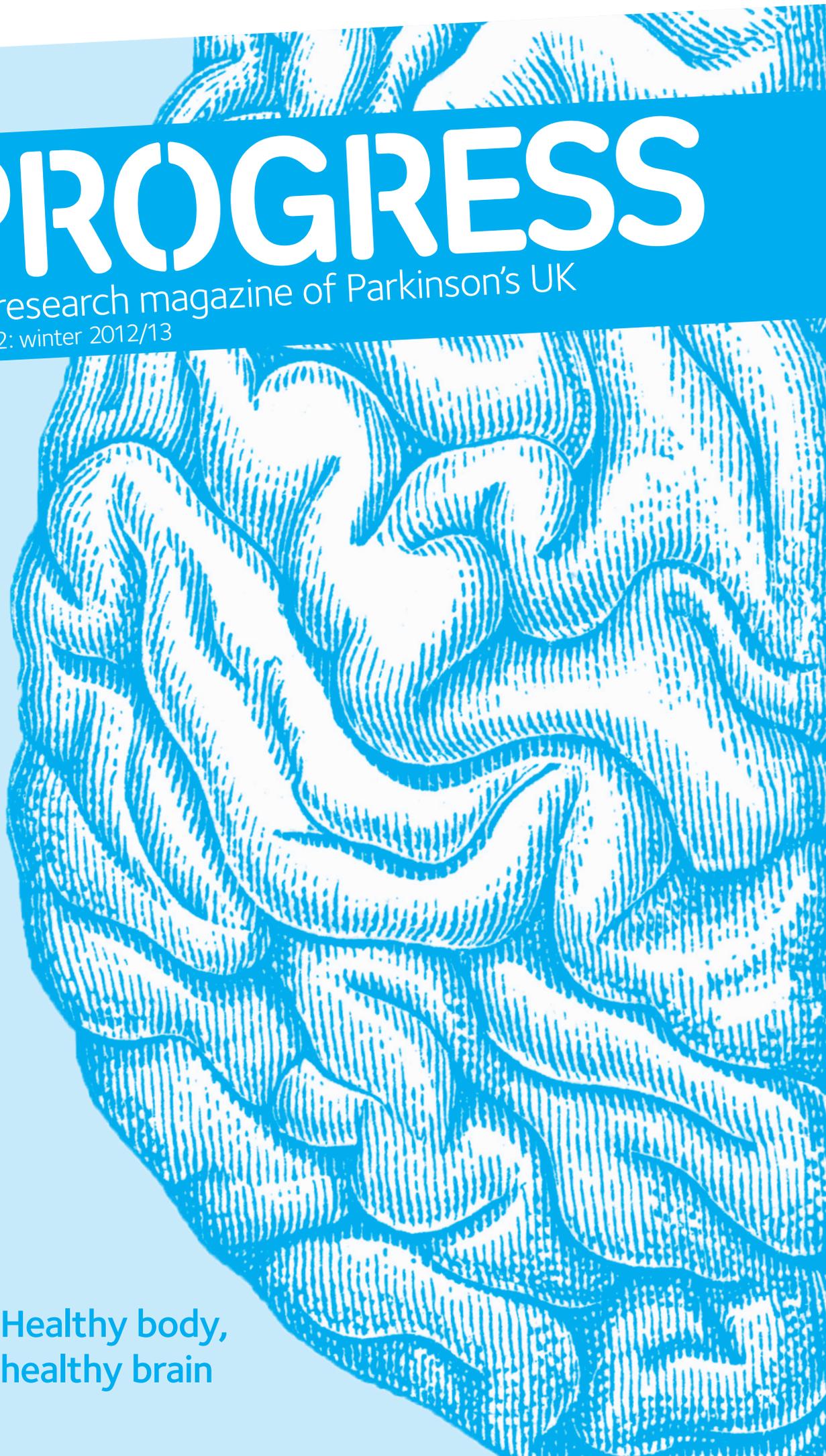


**PARKINSON'S<sup>UK</sup> CHANGE ATTITUDES. FIND A CURE. JOIN US.**

# PROGRESS

The research magazine of Parkinson's UK  
Issue 12: winter 2012/13

Healthy body,  
healthy brain



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# WELCOME

Hello and welcome to the Winter 2012-13 issue of *Progress* – your twice-yearly magazine all about Parkinson's research.

Often in research our focus is on new drugs and treatments, but in this issue we're taking a look at the role lifestyle and environment has to play in Parkinson's.

Our feature article 'Healthy body, healthy brain' delves into the latest research which has revealed some interesting (and surprising) things that may influence risk of developing Parkinson's, and even affect the progression of the condition.

As always *Progress* brings you all the latest news from our research projects. We've interesting results to share from projects exploring impulsive and compulsive behaviour, exercise and hunger hormones. And we introduce you to some of our new research – including exciting projects getting underway in Greece and Croatia.

Finally, I'd like to draw your attention to the wide range of voices throughout the magazine. In this issue we hear from many of our members and supporters who are involved in research at different levels.

Wesley Carr shares his experiences as a research volunteer, our supporters report from our brain bank, and Sheila Roy takes us inside a clinical trial. We also hear from our readers in 'Over to you' on page 18.

We're keen to include more stories, news and views on research from people living with Parkinson's in future issues too – so if you've got ideas for *Progress* or feedback on the magazine please don't hesitate to contact the research team.

Best wishes,

A handwritten signature in black ink that reads "Kieran".

**Dr Kieran Breen**

Director of Research and Innovation

# INTERNATIONAL NEWS ROUNDUP

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At Parkinson's UK we like to keep a finger on the pulse of research happening across the world. Here are some of the latest highlights.

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## 'Pig cell therapy' for Parkinson's

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A potential new treatment using brain cells from pigs has been approved for testing in people with Parkinson's. A New Zealand based company has pioneered this interesting new approach and hopes to start trials in 2013.

The new treatment uses pig cells taken from part of the brain called the choroid plexus. These cells are naturally occurring "support" cells for the brain and when transplanted can help protect the brain and repair damaged nerve tissue. The cells are packaged inside a specially designed capsule which acts like a teabag – allowing beneficial proteins and chemicals to leak out, but preventing the immune system from rejecting the cells as foreign.

The new clinical trial will compare the safety and clinical effect of the new treatment against deep brain stimulation in people with Parkinson's.

Clearly it's still very early days and many years of extensive testing are needed to assess whether this new treatment is safe and effective. But the prospect of using new and healthy cells to help repair the parts of the brain that are damaged by Parkinson's is getting ever closer to becoming a reality.

You can find out more about this area of research on our website at [parkinsons.org.uk/researchnews9oct2012](http://parkinsons.org.uk/researchnews9oct2012)

## New evidence on benefits of physio

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Results from a recent review of all the current research evidence suggest that physiotherapy is beneficial for people with Parkinson's in the short term. But we urgently need studies that look at the longer term effects of physiotherapy.

In this study, a team at the University of Birmingham Clinical Trials Unit reviewed the evidence from 39 physiotherapy studies involving almost 2,000 participants. The team found that physiotherapy, exercise and dance resulted in improvements in things like walking and balance.

But most of the trials were small and over a short period of time (three months or less) so we still need better evidence on the longer term effects of physiotherapy. A number of such studies are being carried out around the world.

This research was led by the University of Birmingham, funded by Parkinson's UK and the UK Department of Health and the findings were published in the *British Medical Journal*.

There's more details on our website at [parkinsons.org.uk/researchnews4oct2012](http://parkinsons.org.uk/researchnews4oct2012)

## The science behind Parkinson's

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Fancy learning more about the nuts and bolts of Parkinson's research?

Check out this Parkinson's website which is a growing body of knowledge about current research <http://en.wikiversity.org/wiki/ParkinsonsScience>. Some of our Research Support Network members are involved in developing it, and they are keen for more people to get involved in the project.

## ENCODE – the next chapter in the genetic revolution

ENCODE stands for the 'Encyclopaedia of DNA Elements'. This project is helping to fill the gaps in our knowledge of the human genome by analysing DNA in greater detail than ever before.

In 1953, Watson, Crick and Franklin described the structure of the molecule that makes up our genomes: the DNA double helix. And in 2001, the first human genome was published, giving us the entire three billion letter code of our DNA. But what most of our DNA is for is still a bit of a mystery. Only 2% of it codes for genes. These are the sections that make proteins, the building blocks of our cells, tissues and organs.

Until now, the other 98% has been nicknamed 'junk DNA'. In fact, the ENCODE project is uncovering that in between our genes there are lots of 'switches' which control when different genes are switched on or off inside our cells.

Understanding how these switches work and how they control our genes could be vital in our search for the causes and ultimately a cure for Parkinson's.

To read the ENCODE research papers and more, visit [www.nature.com/ENCODE](http://www.nature.com/ENCODE) and watch the video: <http://bit.ly/PamuXA>

## Nobel prize for stem cell pioneers

Sir John Gurdon from Cambridge University and Shinya Yamanaka from the University of California, shared the 2012 Nobel prize for physiology or medicine for their contribution to stem cell research.

This research has revolutionised research into conditions like Parkinson's. Read more about this story here: <http://bit.ly/QMzW65>

## Tracking Parkinson's update

Last year we launched Tracking Parkinson's – the world's largest ever in-depth study of people with Parkinson's.

So far more than 800 people have signed up to take part in this groundbreaking project, but

we still need more people who have been diagnosed with Parkinson's in the last three years to get involved. Find out more on our website: [parkinsons.org.uk/tracking](http://parkinsons.org.uk/tracking)

## Dr Philip Robinson 1955–2012

We're very sad to announce that Dr Philip Robinson, a Parkinson's UK-funded researcher at the University of Leeds, passed away in August.

Our thoughts are with his family, friends and colleagues. You can read a tribute to his life and work on the website <http://bit.ly/VF6OAV>

### Find out more

To read more about these stories and all our latest Parkinson's research news, visit [parkinsons.org.uk/researchnews](http://parkinsons.org.uk/researchnews)

## Parkinson's UK Twitter news

We spread the word about research through Twitter. Here are a few examples of our recent tweets:

- Interesting TEDtalks video about how scientists are creating a map of the human brain <http://bit.ly/NT8nJM>
- The Monument Discovery Project is our biggest ever research grant at £5million over five years – watch the video <http://youtu.be/FOtWoFcMBCI>
- *BBC News*: A golden age of discovery in neuroscience <http://bbc.in/NM9xYM>
- *BBC News*: Being active and living a healthy lifestyle into your seventies adds years to life expectancy <http://bbc.in/OyrlCY>
- Watch a film from our Basingstoke research event <http://youtu.be/4oQKnIWevOQ>

Follow us at [www.twitter.com/parkinsonsuk](http://www.twitter.com/parkinsonsuk)

# HEALTHY BODY HEALTHY BRAIN

Research is not just about developing new drugs and treatments. It's also about understanding the range of factors that affect our risk of developing illnesses – and the things that we can do to reduce our risk.

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Some things, like the genes we inherit from our parents, are beyond our control. But there are things we can change, like our lifestyle choices, which may protect us from conditions such as Parkinson's. In this article we take a closer look at how lifestyle affects the risk of developing Parkinson's, and if making subtle changes to day-to-day life can help to manage certain symptoms or even slow the course of the condition.

## Exercise

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We've known for some time that exercise is important for keeping our hearts healthy, bones strong and our waistlines in check. But it's only relatively recently that research has shown just how important exercise may be for keeping our brains healthy too.

**Below:** Alex Flynn has Parkinson's but is doing a 10million metre marathon, involving running cycling and kayaking all around the world.



Studies have suggested that people who exercise regularly may be at slightly reduced risk of developing conditions such as Parkinson's and Alzheimer's later in life. And research using animal models has shown tantalising glimpses of how exercise may even be able to slow the development of Parkinson's.

For rats treated with chemicals that cause Parkinson's, daily running sessions on a treadmill not only improved performance in movement and balance tests, but also helped repair their brains. More of their dopamine-producing nerve cells survived and their brains had higher levels of proteins called 'neurotrophic factors', which help nerve cells grow and stay healthy.

We don't know yet whether exercise can have the same dramatic impact on the brains of people with Parkinson's. But researchers are working hard to find out. Studies so far have shown that exercise may improve both physical symptoms, such as walking, balance and coordination, and mental aspects – including mood, thinking and attention.

### So what exercise should I do and how much?

Good question. Researchers have looked at all sorts of different types of exercise – from t'ai chi to gym training, tango to cycling. But while most researchers agree that exercise is a good idea for people with Parkinson's, there's no one activity that stands out above all others.

In fact, variety may actually be the key to getting the most out of your work out. So try to balance aerobic exercise, like walking or cycling to improve



**Above:** Sally Frank preparing a nutritious meal

your fitness, alongside activities that aid strength, balance, coordination and posture, such as Pilates or dance. The recommended level of exercise is 2.5 hours a week, which may sound daunting – but exercise doesn't have to mean going to the gym. Daily activities like a brisk walk to the shops, gardening or even washing the car all count too – so slotting it into your life may be easier than you think. We're investigating new approaches to exercise. Read more about the results of one of our recent studies which explored using the Nintendo Wii on [page 26](#). You can also get active with our *Keeping Moving* booklet and DVD.

## Diet

So far, studies looking at individual foods and nutrients and their effect on Parkinson's have produced very inconsistent results and researchers have struggled to find many firm links between diet and risk of Parkinson's.

There are a few exceptions. Perhaps the most compelling evidence is for caffeine. Several studies have shown that people who consume more caffeine in their diets are at lower risk of Parkinson's. And more recent research has even suggested that caffeine may improve symptoms for people with Parkinson's.

In the study, 60 people with Parkinson's were randomly assigned to take either caffeine pills or identical drug-free placebo pills. Those taking caffeine took 100 milligrams (the equivalent of a cup of brewed coffee) twice a day for the first three weeks, and then doubled the dose for the second three weeks. After just six weeks, stiffness and other movement problems had improved slightly in those that were taking the caffeine pills.

The benefits were modest compared to the effects of Parkinson's drugs such as levodopa, and this was a small study so more research is needed to confirm these interesting findings. So while caffeine is something many of us consume every day, it is still a drug, and we recommend people talk to their GP or nurse before making any significant changes to their caffeine intake.

While overall the role of diet in Parkinson's seems to be quite subtle, following a healthy and balanced diet is very important for reducing risk of a range of other age-related conditions including diabetes, cancer, osteoporosis and cardiovascular disease.

### So what about supplements?

Eating a well-balanced diet rich in nutritious foods and low in fat and sugar is the best way to make

## Eat, fast and live longer

Some of you may have seen a *Horizon* programme on the BBC last year that investigated the potential benefits of calorie restriction and fasting for improving our health and even protecting our brains.

Although there have been a few animal studies that have produced promising results, so far there haven't been any research trials looking at either calorie restriction or fasting in people with Parkinson's.

As there is no evidence yet that this approach to diet is effective and safe in the long-term it's too soon for people with Parkinson's to start fasting – and as the presenter stressed in the programme, fasting can be dangerous for people who are not in good general health. It could also affect the absorption of medication.

Read about our research into the hunger hormone ghrelin and its potentially protective effects on nerve cells on [page 28](#).

sure you're getting the vitamins and minerals your body needs. Supplements are not usually necessary and so far research has not provided conclusive evidence that any particular dietary supplements are beneficial for people with Parkinson's – but here is a quick update on some that are currently being investigated.

### Vitamin D

Vitamin D helps keep bones healthy – people with low levels are more likely to develop osteoporosis and have falls.

More recently, studies have found evidence that people with Parkinson's are more likely to have low levels of vitamin D. Researchers are now investigating whether boosting vitamin D levels could be helpful for people with Parkinson's.

### Coenzyme Q10

Co-enzyme Q10 is naturally present in the body and in small amounts in a wide range of foods, and has strong antioxidant properties. There have been a number of research studies where people with Parkinson's have taken large doses of this supplement, but the most recent trials were halted due to disappointing interim results.

So at the moment there is no evidence to recommend co-enzyme Q10 as a treatment for Parkinson's.

### Creatine

Creatine is naturally produced in the body and is well known as a supplement taken by athletes to build muscle. But research has also suggested it may have neuroprotective effects and creatine is now in clinical trials for the treatment of Parkinson's.

A phase 2 trial showed promising improvements in symptoms and a phase 3 clinical trial involving almost 2,000 participants over five years is now underway in the USA.

Before taking any 'over the counter' mineral or vitamin supplements consult your GP, specialist, Parkinson's nurse or dietitian for advice. For general information, read our *Diet and Parkinson's* booklet.

## Stress

Many people with Parkinson's tell us they notice that their symptoms temporarily get worse when they feel stressed or anxious. But we don't know yet if stress increases risk of Parkinson's or causes the condition to progress more rapidly.

Studies we've funded using animal models of Parkinson's have suggested that psychological stress may accelerate the death of the nerve cells in the brain – so long-term stress may do more than worsen symptoms.

As with all animal studies we cannot be sure that the findings hold true for human Parkinson's and further studies are required. But finding ways to relax and seeking help if you experience prolonged

periods of stress, low mood or anxiety is really vital for your general health and may even help to protect your brain too.

## Smoking

Smoking increases risk of all sorts of problems including heart disease, stroke, lung conditions, cancer and dementia – but in an odd quirk of nature, research shows that people who smoke have a reduced risk of Parkinson's.

This has led researchers to investigate whether nicotine – the chemical in cigarettes that makes them so addictive – may actually protect the nerve cells affected in Parkinson's. Studies investigating whether nicotine patches may be beneficial for people with Parkinson's are underway at the moment but we don't know yet whether they are safe and effective for people with the condition. Until then, people with Parkinson's should not start using nicotine patches without the explicit recommendation of their doctor.

## Sleep

We've all felt the benefit of a good night's sleep – but does sleep (and lack of it) have more profound effects on our brains?

Animal studies have shown that disrupted sleep patterns can alter the wiring of the brain and affect thinking and memory. And more recently research has shown that people with Parkinson's do better on memory tests after a good night's sleep, and that sleep problems hinder performance. We're funding research to tackle the sleep problems that people with Parkinson's experience which could lead to treatments and therapies that have a dramatic effect on quality of life.

## Can you train your brain?

Sudoku, crosswords and brain training games have been claimed to help keep minds sharp and even potentially stave off thinking and memory problems in later life. But is there any scientific evidence to back up these claims?

In September 2009, the BBC joined forces with The Alzheimer's Society to launch a study to

find out whether brain training actually works. Brain Test Britain involved over 13,000 participants making it by far the largest ever study of computer-based brain training.

The initial results were disappointing. The team found that playing brain training games makes you better at those specific games but not at everyday thinking tasks. However, the results of the second phase of the study, looking at the longer term effects of brain training in people aged 60 and over, are still being analysed.

These participants carried on 'brain training' for twelve months rather than just six weeks to explore whether regular brain training helps delay the effects of ageing on the brain.

### Mind over matter?

More recently, research at Cardiff University has shown that people with Parkinson's may be able to alter their own brain activity to improve their symptoms.

People with early stage Parkinson's were placed inside a brain scanner and shown 'live' images of their own brain activity. Participants were asked to imagine performing complex movements to activate brain areas that control movement, and they saw a corresponding change on the screen.



**Above:** Doyle Wood on his laptop

With practice, they were able to increase and decrease the level of brain activity at will, through thought alone. Crucially, the five participants also showed improvements in movement tests.

This was a small study but it highlights the amazing ability of the brain to change and adapt. Developing techniques that help people learn to train their own brains in this way could lead to non-drug treatments for Parkinson's.

## Feeling inspired?

Lifestyle habits have an impact on every aspect of health – and Parkinson's is no exception.

Research is uncovering how subtle changes in lifestyle may be important not just for managing the symptoms of the condition, but potentially even slowing its course.

If you feel inspired to make changes in your daily life it's important to talk to your GP or nurse and find the things that work for you.

## Seven steps to better health

During the 1960s, Dr Lester Breslow, a public health researcher in the US, found that the key to a long and healthy old age lay in seven simple daily good health habits.

- ☺ Get a good night's sleep of seven or eight hours
- ☺ Do regular exercise
- ☺ Maintain a moderate body weight
- ☺ Eat breakfast every day
- ☺ Eat regular meals but don't snack
- ☺ Don't drink at all or drink moderately
- ☺ Don't smoke

People with more of these habits are substantially healthier than those with less. Remarkably, a 60-year-old with all seven healthy habits should be as healthy as a 30-year-old with fewer than three.



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**Left:** Harry and Patricia Brown playing Scrabble with their grandchildren

# HIGHLIGHTS FROM OUR RESEARCH CONFERENCE

Every two years we bring the very brightest and best researchers together in York to share ideas, develop collaborations and push our search for a cure to a new level.

For the first time, this year we hosted a day of research talks for our supporters and members before the main scientific conference. More than 100 members and Parkinson's UK supporters joined us on Sunday 4 November to hear about everything from genetics to the power of dance.

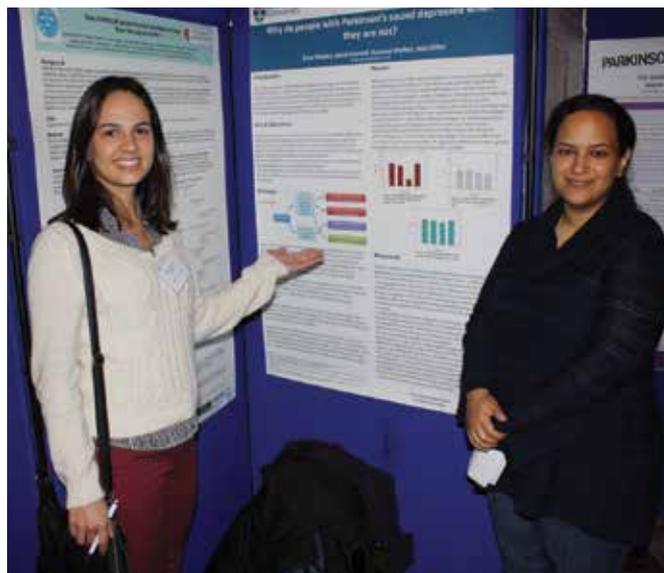
The two-day conference for scientists followed with a jam-packed programme of 27 talks and 110 posters and featured presentations from international experts. It was a fantastic opportunity for more than 200 Parkinson's UK researchers to hear the latest breakthroughs across a wide range of fields.

Throughout the conference we were joined by three passionate volunteers from our Research Support Network who made vital contributions:



**Above:** Researchers listen to a presentation

**Below:** Researchers share their findings in the poster sessions



- Social media enthusiast Viktor spent the conference tweeting and recording short videos with researchers to share on YouTube.
- Photographer Martin helped us by taking lots of photos of our speakers and researchers.
- And former malaria scientist Geoff Butcher gave an inspiring speech about what research means to him as a person with Parkinson's.

“

It was amazing to see the quantity and the quality of research that is being carried out into the various aspects of Parkinson's, from basic research looking for a 'cure', to the more palliative side or 'care'. It really was a privilege to be able to meet so many of the researchers at first hand, and to be reassured that there was so much optimism among them.

”

Martin

## Find out more

For more from York read the blogs on our website: [parkinsons.org.uk/researchconference](https://parkinsons.org.uk/researchconference)

**Pictured:** Brain Bank manager Dr Djordje Gveric with Research Support Network member Micaela Graham-Yooll



# A TRIP TO THE BRAIN BANK

In September our Brain Bank team invited people affected by Parkinson's to visit the Parkinson's UK Brain Bank at Hammersmith Hospital in London.

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Ian Harrison is a PhD student who works at the Brain Bank and was involved in setting up the open day. Ian explains what inspired the team to organise the event:

"As researchers, we're trying to understand and hopefully cure conditions like Parkinson's but our contact with the people affected is actually pretty limited. This was what gave us the idea of having an outreach day.

"For us, it was a chance to explain our work to the patients, carers and families, share what has been achieved so far and our hopes for the future. But as it turned out it, we researchers probably learnt more from the experience than our guests!

"We'd like to thank them for taking the time to come to our labs, and for the inspiration and motivation they gave us."

"The day was extremely informative, challenging at times (in a good way) and very sensitive in its delivery. It appeared to me that a great deal of thought had been given to every aspect of the day.

"It was refreshing to meet face to face with researchers at the forefront of developments in the study of this condition. They all spoke with enthusiasm and clarity, were welcoming of our questions and addressed them with ease.

"I have rarely attended an event where the balance of the quantity and content of information has matched so closely my personal needs. I now have a better understanding of the hurdles that researchers face in their battle to control and ultimately cure Parkinson's. A very worthwhile day – thank you."

**Helen**

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"It was an excellent day and very inspiring. I shall feedback to our group members that all the money donated by them and given to Hammersmith is being used effectively.

"It definitely feels like research into Parkinson's continues to push the boundaries of what's possible. Thanks for the opportunity to see this great work."

**Chris**

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"I loved the day at the Brain Bank. I was so impressed with everything, just everything. Thank you very much."

**Claire**

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"I have developed a serious interest in neurodegenerative conditions. Fantastic and very interesting day. The scientists were lovely and I think they really liked meeting the kind of people that their work is based on helping."

**Edward**



**Above:** Ken Rowlands inspects a brain

## About the Brain Bank

The Parkinson's UK Brain Bank is the UK's largest brain bank dedicated to Parkinson's. They collect the brain, spinal cord and a sample of cerebrospinal fluid from people with and without the condition. These tissues are supplied free of charge to researchers studying Parkinson's all over the world. In the next issue we'll tell you about some of the research our tissue supports.

### Brain Bank stats

- This year the team successfully collected 123 brains – an average of two brains a week.
- This brings the total number of brains the bank holds to over 650.
- The Brain Bank currently has more than 5,500 registered donors (up 438 from last year). Of these, 29% currently have Parkinson's and 71% don't.

### Contact the Brain Bank

Visit [parkinsons.org.uk/brainbank](http://parkinsons.org.uk/brainbank), email [brainbank@imperial.ac.uk](mailto:brainbank@imperial.ac.uk) or call **020 7594 9732**.

# OUR INNOVATION GRANTS GO INTERNATIONAL

## Our European research

To achieve our goals and fund the very best research, we opened up our innovation grants scheme to the international research community in 2012. The response was fantastic – we received a lot of interesting applications and as a result two of the innovation grants we awarded last year were to researchers working overseas.



### Correcting LRRK2 to develop better treatments

**Dr Hardy Rideout**

**Where?** Academy of Athens, Greece

**What?** £35,000 over 12 months

Changes in the LRRK2 gene are the most common cause of inherited Parkinson's. These changes in the gene produce LRRK2 proteins that don't work as they should and cause the death of nerve cells. So correcting these changes in LRRK2 may be the key to better treatments for Parkinson's.

In this project, Hardy and his team will investigate how LRRK2 interacts with other proteins inside the nerve cells that die and look for ways to prevent this happening.

Ultimately, this project could lead to new and better treatments for people with Parkinson's that tackle the root causes of nerve cell death and have the potential to stop the condition in its tracks.



### Investigating changes in proteins in Parkinson's

**Prof Fran Borovecki**

**Where?** University of Zagreb, Croatia

**What?** £34,575 over 12 months

This project will investigate whether people with Parkinson's have subtle differences in the proteins in their blood.

Fran and his collaborators have pioneered studies of the human 'glycome' which have shown that patterns of protein glycosylation vary significantly from person to person.

Most proteins are 'glycosylated' – this means they have chains of carbohydrate or sugar molecules added on after they are assembled. These extra bits, called 'glycans', help make sure the protein works properly.

Changes in protein glycosylation have been found in cancer but almost nothing is known about protein glycosylation in Parkinson's.

Fran and his team will study blood samples to investigate whether people with Parkinson's have a specific 'glycosylation fingerprint'.

If they do it might be important in the development and progression of Parkinson's, and could potentially lead to simple tests to spot the condition early and track its progression.

The search for a cure for Parkinson's is a global challenge involving thousands of researchers working in teams all over the world.



### Predicting risk of dyskinesia in Parkinson's

**Dr Binith Cheeran**

**Where?** University of Oxford

**What?** £19,792 over 6 months

Levodopa is the main drug used to treat the symptoms of Parkinson's. It helps nerve cells in the brain make more of a chemical called dopamine that's important for coordinating movement.

Levodopa works well at first but more than one in three people who take it eventually develop dyskinesia – uncontrolled movements that seriously affect quality of life. But at the moment there's no way to accurately predict who is at risk of developing dyskinesia.

Binith's team will use Transcranial Magnetic Stimulation (TMS), a safe and painless technique, to look for very slight changes in brain activity in people with early Parkinson's who are taking levodopa but free from dyskinesia.

The participants will continue to be assessed at regular intervals – so when some participants do develop dyskinesia the team will be able to see whether it could have been predicted by their TMS results.

If dyskinesia risk can be accurately predicted this would open the door to finding ways to prevent this distressing side effect.



### Using light to study nerve cells

**Dr Sarah Threlfell**

**Where?** University of Oxford

**What?** £34,985 over 12 months

Sarah aims to generate new tools to study the behaviour of different types of dopamine-producing nerve cells in greater detail than ever before.

'Optogenetics' is an exciting new technology that engineers nerve cells to respond to flashes of light.

Light can then be used like a switch to control nerve cell activity – for instance, to trigger dopamine release from specific nerve cells.

This approach is highly specific. Researchers can activate individual nerve cells or specific types to investigate what they do.

Current techniques are much more time-consuming and much less specific as they tend to activate lots of different nerve cells at the same time.

Sarah hopes these new tools will help work out why some nerve cells are more vulnerable in Parkinson's than others. This could ultimately lead to better treatments that can protect these precious cells, which would have a huge beneficial impact on the lives of people with Parkinson's.

# MEET OUR NEW SENIOR RESEARCH FELLOWS

## Changes in mitochondrial DNA in Parkinson's

Dr Gavin Hudson



**Where?** Newcastle University

**What?** £180,083 for 2 years

We've given Dr Gavin Hudson £180,083 for his two-year project which will investigate whether people with Parkinson's have changes in their mitochondrial DNA. Here's what Gavin has to say about his research:

"Mitochondria are the tiny batteries that make the energy our cells need to live and work properly. Research suggests that problems with mitochondria may play a crucial role in nerve cell death in Parkinson's, but the exact cause

of these problems is unclear. I have a hunch that mitochondrial DNA may be a missing part of the puzzle.

"Most DNA is found inside the nucleus – the control centre at the heart of each cell. But mitochondria have a small amount of their own DNA which codes for key genes that play a vital role in energy-production.

"Changes in mitochondrial DNA can be inherited or can happen randomly as we get older. Research has shown that both types of mutation are more common in people with age-related conditions like Parkinson's. But, it's not clear exactly which inherited mutations are important or why some people seem to be more likely to have random mutations.

"In the first part of my new project I will compare variations in mitochondrial DNA between 2,000 people with Parkinson's and 2,000 healthy people of a similar age. I hope to spot any inherited mutations that may increase a person's risk of developing the condition.

"Next, I'll look for random mutations in the brain tissue of people with and without Parkinson's. I'm especially interested to see whether people who inherit mutations in mitochondrial DNA are more likely to have random mutations later in life too.

"I hope my research will help us unravel the complex underlying causes of Parkinson's which could ultimately open up possibilities for developing new treatments."

Every year we award senior research fellowships to promising young researchers who are keen to specialise in Parkinson's research.

## Can we predict Parkinson's?

Dr Alastair Noyce



**Where?** University College London

**What?** £246,439 for 3 years

We've given Dr Alastair Noyce £246,439 for his three-year project which aims to develop simple tests that can identify people who are at higher risk of Parkinson's before the movement symptoms appear. Here Alastair explains the main ideas behind his research:

"One reason why we don't yet have a cure for Parkinson's is because the movement features of the condition only appear once 70-80% of the nerve cells in the part of the brain affected by Parkinson's have already been lost. If we could identify people early – before the movement problems appear – we would be in the best possible position to slow, stop or even reverse

Parkinson's. Problems including loss of sense of smell, sleep problems, constipation, anxiety and depression may occur many years before the movement problems of Parkinson's appear. My research aims to develop computer tests that can accurately identify people at high risk of developing Parkinson's based on their family history and these early warning signs of the condition.

"I started off with a 12-month pilot project in April 2011, funded by a Parkinson's UK innovation grant. With the help of Parkinson's UK we successfully recruited over 1,000 people without Parkinson's aged 60-80 to complete a set of simple tests – including:

- an in-depth online questionnaire about their health and family history
- a 'keyboard tap test' to measure their accuracy and speed of movement
- a 'scratch and sniff' style smell test, which we sent to them in the post

"Over the next three years we'll be asking all our participants to complete the online questionnaire and tapping test on a yearly basis. We'll also invite a selection of participants who score as 'higher' or 'lower' for Parkinson's risk to have a full clinical examinations and perhaps a new type of brain scan that uses ultrasound. Of the participants currently enrolled in the study, statistically only around 10 are likely to develop Parkinson's at some stage in the future.

"But if we can predict Parkinson's, we hope to one day have treatments for those in the early stages that could slow or prevent the condition progressing – which would be a major step forwards towards a cure."

# Over to you...

We're always keen to hear your thoughts on *Progress* magazine – and Parkinson's research in general. Here's the latest selection of your comments, thoughts and opinions.

## JOINING UP THE DOTS

I've read the latest issue a couple of times and am very impressed. In particular, I like the round-up on research, which covers a lot of studies in clear language (without giving me the feeling that I was being 'talked down to').

I'd been feeling a bit pessimistic about the prospects of a cure, or even a means of stopping progression, within the foreseeable future. When I was first diagnosed about eight years ago, there was a lot of optimism about the potential of stem cells, until that Korean researcher was exposed for falsifying his results. After that things went very quiet for a while: people seemed reluctant to publicise their work.

But more recently I have been on some of the visits to research projects which are organized by the Research Support Network and have met a number of researchers working with stem cells, so I'm starting to appreciate just how complex the job is.

Hence, it is heartening to read in *Progress* about how much is going on in other parts of the world.

Maybe the researchers and clinicians will start to join up the dots on the map soon – because as I see my intake of medication increasing every few months, I feel an increasing sense of urgency!

**Mark**

"Progress is very informative and a great asset. Makes me realise that a lot of people are working hard to improve the lives of people with Parkinson's. Thank you to all!" **Anonymous**

**LAST YEAR WE RECEIVED MORE  
THAN 700 QUESTIONS, COMMENTS  
AND MESSAGES ABOUT RESEARCH**

"Very readable, even to wrinkly ex-engineers!" **Richard**

## AN UNEXPECTED CURE FOR EYE PROBLEMS

Thanks for the latest *Progress* – fascinating as ever. I was particularly intrigued by the item about eye problems and Parkinson's.

I was plagued for several years by blepharitis (chronic inflammation of the eyelid) before I was diagnosed with Parkinson's. It's gone now, because 18 months after that diagnosis I had chemotherapy for lymphoma, which seemed to obliterate the blepharitis. Mind you, I wouldn't necessarily recommend a course of chemotherapy just to get rid of sore eyes!

**Chris**

# JOIN THE DISCUSSION

The discussion forum on our website provides the ideal place to talk about research, air your opinions and debate the latest hot topics.

## Effect of food digestion and protein

Over the last 30-40 years a lot of money has been spent on both trying to find a cure for Parkinson's and bringing new drugs to market.

I would like to see more money spent on research into finding a way to overcome the performance issues of current drugs in relation to protein and digestive interaction.

This is a major problem, particularly after you've been taking them for several years. Personally for me after 11 years living with Parkinson's I find this to be my number one concern.

What I would really like is a drug that gets to my brain without running the gauntlet of the digestive system or being impacted by me eating cheese on toast for my lunch.

On the few occasions these days my medication is not impacted by these problems I feel great and almost symptom free.

Maybe the drug companies should develop spray forms of drugs that you can inhale so it goes straight to the brain and not via your digestive system?

### A post by 'Blue-eyes' (forum member)

As other forum users pointed out, inhalable forms of levodopa are currently being developed and trials are underway testing a new medication to speed up stomach emptying.

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

## RESEARCH THAT RINGS TRUE

My favourite article from the last magazine was: 'Improving hospital care'. It was so relevant because of the dreadful experience my husband (and I) had when he was in hospital last year for three weeks.

The irresponsible approach to medication and the attitude to Parkinson's generally urgently need to change.

**Rosemary**

"I have always found *Progress* interesting but think it is a much more attractive read now. Well laid out, makes you want to read the articles and is definitely written in a way that makes it understandable to us all. Good mix of topics." **Anne**



## Keep the comments coming!

Please keep your suggestions, ideas and comments coming in and help us to make *Progress* magazine even better.

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

[research@parkinsons.org.uk](mailto:research@parkinsons.org.uk)  
0207 963 9326

# CHOOSING THE RIGHT RESEARCH

Every application for funding that we receive from researchers is strictly assessed by both scientific experts and people who are directly affected by Parkinson's.

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Together their views help us choose research projects that are excellent and original science, as well as meaningful and relevant to people living with the condition.

The Very Reverend Dr Wesley Carr has been a volunteer 'lay grant reviewer' for about 13 years. Here he explains how he got involved.

"I had just been appointed Dean of Westminster, one of the greatest responsibilities in the church, when the blow struck: I was diagnosed with Parkinson's.

"My wife Natalie saw an advertisement by the Parkinson's Disease Society (as it was then) for lay assessors of research grant applications. I've never been a sporty sort of person but having had a fairly academic career in the church, reading and writing come naturally to me – so I applied and have been involved ever since.

"Slowly but surely I feel I've developed an understanding of the application papers and a feel for the research. Reviewers are spread throughout the country reading applications from scientists working at the edge of research.

"The grants we assess range from the very large, costing many hundreds of thousands, and taper through to smaller projects and support for students doing PhDs.

## Dr Carr's top reviewer tips

### Confidentiality

All the applications we read are strictly confidential but in the end this comes down to personal honesty – nothing can be done to enforce it. You are trusted.

### Scoring

You are required to score each application even if you find it difficult. There are three scores: 1) suitable for funding, 2) suitable if funds become available, and 3) unsuitable for funding. These scores ultimately help decide which projects are funded.

### Support

In my experience the Parkinson's UK research team are very helpful. Lay reviewers can also support each other as we are put into groups and have contact by email, so we can discuss problems or things we don't understand.

"The instructions are pretty clear. With every application is a worksheet with various questions to answer. Researchers must include a summary of their project in plain English in their application. I find that those who struggle with that (and there are surprisingly many) often have a weakness in their application. It's always very interesting to hear the final decisions made by the board and why certain applications are successful or not.

"Would I encourage anyone to apply to become a 'lay reviewer'? If you can read quickly, and have enough time, give it a go. There is a lot



**Above:** Research Support Network members and researcher Dr Liz Hartfield, front right

of paperwork and you must be able to show that you can write your answer succinctly and swiftly. Can you get to the nub of an argument? It's certainly a splendid way to focus the mind. Advances in the understanding and treatment of Parkinson's will come through research.

But that will not be enough, however, if the experiences and views of those who live with the condition are ignored. Being a lay reviewer makes me feel part of a lively and purposeful enterprise. May it soon become redundant. Until then, back to the applications."

### Join our Research Support Network

Everyone can play an active role in our work towards a cure. Join our Research Support Network today and find out how you can:

- take part in research studies
- help us make decisions about the research we fund
- come to research events

- share your experiences with researchers to shape their work
- lend your skills, passion and interest to support Parkinson's research

### Find out more

Email [rsn@parkinsons.org.uk](mailto:rsn@parkinsons.org.uk), call 020 7963 9376 or visit [parkinsons.org.uk/researchsupportnetwork](http://parkinsons.org.uk/researchsupportnetwork)

# RESEARCH RESULTS

We keep a very close eye on the outcomes and results that come from all the research projects we fund. Over the next few pages (p22-28) we highlight the latest findings from six Parkinson's UK-funded projects from our researchers pictured below. They investigate everything from exercising using the Nintendo Wii to impulsive and compulsive behaviour. You can keep up with results from all the projects we fund on the website at [parkinsons.org.uk/researchresults](http://parkinsons.org.uk/researchresults)



An objective measure of dyskinesia

**Dr Stephen Smith**



Understanding impulsive and compulsive behaviour in Parkinson's

**Professor Paola Piccini and Professor Tony David**



Promising results from our Wii-habilitation study

**Professor Cathy Craig**



A diabetes drug with potential for Parkinson's

**Dr Peter Whitton**



Harnessing a hunger hormone to protect cells

**Dr Jeff Davies**

## An objective measure of dyskinesia

In a pioneering project at the University of York, a team led by Dr Stephen Smith are developing a new computer-based system that can measure involuntary movements (known as dyskinesia) automatically.

The project, supported by an innovation grant of £33,935 awarded in 2010, aims to help doctors to manage Parkinson's treatment more effectively.

### Keeping dyskinesia under control

Levodopa is one of the main drugs used to treat the symptoms of Parkinson's, but many people who take it go on to develop dyskinesia.

Accurate measurement of this troublesome side-effect will make it easier to adjust people's medication to ensure the benefits outweigh the problems.

### What the team are doing

The team recruited 10 people with Parkinson's to test their equipment. This involved wearing up to eight wireless sensors on their bodies as they went about their normal daily lives.

The researchers found they were able to measure people's movements accurately and without any discomfort, and they're currently processing all the information they collected.

The grant from Parkinson's UK helped the team to secure funding from the Leeds Teaching Hospitals Charitable Foundation to help take the project forward.

Stephen comments:

"Now we need to consider how best to give people with Parkinson's in the community the opportunity to benefit from this new technology.

"We hope our test could be used to give people with Parkinson's who experience dyskinesia a better quality of life."

**Below:** Wireless sensor monitoring dyskinesia



## What is dyskinesia?

Dyskinesia, or uncontrolled movements, is one of the main side effects of the Parkinson's medication levodopa. These are spasms or muscle movements that happen when you don't want them to. Although not everyone will experience this side effect, dyskinesia can make day-to-day life with Parkinson's even more challenging.

Matt from our online discussion forum says:

"I have dyskinesia pretty often ... and stress makes it worse. I sometimes have to use a straw if I need a drink otherwise I end up wearing it (the drink not the straw ... which is not the general idea!). It can be very awkward trying to move round particularly in public so I try and ride the twitches out before I venture into the public domain."

### Find out more

See our information sheet *Motor fluctuations in Parkinson's*. Our publications can be ordered for free or downloaded at [parkinsons.org.uk/publications](http://parkinsons.org.uk/publications)

## Understanding impulsive and compulsive behaviour in Parkinson's

Two groundbreaking studies have shed new light on the impulsive and compulsive behaviour that can be a distressing side-effect of some Parkinson's drugs.

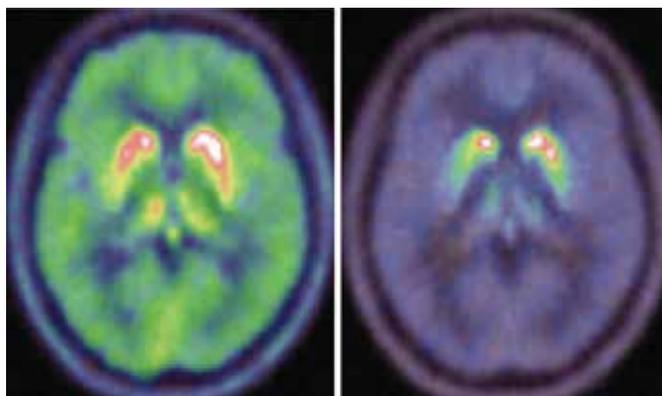
A team led by Professor Paola Piccini at Imperial College London found that some people may be more susceptible to developing these behaviours because of subtle differences in their brains.

And a complementary project at King's College London led by Professor Tony David was the first ever to show that a talking-based therapy can be beneficial.

These parallel studies were made possible by themed research funding of over £640,000 awarded in 2008 targeting this key challenge in Parkinson's research.

### What is impulsive and compulsive behaviour?

Impulsive and compulsive behaviour can include obsessive gambling, eating and shopping, or an increase in sexual thoughts and feelings. Some people can become addicted to their



**Above:** Brain scans showing dopamine in the brain. White areas have the most and blue the least.

Parkinson's medication, taking more than they need to control their symptoms.

Research has shown that around 17% of people with Parkinson's who take dopamine agonists and up to 7% of people who take other kinds of medication, including levodopa, may experience impulsive and compulsive behaviour.

Although only a relatively small number of people experience impulsive and compulsive behaviour, it can have a big impact on the person affected and those around them.

**Below:** Mark Robson, who has experienced impulsive compulsive behaviour, with wife Sam



## Reward gone awry

Paola's team at Imperial College found that people with impulsive and compulsive behaviour had subtle differences in the parts of the brain that respond to reward. This could be used to help doctors to spot people who may be at increased risk – potentially preventing problems before they start.

### Another side to dopamine

As well as helping to control movement, dopamine also plays a big role in the part of the brain that controls reward and motivation. Most Parkinson's drugs work by boosting dopamine signals in the brain. And researchers think this can cause some people to do things that give them an instant reward – even if it has harmful consequences.

The team showed people with Parkinson's with and without impulsive and compulsive behaviour pictures connected to feelings of reward – like food, gambling and sexual images – when they were in two different types of brain scanner.

They found that people with impulsive and compulsive behaviours responded differently to the pictures. MRI scans showed that certain parts of their brains were more active and PET scans showed that their nerve cells released more dopamine.

Paola explains:

“We showed that pictures are enough to trigger a response in the brain that could cause a person to behave differently. A real world example of a trigger could be TV adverts for online gambling.

“Our findings suggest that avoiding triggers could be one strategy to help people manage their impulsive and compulsive behaviour – although this hasn't been tested yet.”

The team are now exploring whether different types of impulsive and compulsive behaviour are linked to different changes in the brain.

### Reference

O'Sullivan SS et al (2011) 'Cue-induced striatal dopamine release in Parkinson's disease-associated impulsive-compulsive behaviours' *Brain*; 134:969–978

## Talking therapy can make a difference

People with Parkinson's who took part in the talking-based therapy trial were able to gain some control over their impulsive and compulsive behaviour, and reported lower levels of anxiety and depression. The level of strain felt by carers didn't improve as much as the team at King's College had hoped, but there were some small changes in the right direction.

### Managing impulsive and compulsive behaviour

Treatment for impulsive and compulsive behaviour usually involves reducing the dose of Parkinson's medication, or trying other types of medication. But it can be tricky to get the balance right between controlling the movement symptoms of Parkinson's and reducing impulsive and compulsive behaviour.

In this study, 45 people with Parkinson's and their carers were allocated a dedicated Parkinson's nurse with skills and experience in mental health. She visited them weekly at home for up to 12 weeks.

Half of the people started the therapy straight away, and the comparison group after a six month delay. Sessions included providing information, looking at beliefs and attitudes and identifying triggers to help both the person affected and their carer develop coping strategies. People were also encouraged to use existing services such as the local community mental health team, their GP and social services.

Tony describes the next steps:

“We need to look at our results in detail to figure out which elements of the treatment were most effective and for which problems. Then we hope to plan a larger trial – probably across a network of centres in the UK.”

### Find out more

See our information sheet *Impulsive and compulsive behaviour in Parkinson's*. If you're experiencing impulsive and compulsive behaviour, call our free and confidential helpline on **0808 800 0303** for support.



**Above:** Demonstrating the Nintendo Wii at the 'Keeping Active' Belfast event in April 2012

## Promising results from our Wii-habilitation study

In one of the first studies of its kind, a team at Queen's University Belfast have shown that using the Nintendo Wii to exercise could have real benefits for people with Parkinson's.

We awarded Professor Cathy Craig an innovation grant of £34,709 for this project back in 2010. We've had overwhelming feedback from people with Parkinson's who find that the Wii is a great way to exercise at home.

### About the Wii

The Nintendo Wii is a home video games console. It first went on sale in 2006 and it's estimated that half of UK households now own one.

Unlike conventional video games, Nintendo Wii uses a handheld remote control and a 'balance board' that you stand on.

Motion and pressure sensors detect arm movements or the way your weight shifts on the balance board, allowing you to control games on a television screen with your body.

The Wii may be particularly useful for people with Parkinson's because it can help to improve skills like hand-eye coordination and balance, not just fitness.

In this study, 19 people with Parkinson's played Wii Fit and Sports games at home for eight weeks – how often or when they played was up to them. A further 10 people tested a bespoke system in the lab.

Cathy answered the following key questions about the project:

### What inspired you to study this area of Parkinson's research?

"The evidence is growing for the benefits of regular exercise for people with Parkinson's. We wanted to find out if new technology that uses real body movement to control onscreen games can provide a new, fun way of encouraging people with Parkinson's to be more active.

### What were your goals for the project?

"Our main goal was to see if playing activity-based games on the Nintendo Wii over a period of time can improve balance and general wellbeing – symptoms that aren't improved by Parkinson's drugs.

"We also looked at patterns of behaviour to find out if people with Parkinson's enjoyed and engaged with the system – at the same time looking for ways to improve it.

### What have you found?

"We showed that playing on the Wii can improve balance in people with Parkinson's. This led to improvements in walking, posture and flexibility – one person said they felt like they were 'peeling off the layers' of Parkinson's.

"We also found that playing these games made everyone feel more positive and energetic. For some people it made a real difference in their confidence. Many people said it made them realise how much they can still do, allowing them to forget about their Parkinson's.

### What are the next steps?

"We hope to be able to monitor levels of activity when playing games through smartphone technology and develop a prompt system that will encourage people to exercise.

"Future research should focus on creating guidelines for people with Parkinson's on how to use this technology to maximise the health benefits.

### How will your research help people with Parkinson's?

"Our study has shown that using the Wii can have a real impact on the lives of people with Parkinson's. This interactive and fun way of exercising is something that can be done with friends and family, helping to boost confidence, mood and wellbeing."

#### Find out more

Visit [parkinsons.org.uk/wii](http://parkinsons.org.uk/wii) for information about Parkinson's and the Wii, including personal stories and guidelines for using the Wii Fit balance board.

**Below:** John Crossley uses the Nintendo Wii



## A diabetes drug with potential for Parkinson's

A recently completed project at University College London has shown that the diabetes drug exenatide can improve symptoms and rescue dying nerve cells in two rat models of Parkinson's.

The three year project was funded by a grant of £171,671 awarded to Dr Peter Whitton. Now, exenatide is being tested in a small phase two study of 40 people with Parkinson's at University College Hospital in London.

### What is exenatide?

Exenatide originates from the saliva of the venomous lizard the 'Gila monster' which is native to southwestern America and Mexico. It's already used by people with diabetes to help control their glucose levels. The drug can also cross from the blood into the brain, and seems to act as a 'growth factor' – supporting nerve cells and helping them survive.

Peter explains:

"We think exenatide works through a combination of protecting existing nerve cells and possibly even stimulating the growth of new ones. We're currently developing a new animal model of Parkinson's which we hope will help us understand this better."

### New uses for old drugs

Investigating drugs that are already used for other conditions is proving to be a fruitful area for Parkinson's research. These drugs are already proven to be safe so they can move through to testing quicker. This approach – known as drug repositioning – is a key focus for Parkinson's UK. Other important work we've funded includes investigating iron removing deferiprone, which is now also being tested in people with Parkinson's.

### Reference

Rampersaud N et al (2012) 'Exendin-4 reverts behavioural and neurochemical dysfunction in a pre-motor rodent model of Parkinson's disease with noradrenergic deficit' *British Journal of Pharmacology*;167:1467-79

## Harnessing a hunger hormone to protect nerve cells

Researchers at Swansea University have shown that boosting levels of a stomach hormone called ghrelin can protect nerve cells and reduce movement problems in a rat model of Parkinson's.

This project, funded by an innovation grant of £34,939 awarded to Dr Jeff Davies in 2010, highlights the potential of using eating patterns to slow the progression of Parkinson's.

### Why ghrelin?

Ghrelin is released into the bloodstream when the stomach is empty. It travels to the brain to signal that it's time to eat, and is one of the ways that our body regulates appetite. Research suggests that ghrelin can protect the nerve cells that are lost in Parkinson's.

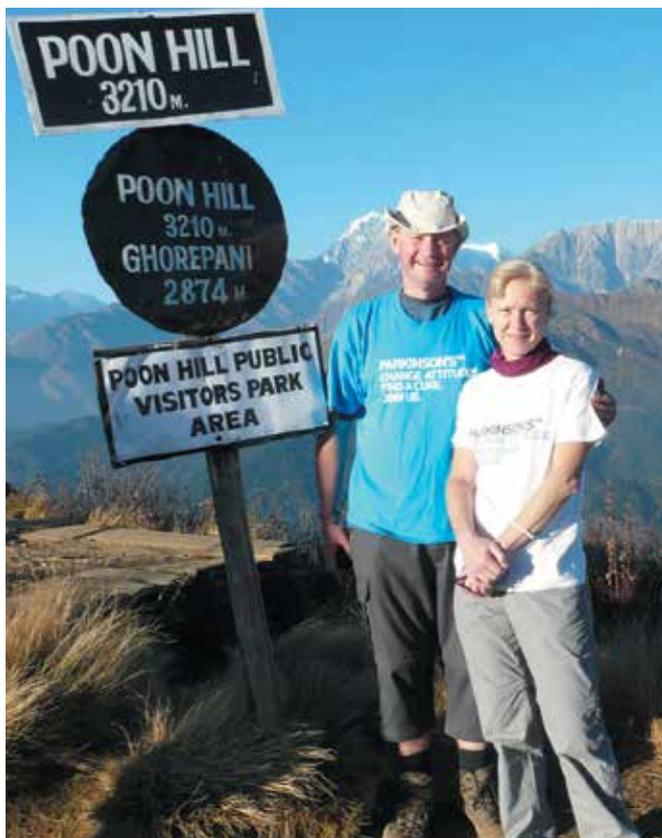
Eating meals at regular intervals enhances the natural rhythm of ghrelin in the blood. So Jeff wanted to investigate the effects of a strictly controlled eating pattern in rats with Parkinson's. To find out if high levels of ghrelin bring even greater benefits, some rats were given ghrelin continuously through a pump.

### What the team found

Rats given regular meals had less problems with movement compared to rats that ate constantly throughout the day. But a continuous supply of ghrelin worked even better – protecting nerve cells and preventing movement problems altogether. The team also showed that ghrelin can protect living nerve cells in a dish from the effects of harmful chemicals.

Jeff looks to the future:

"We're working with a drug company to find out if ghrelin works in other models of Parkinson's. If it does, it's more likely to work in people with the condition. Drugs that mimic the effects of ghrelin in the body are already being developed, and have passed early safety tests in people. We hope our research will ultimately lead to a clinical trial to find out if these drugs are safe and effective for people with Parkinson's."



# CONQUER THE SUMMIT

Mount Toubkal is North Africa's highest peak. It forms part of the High Atlas Mountains, which run south west through Morocco.

In September 2013 a team of supporters will trek steep, rocky terrain to reach the summit of Mount Toubkal at 4,167m – raising thousands of pounds for research along the way. Roddy Lee, who was diagnosed with Parkinson's in 2007, has taken part in several overseas adventures for us:

"I trekked 100 kilometres through the Sahara desert in 2009, around part of the Annapurna Circuit in Nepal in 2010 and trekked through Jordan to reach the ancient city of Petra in 2012.

"I did all of these events to raise funds for Parkinson's UK. I enjoy taking part in overseas events and knowing that the funds I raise go towards vital research to help find a cure for Parkinson's makes every mile worthwhile."

## Are you up for the challenge?

The sponsorship from Trek Toubkal (2-7 September 2013) is going directly to fund Parkinson's research, but if this challenge does not suit you we have plenty of other exciting overseas adventures lined up for 2013:

- **Cycle London to Paris: 4-8 September**
- **Trek Nepal: 9-19 November**
- **Cycle Rajasthan: 23 November-2 December**

## Find out more

To find out more about all our overseas trekking and cycling challenges, call the Events team on **020 7932 1356**, email [events@parkinsons.org.uk](mailto:events@parkinsons.org.uk) or visit [parkinsons.org.uk/overseas](http://parkinsons.org.uk/overseas)



**Above:** Roddy Lee and photos from previous treks

**Pictured:** Sheila Roy, left, with branch and volunteer support officer Lorraine Chilton



# INSIDE A CLINICAL TRIAL

Sheila Roy is one of fifteen people in the world who have had an innovative new gene therapy treatment for Parkinson's as part of a clinical trial. Here Sheila tells us about her experience in the trial and how life has changed for her.

I've had Parkinson's for 17 years, and in 2011 it was getting to the point where I couldn't actually function. I was referred for deep brain stimulation because I was having so many problems. That was the first time that I heard about gene therapy because they were looking for a few people to try it as part of a research project.

The difference in this treatment from anything else that's been around for the last 45 years is that it aims not just to replace dopamine artificially (as current drugs do), but to get your own brain cells to produce dopamine themselves. As soon as I heard about the study I felt that it was something very different and something that I was very keen to do.

## **Taking part**

Before I could take part I had to go through all sorts of tests to make sure I was a suitable candidate for the treatment. The operation itself involved having six needles inserted into my brain and took 11 hours.

Many of my friends thought it was too risky. And now I look back on it I probably should have been more scared. But I did it without hesitation because I was so sure that it was the right thing to do.

Since the operation, I've had to make frequent visits to the hospital for tests – brain scans, x-rays, blood tests, neurological tests, memory tests and many more. Each time I have to come off all my medication for two days and those two days are real 'cold turkey'. It's a very difficult thing to do but that was my part of the bargain and part of being in a clinical trial.

### Making progress

Since having the gene therapy, the most important thing to me is that I'm beginning to see a glimmer of the person I used to be.

I used to have a very bad tremor and that has completely disappeared. It's made a big difference to me in terms of how I communicate. I'm much more confident, my mood has lifted and I feel much more sociable. I'm also sleeping much better and having fewer falls since having the treatment.

I've gone from seven hours to eleven hours a day when I'm 'on' – when my drugs are working and I'm fully functional. So now most of my day is active and it makes such a difference.

Most excitingly I have been able to reduce my medication from ten tablets a day to six or seven over the last year – and I hope to continue improving and reducing my drugs.

### Not a cure

While many things have improved I'm certainly not cured – anyone can see that just by looking at me, and I still have problems.

I still sleep badly, can't turn over in bed and have terrible nightmares. I also still have problems with uncontrolled movements (or dyskinesia) and they're very difficult to deal with. But the dyskinesia is partly because I'm not just relying on my medication for dopamine now – the cells in my head are producing their own too. So it's about reducing my drugs so that I get the right balance of dopamine inside my brain.

### Hope for the future

One question that people ask me is 'would I do it again?' – and I would, I'd do it again tomorrow. It's not a cure or a miracle. And it may not solve everyone's problems but it may solve a few. It has certainly made a difference for me.

With Parkinson's you tend to feel like you're going downwards but for the last six months I've felt I've reached a plateau and in the last few weeks I feel I'm improving for the first time. And it gives me hope that one day it will be possible to turn this condition around.

There's never been a time like this for having a chronic condition because there's so much investment and so many discoveries.

Gene therapy could be the first of a new range of treatments for Parkinson's. So cross your fingers and hope that they come up with a few more.

## What is gene therapy?

Our genes are the instruction manuals that tell our cells what to do to keep us alive and well. The idea of gene therapy for Parkinson's is to insert specific genes into cells that aren't working properly – to help them work better or perhaps prevent them from dying.

There are a number of different types of gene therapy currently being tested in people with Parkinson's. The trial Sheila is involved in is testing ProSavin – a gene therapy that works by adding three genes nerve cells need to make dopamine (the chemical that is lost in the brains of people with Parkinson's). The early results for ProSavin look promising but larger, longer trials are needed to further explore this exciting treatment.

We're keeping a close eye on the ProSavin studies and will highlight any opportunities to take part on our website: [parkinsons.org.uk/researchstudies](https://parkinsons.org.uk/researchstudies)

# COLLABORATION IN ACTION

Our mission is to find a cure and improve life for everyone living with Parkinson's. It's a huge challenge and not one that we can tackle alone. That's why we're working with other charities and partners to accelerate the pace of discovery and the development of new therapies. In this article we explain how teamwork is bringing us closer to a cure for Parkinson's.

## The Cure Parkinson's Action Group

Nick Johnston is a merchant banker who has spent his entire career either working for, or with, healthcare companies. He co-founded a company exploring therapies for cystic fibrosis as well as working with companies, both large and small, to bring new therapies to patients.

"The Cure Parkinson's Action Group (CPAG) has been set up to support Parkinson's UK on its strategy to achieve greater collaboration and cooperation in all areas of Parkinson's research.

"The group brings together different members of the Parkinson's community, including people living with the condition, clinicians, regulators and other interested parties – including colleagues from The Cure Parkinson's Trust.

"Together we discuss how best to fulfil Parkinson's UK aim of generating broad and comprehensive research, and facilitating an environment to find, or funding the research of, a cure for Parkinson's.

"I became involved to provide insight and perspectives from the broader healthcare industry, as well as to provide ideas on how the Parkinson's community can work together to improve research in the UK, especially at a time when competition for funding is so high.

"At the moment we're focusing on:

- improving the quality of information about research which is available to people with Parkinson's

- increasing participation in clinical trials
- encouraging more research into Parkinson's both in the UK and worldwide

"As Parkinson's UK continues its tireless work in many different areas, I believe CPAG will play a vital role in the pursuit of the common goal: finding a cure for Parkinson's."

### Did you know?

We teamed up with the Lewy Body Society last year to fund two new innovation grants exploring Lewy body dementia.

## Improving access to clinical trials

Dr Kay Julier, our research liaison manager, works with researchers and other organisations to improve access and involvement in Parkinson's research studies.

Kay explains how we're working with the Michael J. Fox Foundation to make it easier for people with Parkinson's to take part in clinical research.

"It can be hard to find clinical trials that need someone with your specific medical history. We're working with the Michael J. Fox Foundation and other organisations, to make it easier for people with Parkinson's to take part in research. Fox Trial Finder, a new clinical trial matching tool developed by the Michael J Fox Foundation, allows you to register information about yourself and your Parkinson's then it looks for trials in your area which are looking for people like you.

It was launched in the UK in April 2012 and we are keen to hear from people who have registered. Hearing about your experiences with Fox Trial Finder will help to optimise the tool for the future.”

### Did you know?

We're learning more about Wikipedia and hoping to improve the the quality of information about Parkinson's it provides.

## A voice in Europe

Dr Kieran Breen, our director of research and innovation, represents us on a wide range of committees, providing a vital voice for Parkinson's research both in the UK and international arenas.

Here, Kieran explains how our involvement with the European Parkinson's Disease Association is making sure that Parkinson's research remains a real priority throughout Europe.

“The EU and its policies have a huge impact on research here in the UK. So joining forces with the European Parkinson's Disease Association (EPDA) is vital to making our voice heard throughout Europe. Last year, we represented the EPDA during the development of a new European research funding programme for neurodegenerative conditions. This will help to coordinate and streamline Parkinson's research within Europe and help ensure that Parkinson's is included in the upcoming EU five-year research plan called Horizon 2020.”

## Joining forces with other charities

Becky Purvis, is head of policy at the Association of Medical Research Charities – which brings together over 100 member charities and partners in the UK to work towards common goals.

Here, Becky explains how campaigning on research issues with one united voice is changing the UK research landscape:

“Working together makes a difference. Recently we joined forces to feed into the plans to change the NHS, and we now have a national health system with research at its heart. Every part of the NHS now has a duty to promote research, and patients can expect more and more opportunities to be involved in research and benefit from the results. But our work isn't finished. As these changes are made, we are working together to ensure research is built-in throughout the health service.

“The strength of working together, with recognisable names like Parkinson's UK, reinforces all our individual messages and means we can make change happen and ensure every penny donated goes as far as possible to improve healthcare.”

### Did you know?

We save on the costs of funding our Brain Bank by sharing the same research facility and dedicated team of staff with the MS Society Brain Bank.



# DR JAMES PARKINSON – MEDICAL PIONEER

Dr James Parkinson (1755–1824) was the first person to recognise Parkinson's, in his *Essay on the Shaking Palsy*, published in 1817. A pioneer not only in medicine but also in his science and politics, James Parkinson's achievements continue to inspire researchers today.

The son of an apothecary and surgeon, James Parkinson was born on 11 April 1755 (the reason for Parkinson's Awareness Week in April each year). James Parkinson studied at the London Hospital Medical College, qualifying as a surgeon when he was 29. He lived most of his life at 1 Hoxton Square, Shoreditch, London, where he also practised medicine. A commemorative blue plaque can be seen on the house that now stands on the site.

## The 'Shaking Palsy'

James Parkinson was an active member of the medical community in London. He wrote papers, pamphlets and several books advising on health and medicine, but his outstanding contribution to medical science was his *Essay on the Shaking Palsy*. In this famous essay, James Parkinson was the

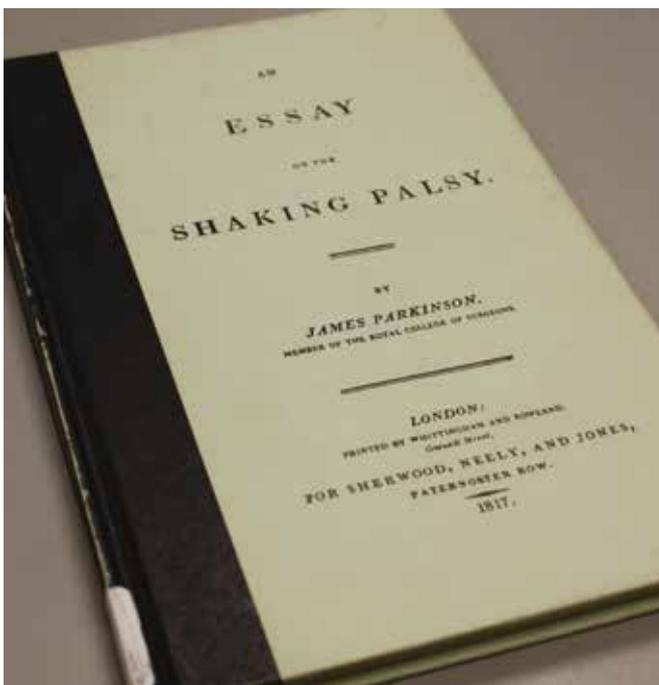
first person to set out a clear description of the condition, which still holds true today. This was based on observation of six cases he had either met in his own practice or seen during walks in his neighbourhood.

## An inspirational figure

Parkinson's UK-funded researcher Dr Patrick Lewis published an article in the *Journal of Parkinson's Disease*, describing the life and career of James Parkinson, in September last year:

"I was inspired to write about James Parkinson after reading his famous essay. I think James Parkinson would marvel at the progress that has been made in diagnosing, understanding, and treating the condition that now bears his name.

"But I'm sure he'd be surprised and disappointed to discover that, almost two centuries after his essay, we are yet to find a cure for this devastating condition. Working as a Parkinson's researcher myself, I find learning about the history of the condition, how far we've come and how much we still need to do really motivating."



## Find out more

Read more about James Parkinson's remarkable life at [parkinsons.org.uk/jamesparkinson](https://parkinsons.org.uk/jamesparkinson)

## Reference

Lewis P (2012) 'James Parkinson: the man behind the Shaking Palsy' *Journal of Parkinson's Disease*;2:181–187.

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## Helpline

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18001 0808 800 0303 (Text relay for text phone users)

[hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)

The helpline is open Monday to Friday 9am–8pm,

Saturday 10–2pm

\*calls are free from UK landlines and most mobile networks

## Regional and country teams

For details of our regional and country teams, visit

[parkinsons.org.uk/regionalteams](http://parkinsons.org.uk/regionalteams) or call our helpline.

## Information and support workers

For details of your local Parkinson's UK information and support worker visit [parkinsons.org.uk/isw](http://parkinsons.org.uk/isw) or call our helpline.

## Parkinson's UK local groups

For details of your nearest group visit

[parkinsons.org.uk/localgroups](http://parkinsons.org.uk/localgroups) or call our helpline.

## Research support network

You can find out more our research support network at [parkinsons.org.uk/researchsupportnetwork](http://parkinsons.org.uk/researchsupportnetwork) or by getting in touch with us at [rsn@parkinsons.org.uk](mailto:rsn@parkinsons.org.uk) or by calling 020 7963 9326.

## Publications

Available online at [parkinsons.org.uk/publications](http://parkinsons.org.uk/publications) or by getting in touch with us on 0845 121 2354.

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Don't forget you can also find *Progress* online at [parkinsons.org.uk/progress](http://parkinsons.org.uk/progress)

Progress is produced by the Parkinson's UK Research and Innovation team in collaboration with the Resources and Diversity team.

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