make new brain cells from stem cells. These cells can integrate into the brain, release dopamine and improve motor symptoms in rats and mice with similar brain changes to those seen in people with Parkinson's. This paves the way for a really exciting period in Parkinson's research as scientists work together to develop a potential new treatment for the condition.

### What's been your proudest achievement in research so far?

In terms of research discoveries, my proudest achievement was when I discovered that dopamine-producing cells from foetuses were capable of improving both motor and non-motor symptoms in a rat model of Parkinson's. This opened up a whole avenue of exciting research, into whether cell therapies could potentially help improve a much wider range of symptoms than we previously thought, including non-motor symptoms.

In terms of my own career, my proudest achievement is, without a doubt, being awarded a 2015 Senior Research Fellowship from Parkinson's UK. I have previously worked on Alzheimer's and Huntington's, but this award allows me to focus my efforts on Parkinson's full-time.

### What's your new Career Development Award all about?

During this Fellowship, I will be using dopamine cells made from human stem cells and studying their ability to improve motor and non-motor functions in rats with Parkinson's-like symptoms. First I will investigate which dopamine cells survive, integrate and function best to improve motor symptoms. Then I will study whether these cells can also improve non-motor symptoms such as memory loss, anxiety, changes in smell and difficulties with thinking.

### What do you hope your project will ultimately achieve?

We know that the motor symptoms of the condition need to be tackled, but people's quality of life can also be affected by non-motor symptoms such as pain, anxiety, sleep problems and fatigue. There are currently very few treatment options available to help with these symptoms. My ultimate aim is to develop stem cell therapies into treatments that can improve as wide a range of symptoms as possible, to help improve the quality of life for people with Parkinson's.

### Replacing cells lost in Parkinson's

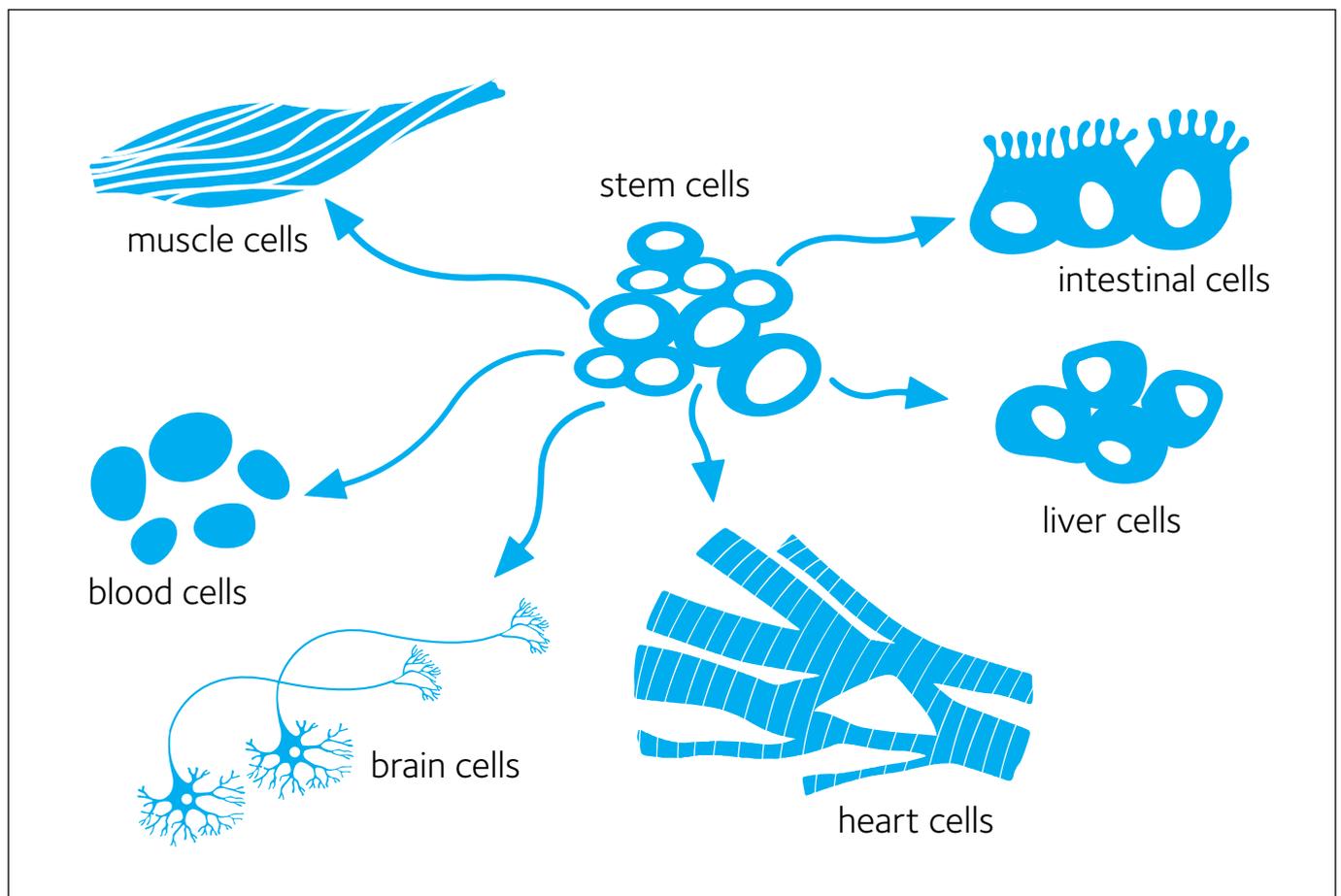
Parkinson's is caused when brain cells that produce the chemical dopamine die. Dopamine allows messages to be sent to the parts of the brain that co-ordinate movement.

As dopamine-producing brain cells are lost, the symptoms of Parkinson's appear.

Stem cells are nature's building blocks for other types of cell – they can be converted into other cells in the human body.

Scientists have worked out how to turn stem cells into the dopamine-producing cells in the human brain.

These cells have the potential to replace the cells that die in Parkinson's.



Stem cells have the ability to become lots of different cell types

# THE HUNT FOR PROTECTIVE GENES

Hidden in some genes is the information we need to live longer, healthier lives. But before we can benefit from this we need to identify which genes hold the secrets that can help us.

We all have our own unique mixture of genes that we inherit from our parents. Variations in our genes control more than just who we are and what we look

like – some genes can increase our risk of different illnesses whilst other genes may protect us.

## A genetic cause of Parkinson's

For the vast majority of people with the condition, the exact cause of Parkinson's is unknown – it is likely to involve a complex interaction of environmental, lifestyle and genetic factors. We still have a lot to learn about why some people develop Parkinson's when others don't and the role that our genes play in this.

Over the last 20 years, scientists have discovered that changes in a handful of genes can cause inherited forms of Parkinson's – but these are very rare. These genes include PINK1, Parkin, LRRK2 and GBA1. Variations in these genes may be linked to Parkinson's in around 5% of people. We call these genes 'risk genes' because changes in them increase the risk of Parkinson's, but not everyone with these changes will go on to develop the condition.

## What's in a gene?

A gene is a section of DNA that provides the instructions to make a protein. These proteins are the building blocks that make our cells, tissues and organs.

So if our DNA was a cookery book, a gene would be a single recipe. And if the gene was the recipe for a Victoria sponge, the protein would be the cake.

Like a cookery book contains many recipes, our DNA has many genes – around 23,000 in humans – and just as a recipe may vary slightly between cookery books, genes can vary slightly from person to person.

Genes control everything that happens in our cells. Slight variations in genes result in subtle differences in proteins, and these differences can affect how well the protein works.

Sometimes changes in the gene may make a protein that doesn't work as well, which make cells sick. Other times different variants of a gene may make a protein that works better than normal.



## Finding protective genes

People with Parkinson's have helped researchers find Parkinson's risk genes. But to find protective genes we need to look at people who haven't developed the condition. The best possible group to study to find protective genes are those who carry a risk gene but do not develop Parkinson's in their lifetime. Something hidden in them is protecting them from the condition – if we can find it, this could help researchers design therapies to protect others.

## Protecting the future

Research into protective genes in Parkinson's is still in its early stages, but in other conditions some genes have already been identified. For example scientists at Harvard discovered that a protein called REST can protect people from dementia. Similarly variants of other genes have been found to protect against heart disease and type 2 diabetes. These findings could help scientists develop new therapies that have the potential to treat and even protect people from various conditions.

## New Parkinson's research to find protective genes



**Who?** Dr Emmanouil Metzakopian

**Where?** Sanger Institute,  
University of Cambridge

**What?** £217,062 over 36 months

This year Dr Emmanouil Metzakopian has been awarded a new Career Development Award to search for protective genes in Parkinson's. We talk to him about what inspired his interest in

Parkinson's research, his research so far and his hopes for this new three-year project.

## Why did you decide on a career in Parkinson's research?

From my early years in the university studying biochemistry, I became interested in how the brain develops and functions. I was interested in how certain emotions happen, such as the feeling of reward when you do something good.

During my PhD I studied the part of the brain that is responsible for some of these functions, the midbrain. This is one part of the brain that is affected in Parkinson's.

My interest quickly moved from understanding how the brain functions to how Parkinson's progresses and to the search for genes that can slow Parkinson's and increase the quality of life of people affected by the condition.

## What's been your proudest achievement in research so far?

One of my proudest moments was receiving the Career Development Award from Parkinson's UK. This award will help me continue my search for protective genes in Parkinson's, which could be used to make new therapies and possibly develop a cure.

## What's your new Career Development Award all about?

The aim is to find ways to protect dopamine-producing brain cells when they are stressed and dying.

My team will use state-of-the-art technology called 'genetic editing' to change the DNA in brain cells grown in the lab. We will use thousands of brain cells and change a different part of the DNA in each of them. This will help us find genes that are protective in Parkinson's.

The long-term goal of my research is to understand how genes can protect against Parkinson's and ultimately use this information to develop new and better treatments.

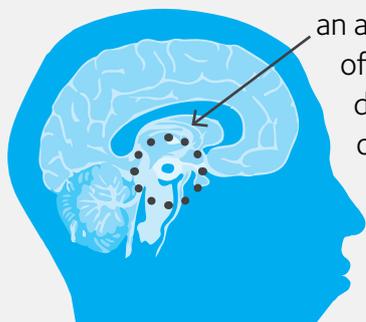
# INSIDE A PARKINSON'S BRAIN CELL

Research has taught us a lot about how the brain works and what goes wrong in Parkinson's. We now know that the symptoms of Parkinson's are caused when the cells that produce a chemical called dopamine die. Here we look at how our brain cells work – and what may happen to the cells affected in Parkinson's.

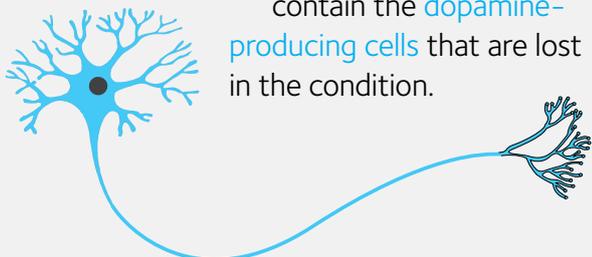
## Cells make up our bodies

Our bodies are made up of billions of cells. Different types of cells make up our different organs – for instance lung, liver and brain cells.

The brain cells affected in Parkinson's are found in the **substantia nigra** – an area, about the size of a 10 pence piece, deep in the middle of the brain.



You have two of these areas, one on each side of the brain. They contain the **dopamine-producing cells** that are lost in the condition.



synapse

## 1 COMMUNICATIONS

Brain cells use chemicals to communicate with each other and control our bodies. Communication between cells happens at the end of cell branches called synapses. Not all brain cells produce the same chemicals. Dopamine is a chemical messenger produced by some brain cells that helps control movement. In Parkinson's, the brain doesn't have enough dopamine because some of the cells that produce it have died. This affects the way brain cells communicate and control the body causing the symptoms of Parkinson's. Around half of these dopamine-producing cells in the brain are lost before many of the symptoms become noticeable.

## 4 PROTEIN CLUMPS

All cells have a transport system to move important cargo, such as cell building blocks and materials, to where they are needed.

The cells affected by Parkinson's are longer and more complicated than other types of brain cell. This means they need a really efficient transport system to move cargo to and from the ends of the cell.

Researchers have discovered "traffic jams" caused by clumps of protein stop materials getting to where they are needed.



## 2 ENERGY PRODUCTION

Dopamine-producing brain cells are some of the most active cells in the entire brain. They need lots of energy to do vital jobs such as communicating, carrying out repairs and getting rid of waste.

Cells make energy using little power stations called mitochondria. In some cells affected by Parkinson's these mitochondria do not work efficiently.

Without enough energy cells get sick. Malfunctioning mitochondria also produce more toxic by-products that build up and damage cells.

## 3 GENETICS

DNA found in the nucleus of cells acts like the instruction manual for everything the cell does. DNA is organised into sections called genes and changes in a handful of genes are known to cause inherited forms of Parkinson's – but these are very rare.

Researchers have found that genes called PINK1, PARKIN, LRRK2 and GBA1 are important for how brain cells function. Changes in these genes can cause the brain cells not to work properly and are linked to Parkinson's in around 5% of cases. The exact causes of the other 95% of cases are unknown.

## 5 WASTE RECYCLING

Sticky clumps of protein – called Lewy bodies – form inside brain cells affected by Parkinson's. These Lewy bodies may clog cells up, stopping them working properly and causing problems.

Alpha-synuclein is an important protein in Parkinson's as it is the main protein found in Lewy bodies.

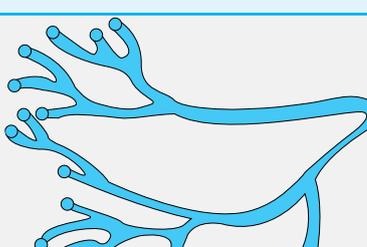
Alpha-synuclein also plays an important role in the spread of Parkinson's from one cell to the next. It stows away in little 'capsules' (called exosomes) that move between cells to transport materials.

## 6 TRAFFIC

Cells constantly produce waste – broken and old proteins and bits of debris.

The cell has dedicated waste disposal systems (called the lysosomes and proteasomes) that help recycle and break down debris so that it doesn't clog up the cell.

Research has found some cells affected by Parkinson's have problems with waste disposal – either because the system gets overloaded or just can't recycle fast enough.



# MY LIFE IN RESEARCH

I first met neuroscientist Bill Langston 25 years ago, when I produced a documentary for the BBC television series *Horizon* called *The Case of the Frozen Addicts*.

The film told the story of six young drug abusers in California who were mysteriously struck with the symptoms of advanced Parkinson's. Bill discovered the unlucky individuals languishing in psychiatric wards and jail cells and managed to treat their symptoms with the Parkinson's drug levodopa.

The young people, it turned out, had injected a bad batch of 'designer' heroin. Unfortunately for them, the backstreet chemist had made a terrible mistake and created a toxic chemical called MPTP.

While tragic for the victims, this deadly molecule proved to be of immense scientific importance. Scientists had been hampered in their efforts to study Parkinson's because humans are the only animals to contract it naturally.

To make real progress, scientists need ways to study diseases in animals – this is called using an animal model. So MPTP changed everything for scientists interested in Parkinson's. This neurotoxin could rapidly produce Parkinson's symptoms in animals, as it had in the six addicts.

As Bill put it, MPTP was: "A bracing tonic . . . Suddenly we had ways to study why cells die in Parkinson's. With the animal model, we could test new medicines as fast as you could make them."

Langston is now an internationally renowned neuroscientist and my film established my reputation as a documentary producer and science journalist. In 2012 Bill and I met again at his home in the Californian hills and spent hours talking about some

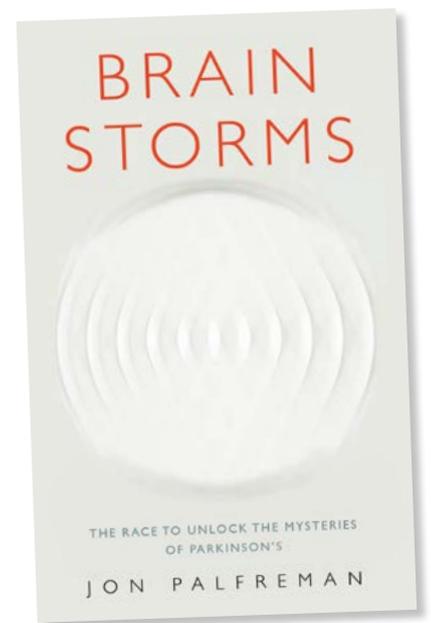
of the remarkable advances in Parkinson's research that have taken place over the past two decades.

But this time, I wasn't just there as a journalist. I had a compelling personal reason for my renewed interest in Parkinson's. At the age of 60, I'd been diagnosed with the condition myself.

While the news was tragic for me personally, I soon realised that as a science journalist, I was better placed than most to figure out the state of Parkinson's research and ascertain what kind of future I and other patients face.

The result of those efforts is my forthcoming book, *Brain Storms: the Race to Unlock the Mysteries of Parkinson's Disease*. *Brain Storms* charts the victories and setbacks of a massive international effort to defeat the condition. It is also a profoundly personal investigation of the struggles of living with Parkinson's.

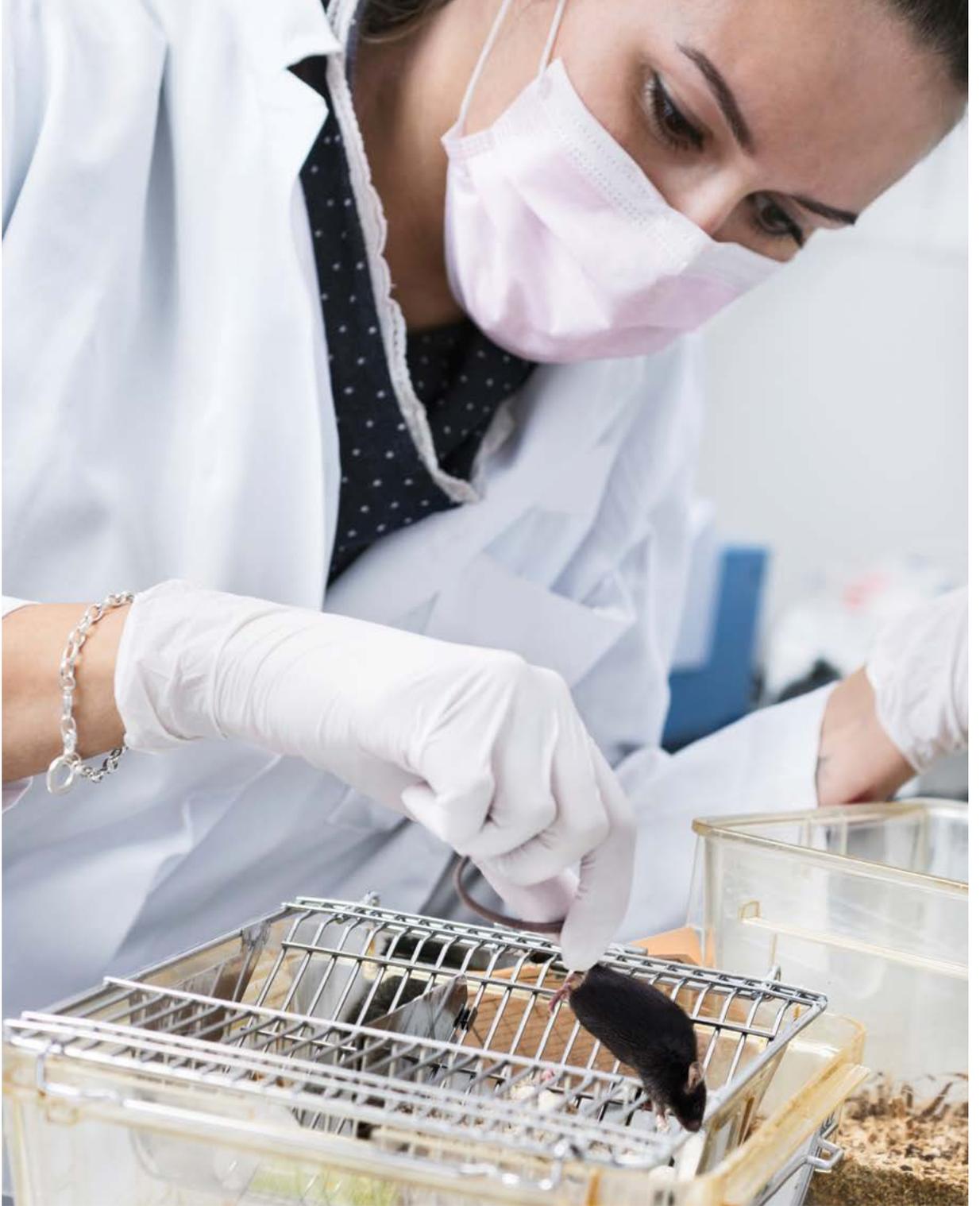
From a ballet dancer who tricks her body to move freely again, to a "frozen" patient who cannot walk but astounds doctors when he is able to ride a bicycle, it highlights the ingenious ways patients courageously cope with having their bodies steadily taken away from them.



Jon Palfreman, PhD, is Professor Emeritus of Journalism at the University of Oregon.

He is an award-winning journalist, has produced more than 40 documentaries for the BBC and PBS, and is the author of *The Case of the Frozen Addicts* and *The Dream Machine*. *Brain Storms* is published in the UK by Rider Books.

# UNDERSTANDING ANIMAL RESEARCH



In the last century, research involving animals has led to major breakthroughs in human health.

From the vaccine for smallpox to organ donation, cardiac pacemakers to chemotherapy for cancers, almost every advance in medical treatment has involved animals at some stage in its development. This research has saved and improved the lives of millions of people, as well as

contributing to improvements in animal health. But despite major scientific advances, such as computer modelling, studying brain cells grown in the lab or donated brain tissue, animals still have an important role to play in medical research.

In July 2015 members of our Research Support Network visited the Medical Research Council Brain Networks Dynamics Unit at the University of Oxford to learn more about how animals are helping us understand some of the mysteries of the brain and Parkinson's.

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“Since being diagnosed with Parkinson’s I have become far less squeamish about the use of animals in research. But I feel that I should be better informed, to be sure that I am not just turning away from something unpleasant. I also wanted to be able to explain to friends and family how and why research is carried out on animals. It isn’t enough to say ‘Because I’m worth it!’ I was, happily, reassured as to the welfare of the animals. The researchers seem very fond of their lab animals (as farmers are of their livestock) and the mice are very well cared for.”

**Dawn**

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### How and when are animals used in Parkinson’s research?

Animals can only be used if the research is important enough to justify their use and cannot be done using any other method.

Researchers must also prove that every effort has been made to:

- reduce the numbers of animals used
- refine experiments to minimise any pain or discomfort
- replace animals wherever possible

### What progress has been made in developing alternatives?

Huge progress is being made which is reducing and replacing the need for animals in some areas of research. The main alternatives include:

#### People

Studying people with and without the condition is an essential part of Parkinson’s research. Major studies involving thousands of participants are helping us understand the condition better than ever before.

But while brain scanning techniques are improving all the time, we still cannot see what is going on inside the brain in enough detail.

#### Human brain tissue

Studying brain tissue donated to the Parkinson’s UK Brain Bank continues to be an essential tool for researchers worldwide. But because the brain cells are no longer alive, you cannot study their behaviour, and donations usually come from people in the later stages of Parkinson’s which means it’s hard to study the earlier stages of the condition.

#### Cells in the lab

Massive progress is being made in our ability to grow brain cells from skin cells which gives us a chance to watch how individual cells behave at extremely close quarters. But brain cells grown in a dish cannot replicate how a whole brain works.

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“The case for animal research was made in a clear, simple way explaining that most were carried out on the fruit fly or mice and only when there was no other way. A computer is an electrical machine while the brain is chemical and electrical organ of living cells. Just as it is not possible to understand what a broken computer is capable of, the functions and ability of the brain can only be really understood in the living.”

**Paul**

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#### Computers

Enormous investment is being poured into developing computer models of the human brain – including a project funded by the European Union costing over €1 billion.

However these projects are still in their early stages and as yet, computer models that can reproduce the complex working of the human brain are still some way off.

#### Animals

We still need to study animals to help us understand the complexities of how our brains work and how conditions like Parkinson’s develop. We also still need to use animals to test new treatments to make sure they are safe before giving them to people.

### How is research involving animals regulated?

Animal research in the UK has been regulated by central Government since 1876, and the special controls relating to laboratory animals were revised and extended in 1986 by the Animals (Scientific Procedures) Act.

“Although I understand the need for animals in research I have felt concerned about the levels of care for the animals and effective monitoring and control of their use. I was also interested in the types of animals used for particular research and the reasons for their selection. It was great to hear about the research the unit was undertaking with the involvement of animals. I was pleased to learn about the stringent levels of licensing, the adhoc checks from government inspectors and the regular involvement of vets.”

**Roger**

All research is carried out in line with strict Home Office regulations. Three separate types of licence are required for animal research or testing: One for the institution where the research is taking place, one for the researcher carrying out the research, and one for the specific research project.

The Home Office employs a dedicated team of qualified doctors and vets as inspectors to ensure all research complies with the regulations. In addition to assessing licence applications, inspectors visit each research establishment on average once a month – often without advance warning.

### How are the animals taken care of?

Animal welfare is taken extremely seriously. Every institution is required to appoint a Named Animal Care and Welfare Officer (NACWO), who is responsible for ensuring the highest standards of care for all the animals at the institution.

All animals are checked frequently to ensure that they are in good health and have fresh food and water. The animals also have enriched environments in their cages including play tunnels and bedding to keep them active and comfortable. Any discomfort or suffering is kept to a minimum by appropriate anaesthetics or painkillers.

### Does Parkinson's UK support research involving the use of animals?

So we can improve treatments and ultimately find a cure for Parkinson's, some of the research we fund involves the use of animals.

Approximately 40% of the projects we're currently funding involve the use of animals. The majority of these are mice and rats but we are also supporting research which involves fruit flies, worms and fish. We take the use of animals in research very seriously, as do the researchers we fund.

“From our point of view it was a great afternoon and well-worth the effort. It is also very important for us researchers (especially the younger ones) to meet and interact with people with Parkinson's. It is sobering and helps us focus on why we're doing our research.”

**Professor Paul Bolam**

### Find out more

Visit [www.understandinganimalresearch.org.uk](http://www.understandinganimalresearch.org.uk) or contact [research@parkinsons.org.uk](mailto:research@parkinsons.org.uk) for further information.



# FAITH AND PARKINSON'S

Dr Clare Redfern is a member of a research team based in East Anglia. The team are investigating how people's religious and spiritual beliefs may develop and change through their experience of Parkinson's.

Many researchers are interested in the cognitive and emotional effects of Parkinson's, but what about a person's religion or spirituality? This was what my supervisor, Alasdair Coles, a professor at Cambridge University and hospital chaplain at Addenbrooke's Hospital, wanted to find out.

I interviewed 42 people with Parkinson's across East Anglia, as well as a similar number of participants who didn't have Parkinson's. We used questionnaires and interviews to find out how religion or spirituality affects people with Parkinson's, and also how developing Parkinson's might influence a person's beliefs and practices.

We involved people with a range of faiths, including people with spiritual, religious and non-religious beliefs. We were interested in how often people took part in practices such as meditation, prayer or attending religious meetings. We also investigated the importance of spiritual and religious experiences and beliefs, and whether participants felt that developing Parkinson's had affected their beliefs and practices.

Research has found that Parkinson's can cause changes in thinking – so we wanted to know if these changes could directly affect the ability to practise faith or spirituality. For example, could religion and spirituality become less relevant?

Or on the other hand, could faith become more important to someone with Parkinson's and play an important role in coping with the emotional upheaval of developing a serious illness?

We discovered that the practical and emotional aspects of Parkinson's can make it harder for some people to attend and take part in religious meetings. Similarly, private practices such as prayer might be harder because of lower energy levels, dyskinesia or problems concentrating.

But despite the challenges, our study showed that faith remains important to many people with Parkinson's. Of course, people have very different attitudes to religion and for some it is irrelevant. But for others faith can help ease distressing symptoms, and practices such as prayer and meditation were often considered helpful in combatting low mood. We hope our study might raise more awareness of the difficulties that people with Parkinson's could have in practising their faith and also of the potential benefits it could bring.

Some of you have shared experiences and feelings about faith and Parkinson's on our forum. Here are some of our favourites:

"My belief in God has never altered or faltered. I don't usually shout about my faith, I don't go to church anymore. It is part of what makes me 'ME' and I am happy with that." **Lin**

"I became more religious as my Parkinson's progressed. The more I read, the less religious I became. Does anyone know where I can get a hold of a Jedi Manual? I figure that may be more up-to-date and relevant." **Erk**

"I was a confirmed atheist long before I got Parkinson's and nothing has changed." **Innonimate**

"We should never ridicule the fact that someone believes as those beliefs may be vital and precious to them." **Turnip**

Join the discussion at [parkinsons.org.uk/forum](https://parkinsons.org.uk/forum)



## How my faith helps me

Mr Hong Ho is 68 and has had Parkinson's for 12 years. Originally from Vietnam, Mr Ho now lives in Cambridge with his wife who takes an active role in encouraging her husband to keep well.

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## Tell us a bit about yourself

"I trained as a doctor in Vietnam and came to the UK more than 30 years ago. I was brought up in a traditional Buddhist family, but it was only when I was in my 30s, after the Vietnamese war had created such turmoil, that I turned seriously to Buddhist practice. When I learned to meditate, my mind started to calm down and not be so rushed – I became peaceful."

## Do you think your Parkinson's has affected your beliefs?

"Having Parkinson's has increased my Buddhist beliefs. It has made me learn to meditate and practise mindfulness (a meditation technique) more carefully. I have learnt to be kind to myself and to others. I've learnt that whatever happens not to feel angry. The more I have negative thoughts about my Parkinson's the worse it gets – even to the levodopa not working."

## Do your symptoms affect your practice?

"I often find it difficult to meditate. Even if I can control the physical movements, I feel internal agitation and distractions. Practising mindfulness helps me acknowledge these internal feelings and accept them. The physical movements might still be there but my mind becomes calmer and I can smile. Because of my practice I can live in peace with these symptoms – they are still there but I feel OK."

# RESEARCH RESULTS

Since 2005 we have supported more than 130 research projects. We keep a close eye on all our research and over the next few pages we share some of the latest and most important results. You can keep up with all the latest developments at [parkinsons.org.uk/researchresults](https://parkinsons.org.uk/researchresults)

## The Oxford Parkinson's Disease Centre

Established in 2010, the Oxford Parkinson's Disease Centre is a unique, collaborative initiative that brings the best scientific minds together to speed up the search for better treatments and a cure.

The team are trying to answer some of the biggest questions about the condition that have stumped scientists for decades.

What causes Parkinson's? How does the condition progress and develop? Why does Parkinson's vary so much from one individual to the next? How can we diagnose and monitor Parkinson's accurately? How can we stop precious brain cells dying?

Only by answering these fundamental questions will we be able to develop treatments that can slow, stop and reverse its progress.

"This groundbreaking centre is special because it's truly multidisciplinary. As a cell biologist who works primarily in the lab, I've learnt a huge amount from my colleagues who work in the clinic – and from the patients and their families who are taking part in the project."

**Professor Richard Wade-Martins**

## What progress has been made so far?

### We understand Parkinson's better than ever

The OPDC is leading one of the largest studies of people living with Parkinson's anywhere in the world with more than 1,400 participants including people with the condition, partners and siblings. These dedicated participants have already helped the research team discover key differences between people with Parkinson's. Men are more likely to



experience problems with memory and sleep, whereas women tend to experience more problems with posture and balance. People diagnosed at an older age tend to have more symptoms at an earlier stage in the condition.

The team have also taken steps towards developing personalised treatments by separating people with Parkinson's into different groups based on their symptoms and the progress of the condition.

### We're closer to accurate, early diagnosis

Diagnosing Parkinson's is a complex and often slow process. Currently there is no single, definitive test that can accurately diagnose the condition.

To address this, the team are studying blood samples and brain scans to develop better tests that can diagnose Parkinson's accurately at an early stage of the condition.

The team have shown that MRI brain scans can diagnose early stage Parkinson's with an accuracy of 85%. In addition they've identified subtle differences in blood proteins in people with the condition compared to healthy controls.

### We've created a brain cell bank to aid research

To really understand why and how brain cells are lost in Parkinson's, we need to study them in the lab.

The team in Oxford are using cutting edge stem cell techniques to grow brain cells from tiny samples of skin donated by people with the condition.

These cells are allowing scientists to study their behaviour more closely than ever before, and identify new ideas for therapies that could save more precious cells.

### Developing realistic rodent models

One of the greatest challenges facing Parkinson's research across the world is the lack of suitable animal models for developing and testing new drugs and treatments.

The team in Oxford are tackling this too and have successfully produced mice and rats which develop Parkinson's symptoms as a result of subtle but specific genetic changes that are known to play a part in the human condition.

These mice and rats will shed important light on the very earliest changes that happen inside the brain in Parkinson's and help to pinpoint opportunities for developing new treatments. The rats and mice will also provide a crucial tool in testing new drugs.



## What's next?

The Oxford Parkinson's Disease Centre has been awarded a further £6million for the next five years to continue their vital work towards:

- **New and better treatments for Parkinson's with fewer side effects**  
The team will use the knowledge and insights they gain from studying their new rodent models and brain cells to identify promising targets for new therapies for Parkinson's. They will also collaborate with pharmaceutical and biotech companies to bring potential new therapies to people with Parkinson's that can slow or stop the development of the condition.
- **Simple ways to diagnose and monitor Parkinson's much more accurately**  
The team will continue to follow people with Parkinson's in the study to help them develop new and much more sensitive diagnostic tests using brain scanning and blood samples. They will also explore the potential of using new technologies – such as smartphone applications – to monitor Parkinson's symptoms remotely.

# RESEARCH RESULTS

## Improving balance and preventing falls in people with Parkinson's

In 2011, we awarded a £250,000 Career Development Award to Dr Emily Henderson at the University of Bristol to support a clinical trial of a drug called rivastigmine in people with Parkinson's. Rivastigmine is currently used to treat people with memory problems but researchers believe it may also help to improve balance and prevent falls in people with Parkinson's.

Problems with walking, balance and falls are common in Parkinson's. Falls can result in broken bones, injuries and a loss of confidence in getting out and about, which can have a serious impact on people's quality of life. At present there are very few treatments to improve balance and prevent falls.

### What they did

The research team recruited 130 patients from the south west of England with Parkinson's who had fallen in the past year.

Participants were split into two groups. The first group was given a dummy drug or placebo and the second was given rivastigmine capsules for eight months. Participants were then assessed through a number of simple tests.

### What they found

The research team announced initial results of their clinical trial at the 19th International Congress on Parkinson's Disease and Movement Disorders in San Diego in June 2015.

Preliminary results suggest that rivastigmine can reduce the number of falls people with Parkinson's experience by 30%. The research team also found that the gait of those who had taken the active drug was more stable compared to those who had been taking the dummy drug.

Dr Emily Henderson, a PhD researcher funded by Parkinson's UK, from Bristol's School of Social and Community Medicine, said:



While these results look promising it is important to note that they are preliminary findings which are yet to be peer-reviewed and published. This study was over an eight-month period and a larger, longer-term study is now needed to confirm these findings. If this is the case then appropriate use of this drug could reduce the fear of falling for patients with Parkinson's.

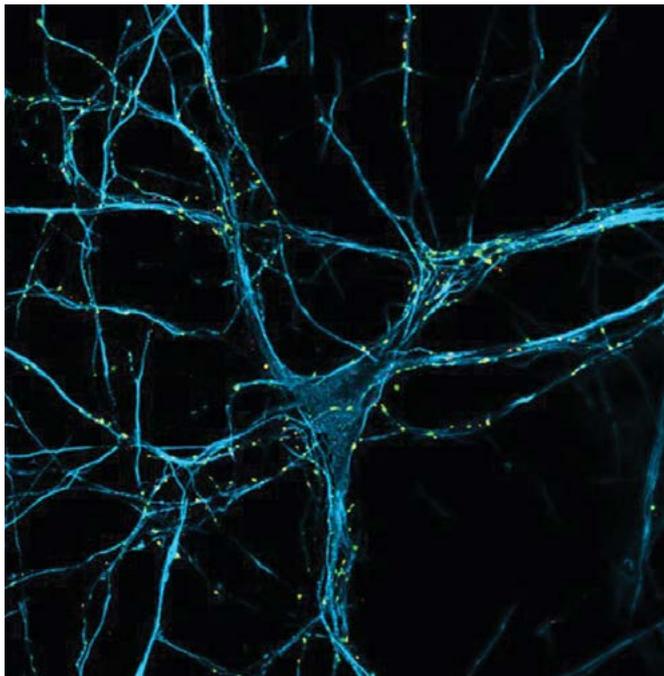
## Saving synapses: helping nerve cells stay connected in Parkinson's

During the early stages of neurodegenerative conditions such as Parkinson's, connections between nerve cells – known as synapses – are lost.

Now Parkinson's UK funded researchers at University College London have shown that a special family of proteins called Wnt proteins are vital for protecting synapses and may point the way towards new treatments.

Mice with changes in Wnt proteins lose synapses and develop Parkinson's-like movement problems. But restoring the Wnt proteins in the mice

reversed the loss of synapses and led to an improvement in movement symptoms.



Lead researcher Professor Patricia Salinas comments:

“This project provides the Parkinson’s research community a new insight into the role of the Wnt proteins in the death of these precious dopamine-producing nerve cells and possible new targets for therapies. Ultimately this knowledge takes us a step closer to understanding how we might be able to slow, stop or reverse the progression of Parkinson’s for people living with the condition today.”

## Investigating an iron-handling drug for Parkinson’s

Iron is essential for the normal function of the body and the brain. To stay healthy, cells need to have the right balance of iron. In Parkinson’s too much iron can be toxic and cause nerve cells to die.

Parkinson’s UK funded researchers at the University of Leeds working with an Australian biotech company have shown that a potential drug, called PBT434, can protect nerve cells by reducing the build-up of toxic iron.

The team worked in collaboration with Australian company Prana Biotechnology to test PBT434 in mice whose nerve cells accumulate toxic iron. PBT434 protected nerve cells and reduced the build-up of iron.

James and his team will now continue to investigate how PBT434 interacts with different proteins involved in iron transport and how the drug can protect nerve cells in Parkinson’s. Prana Biotechnology, who owns the drug, aims to carry out more testing and hopes to test PBT434 on people in clinical trials.

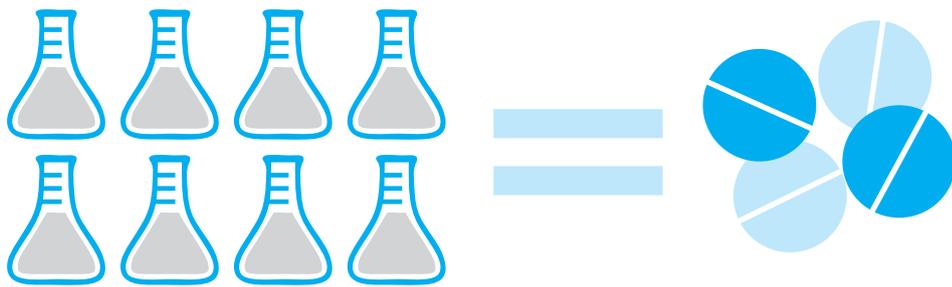
“We believe drugs like PBT434, which target toxic-iron, have the potential to slow or stop the progression of Parkinson’s. Understanding how it works will help us design better Parkinson’s drugs with fewer side effects. Our research has helped a potential Parkinson’s treatment progress towards clinical trials.”

**Dr James Duce, pictured below left**



# PARKINSON'S RESEARCH

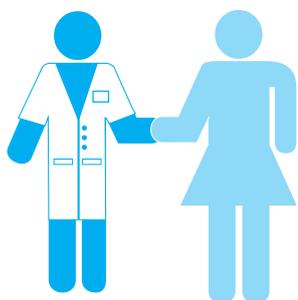
Better **treatments** and **therapies** for Parkinson's can only be developed if **people take part in research**



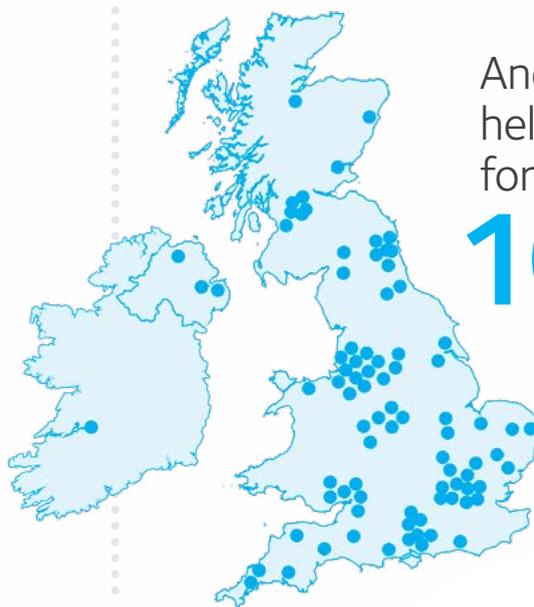
**70%** of people affected by **Parkinson's** want to take part in research



But only **24%** have!

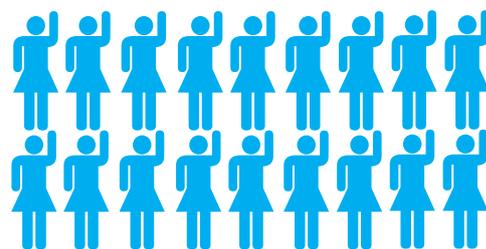


So we bring people affected by Parkinson's and researchers **together**



And, since 2012, we've helped **find participants** for more than

**100** Parkinson's research studies



**But we still need people to take part in Parkinson's research!**

Stay up-to-date with all the latest research and opportunities to take part by joining our **Research Support Network**.



FIND OUT **MORE**

[parkinsons.org.uk/rsn](http://parkinsons.org.uk/rsn)

# NEEDS YOU!



Andrew Leach, a member of our growing Research Support Network, shares his experiences of research and why taking part is so important.



"I was diagnosed with Parkinson's about three years ago and my GP encouraged me to find out more about the condition. He suggested sites such as Parkinson's UK, which led me to the local group. A researcher spoke at one of the first meetings I attended."

## Every study is different

"It's important to understand the difference between research studies. Most research studies may involve having your symptoms monitored, filling in questionnaires, and perhaps giving blood. So these are a good place to start.

"Clinical trials, on the other hand, involve some change to your treatment, possibly testing a new drug or perhaps some form of therapy."

## The Exenatide trial

"Having taken part in about 15 research studies of various types over about two years, I started looking for a clinical trial I could join.

"Eventually I found a trial that seemed to tick the boxes for me. It is called Exenatide-PD and is taking place in London at the National Hospital for Neurology.

"It involves an existing drug called Exenatide – which is currently used to treat people with type 2 diabetes. So I contacted the project leader and volunteered."

## What does taking part involve?

"It's quite an intensive trial. Every week I have to inject myself with the drug – or maybe the dummy drug, I won't know which until the trial is complete. It's only a little needle which goes just under the skin in my stomach, but I'm a bit of a wimp and will be pleased when I have done the last one in the middle of August!

"I also have to have a lumbar puncture at the beginning and end of the trial as well as have blood tests and brain scans."

## Why did you take part?

"Occasionally I ask myself that. I don't expect any of the studies I take part in to provide a direct benefit to me. Developing new treatments has to progress carefully and takes time.

"If any of them does – that would be a bonus. I really hope that something I volunteer for makes life better for those living with Parkinson's in the future. The researchers have, without exception, been pleasant and had time to explain what they're doing and often have more time to discuss my Parkinson's issues than my regular neurologist is able to give me. "

## Are there any drawbacks taking part?

"I can't think of many. You need to have the time to attend, of course, but now I've retired that's not too much of an issue."

## Would you encourage others to get involved in research?

"If you haven't taken part in any research I would encourage you to try it. Start with a small study or two, if you enjoy them then you could consider a clinical trial.

"Even if you don't have Parkinson's yourself, many studies need healthy volunteers to act as a control. Read through the documentation carefully and ask questions before you say yes. The Parkinson's research community needs YOU!"

# BEHIND THE SCENES AT THE BRAIN BANK

Last year the Parkinson's UK Brain Bank, based at Imperial College London, collected the brains of 82 people with Parkinson's and 20 people without the condition.

Our Brain Bank is one of the most active in the world and sends vital tissue samples to research teams studying Parkinson's across the UK, Europe and beyond. Running the Brain Bank is extremely complex so every year a panel, made up of leading scientific experts and people affected by Parkinson's, reviews its work to ensure that the Brain Bank is being run as effectively as possible.

This year two new volunteers, Anne and Graham, from our Research Support Network joined the panel to provide their perspectives on the work of the Brain Bank. Here they reflect on their first experience of the panel.

*"I have no hesitation in recommending others to take the plunge and volunteer."*



## Anne Ferrett...

"I cared for my mother for 10 years with Parkinson's, until she died aged 91 in 2013. Mum had wanted to donate her brain and although we talked about it, she never signed the forms. But I did.

"So when I saw the opportunity to join the Assessment Panel I thought I might be able to contribute. I am a staff governor at school, was a bereavement volunteer and supported my mother. Those experiences will I hope help me bring the views of those with Parkinson's into the Brain Bank meeting.

"Having attended my first meeting I realise that the Bank is very complex – the monitoring and reviewing of its work and the processing of research applications and distributing tissue is impressive.

"I'm keen that more updates about the research studies the Bank enables are shared to show just how valuable these tissues are to the scientific community. I also believe we need to do more to highlight difficulties in collecting tissue to better prepare donors and their families if an intended donation is not possible.

"As a non-scientist, I felt a bit daunted as to what I could contribute – especially after receiving all the relevant papers for the meeting! But I was able to speak out when the issues being discussed were directly related to donors and their families.

"I spoke about my direct experiences with the idea of donating and what it felt like talking about brain donation with my Mum. My comments were listened to and responded to with concern.

"At the end of meeting I read a poem my mother had written about living with Parkinson's – a fitting way to end the meeting, another panel member said."

## Graham Thorp...

"I was keen to join the Assessment Panel because I have always thought the Brain Bank is an excellent way to encourage research. I also felt I could represent the views of people with the condition as I have had Parkinson's for 15 years.

"My biggest challenge was actually getting to and from the meeting. The meeting was held at the Brain Bank in London and I live in Leicestershire. I find travelling by public transport very challenging so I drove down to London the night before and stopped in a hotel.

"Everything worked out until it was time to leave as my medication let me down, but members of staff were quick to help and got me back to my car.

"The second biggest challenge was reading the vast quantity of papers and documents prior to the meeting as some of the items are quite technical. But you can only do your best and I felt adequately briefed and confident of making a constructive and positive contribution. I have never been backward in coming forward and pitched in as I thought necessary. As I have found in previous meetings, the academic and clinical professionals listened to what I had to say and I never felt ignored or overwhelmed.

"I firmly believe the opportunity to contribute as a person with Parkinson's is important and gives us a voice in how research resources are directed and used. It helps with the scrutiny of decisions and keeps the professionals focused on the needs and priorities of people living with the condition.

"It is an effort to take part but it's rewarding too and I have no hesitation in recommending others to take the plunge and volunteer. I don't know if I will be physically able to go to the meeting next year but I am looking forward to the opportunity and will try my best."



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"As a non-scientist, I felt a bit daunted as to what I could contribute."

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### Feeling inspired?

Find out about all the different ways to get involved in Parkinson's research by joining our Research Support Network.

Visit the website [parkinsons.org.uk/rsn](https://parkinsons.org.uk/rsn)

Email [rsn@parkinsons.org.uk](mailto:rsn@parkinsons.org.uk)

Call **020 7963 9398**

# GET KNITTING



## Product details:

Dave the Worm knitting pack

PAUK1071

£8.99

Here's a great way to support Parkinson's – knit your very own Dave the Worm toy! The smallest and cuddliest member of the Parkinson's UK research team, Dave is helping to raise awareness of the condition and bring us closer to a cure.

### Your knitting pack

Each pack contains a knitting pattern and enough yarn to make two Dave toys.

Your completed Dave will measure approximately 33cm x 28cm x 12cm diameter. Needles and stuffing not included. All profits go directly to the vital work of Parkinson's UK.

Order at [parkinsons.org.uk/shop](https://parkinsons.org.uk/shop), call **0844 415 7863** or email [shop@parkinsons.org.uk](mailto:shop@parkinsons.org.uk)



### What on earth have worms got to do with Parkinson's?

Well, Dave's not just any worm. He's a *C. elegans* worm, and he's actually just a millimetre long. Despite being a tiny invertebrate, Dave has 302 nerve cells, eight of which are just like the ones in the brain affected by Parkinson's. And by studying these cells, scientists hope to learn more about Parkinson's and how it develops.

### Want to be extra awesome and join Team Worm?

You can by sponsoring a worm like Dave for £5 a month. Every penny goes to Parkinson's research, so you'll be helping to find better treatments and, ultimately, a cure. Just visit [davetheworm.org](https://davetheworm.org) to find out more.

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*Progress* magazine is our free twice yearly magazine focused on the latest research into Parkinson's.

You can find previous issues and subscribe to *Progress* on our website [parkinsons.org.uk/progress](http://parkinsons.org.uk/progress) or by contacting the research team directly by email [research@parkinsons.org.uk](mailto:research@parkinsons.org.uk) or phone **020 7963 9313**



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The helpline is open Monday to Friday 9am-7pm, Saturday 10-2pm

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