

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

# PROGRESS

The research magazine of Parkinson's UK  
Issue 18 Spring 2016

Unlocking new  
and better treatments

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# WELCOME

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This issue our welcome comes from research supporter Simon Cran-McGreehin whose father has had Parkinson's for 20 years. Simon has been involved with our Research Support Network for four years.

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This edition of *Progress* is packed full of fascinating articles about research into Parkinson's. I'm particularly excited about a new initiative called the Critical Path for Parkinson's.

In this issue, we hear more about how this new collaboration with academics and pharmaceutical companies could make clinical trials faster, cheaper and more likely to succeed in finding new treatments for Parkinson's.

This is so very important to all of us affected by Parkinson's – we all want to see more effective treatments that can slow down the condition, or even reverse it. That is the big challenge that Parkinson's UK is trying to overcome – it is the charity's ultimate aim. But I've learned from staff at the charity that this is a very tricky problem.



Simon's father introduced him and his wife, Alexandra, to hill-walking in Scotland.

Since dopamine was first used as a treatment over fifty years ago, there have been no major drug breakthroughs. And that's not for want of effort – committed researchers have tried so hard so many times, but promising new drugs kept failing at the final hurdle.

The drugs didn't prove their benefits in clinical trials, and so were not approved for use. In the end sadly many pharmaceutical companies thought that it was hopeless to try any more.

The problem might not be with what drugs are tested, but how they are tested. For example, it is now known that there are different types of Parkinson's, some of which may not respond to some drugs. So if drugs had been tested on only certain types of Parkinson's then the results might have been different.

This is where the Critical Path for Parkinson's initiative comes in. The partnership will bring together experts to share data and design better clinical trials that take into account the complexity of Parkinson's.

This is good science but it is also good business: if clinical trials can be faster, cheaper and more likely to succeed then pharmaceutical companies will return to continue the search for better treatments.

I hope that you enjoy reading this issue of *Progress*. And, remember, if you want to learn even more about Parkinson's research, how you can take part in trials of new treatments and contribute to work that makes a difference, please join the 2,000 (and growing!) members of the Research Support Network!

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

# INTERNATIONAL NEWS ROUNDUP

We scan the horizon for all the latest developments in Parkinson's research across the world. Here are some highlights from the last few months.

## Innovative cell therapy moves to next stage of trials

In February, Australasian company Living Cell Technologies received approval to take their innovative cell therapy – which is called NTCELL – into the next phase of testing in people with Parkinson's.

NTCELL is a specially coated capsule of cells that is transplanted into the brain. After transplantation, cells in the capsule produce proteins called growth factors that help brain cells to grow and repair themselves. The hope is that this therapy could halt the progression of Parkinson's.

NTCELL was first tested in four people with Parkinson's in 2015 and this small scale study showed that this approach seems to be safe. Now the company have been granted approval by the authorities to start the next phase of trials in 2016.

Despite this research taking place on the opposite side of the world, we're keeping a close eye on progress and will report any further developments in future issues of *Progress* magazine.

You can find out more about NTCELL on the company website:  
[www.lctglobal.com](http://www.lctglobal.com)

## New stem cell study helps explain spread of Parkinson's

In February, our scientists at the Parkinson's UK-funded Oxford Parkinson's Disease Centre announced the discovery of new clues as to how Parkinson's spreads from cell to cell.

Alpha-synuclein is a naturally occurring protein that is believed to play a central role in the spread of Parkinson's.

The research is the first to link the release of this protein with the most common genetic risk factor in Parkinson's – GBA1.

Professor Richard Wade-Martins, Head of Oxford Parkinson's Disease Centre, explains:

"We already know that Parkinson's may spread when alpha-synuclein escapes from affected cells into the brain, where it can then get taken up by other cells. Thanks to this study, for the first time we know how the protein is released, giving us new clues on how this spread happens. Most importantly, these findings open up new avenues into investigating potential new therapies or treatments that could stop the spread of alpha-synuclein and slow the condition's progression."

[parkinsons.org.uk/  
researchnews18feb2016](http://parkinsons.org.uk/researchnews18feb2016)

## Take part in 100 for Parkinson's

A new global study launched in February to find out if daily health tracking using smartphones can improve the quality of people's lives.

The 100 for Parkinson's project will collect anonymous data to help improve our understanding of Parkinson's and shape future research. To succeed, the project needs both people with and without Parkinson's to record their activities for 100 days. It will be the largest study of this type – collecting data on the lives of 100,000 people. The app has been designed by uMotif, a UK digital health startup, and can be downloaded on a smartphone or tablet. As well as collecting data, it provides people with the tools to record and manage their own symptoms and wellbeing. To find out more and take part, visit our website using the link below:

[parkinsons.org.uk/researchnews25feb2016](http://parkinsons.org.uk/researchnews25feb2016)

## Dyskinesia drug moves closer

In December, US pharmaceutical company Adamas announced positive findings from a late stage clinical trial of extended-release amantadine.

People with Parkinson's who took the drug experienced less dyskinesia compared to people who received a placebo. Amantadine is already available as a treatment for Parkinson's and is sometimes used to help manage uncontrollable movements – known as dyskinesia – alongside other Parkinson's medications. However, in its current form the drug has only a mild benefit and its effectiveness may be short-lived. On the back of these positive results, Adamas now hope to get approval from the regulatory authorities to make this new longer-acting form Amantadine available to people with Parkinson's. You can find out more on the Adamas company website: [www.adamaspharma.com](http://www.adamaspharma.com)

## News in brief

### Milk, pesticides and Parkinson's

A study published in December suggested a link between pesticides in milk and the development of Parkinson's. Our Clinical Director, Professor David Burn commented on the results and emphasised that people certainly should not be concerned that drinking milk will give them Parkinson's.

### Human mini-brains to speed up research

*The Telegraph* reported on tiny human mini-brains which have been created by scientists to speed up cures for Alzheimer's and Parkinson's. The mini brains, which are around the size of an insect eye, contain human brain cells and even show evidence of electrical activity.

### Could saliva help detect Parkinson's?

US research has shown that testing a portion of the glands that produce saliva may be an avenue to diagnosing early Parkinson's.

### A glove that can reduce tremor

A drug-free alternative to treat Parkinson's tremor could be on the horizon – in the form of a glove. The proposed GyroGlove is being developed by a team at Imperial College London and uses the laws of physics – rather than chemistry – to stabilise and control tremors mechanically.

### Super material graphene safe to use in brain

The discovery of graphene won the Nobel prize for physics in 2010. Now researchers have shown that this super material can be safely used to make electrodes that can be implanted in the brain. This could be used in future to improve treatments like deep brain stimulation for Parkinson's.

Keep up with all the latest research news as it happens by joining our Research Support Network: [parkinsons.org.uk/rsn](http://parkinsons.org.uk/rsn)



Clinical  
trials

# A FUTURE OF BETTER CLINICAL TRIALS

In recent years, a number of promising treatments for Parkinson's have failed to show benefits in clinical trials. But is this because the treatments don't work or due to the way the trials were designed?

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## What are clinical trials?

Clinical trials are used to prove the safety and effectiveness of new treatments and therapies by carefully testing them in people.

There are multiple phases of clinical trials that a treatment must pass through before it is made available to people. These phases individually take years and together can take decades. Clinical research is often the most expensive part of research into new treatments, and the vast majority of clinical trials are conducted by large pharmaceutical companies who can afford to invest in these studies.

Ultimately the aim of a clinical trial is to provide enough evidence that a treatment is safe and effective to get it officially approved. Regulatory organisations, such as the European Medicines Agency, will decide if there is sufficient evidence to approve the new treatment for use in people.

If there is insufficient evidence of the benefit of a new treatment then further clinical trials will be required, slowing down the delivery of treatments to the people who need them and possibly making them more expensive.

## Phases of clinical trials

### Phase 1

New treatments are given to a small number of people to test safety and investigate the best dose. While the safety of the treatment will have been tested previously in other ways, this will be the first time it is tested in people.

### Phase 2

Treatments are tested on people who have the condition to see if they can have a beneficial effect.

### Phase 3

For the final stage of clinical trials, a treatment must demonstrate that it is safe and effective in a large number of people. Phase 3 clinical trials often take place over extended periods of time and are very expensive.

## Investing in clinical trials

There are lots of potential treatments that could progress into clinical trials, but the large investment of time and money required to complete clinical trials means that pharmaceutical companies only take forward the most promising research.

Not all clinical trials are successful and during difficult economic times, when money is tight, drug companies are even more selective about picking the best research to take forward.

Additionally, Parkinson's research is seen as a difficult area. There is a very poor track record as a number of potential new treatments for Parkinson's that have failed at the final hurdle. This now deters investment into even very promising Parkinson's research.

But we, and many others in the research community, believe the problem may not be that the drugs don't work but that there are problems with how the clinical trials are designed. If these problems can be overcome then there could be a higher chance that clinical trials will succeed, and companies will be more willing to invest.

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“As Director of Research and Development at Parkinson's UK, one of the questions I hear most often from our supporters is: ‘Why have there been no new treatments for Parkinson's in the last several years?’ – it's a very good question and not one with a simple answer. But the most pressing reason is that the clinical trial process for Parkinson's treatments simply isn't up to scratch.”

**Dr Arthur Roach**

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## A second chance

When clinical trials fail it can mean that treatments with real promise get discarded or shelved for long periods of time.

You may be aware of our current clinical trial of GDNF – a treatment we believe has the potential to slow the course of Parkinson's.

But you may not be aware of GDNF's history. The first small trial of GDNF for Parkinson's was actually carried out over a decade ago and produced extremely positive results.

This led to larger follow-up trials being carried out, which unfortunately produced inconclusive results.

Although these may have been due to problems with the way the drug was delivered, GDNF was shelved while researchers focused their efforts on other treatments they considered easier and more promising.

Luckily for GDNF, it is getting a second chance in our current trial and we expect to be able to share the results towards the end of 2016.

Find out more about the trial at [parkinsons.org.uk/gdnf](http://parkinsons.org.uk/gdnf)

## How we're improving clinical trials

The answers to better trials may already be out there. Lots of clinical trials and studies have generated huge amounts of valuable information and data about Parkinson's. We believe this data could hold the key to designing better clinical trials. But we are not making the most of it.

### Bringing it all together

We're partnering with the Critical Path Institute – an American non-profit organisation that specialises in developing tools to make clinical trials more efficient and effective. Together, we will bring all the key players together to share their data, expertise and ideas for making clinical trials for Parkinson's better.

If successful, the Critical Path for Parkinson's will make clinical trials for Parkinson's faster, cheaper and more likely to succeed. This should encourage more drug companies to invest in developing new treatments for Parkinson's and ultimately help us achieve our mission to deliver new and better treatments in years, not decades.

## Who are we working with?



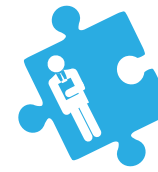
### Drug companies

Seven major drug companies have joined us and will be sharing their data and expertise.



### Parkinson's researchers

We're working with leading Parkinson's researchers, including the teams behind our major studies who will be contributing their data.



### Regulatory authorities

We will consult with regulatory agencies every step of the way, as they ultimately need to approve the use of the new tools we develop.

# 1 PROBLEM



## DIAGNOSING PARKINSON'S

It may sound surprising but we believe that around one in 10 people involved in clinical trials may not have Parkinson's at all. They are unlikely to respond to the treatment which means the results of the trial are skewed.

This could lead to perfectly viable treatments being unfairly discarded. Diagnosing Parkinson's is especially challenging in the earlier stages.



There is a type of brain scan that may be able to help especially in the early stages. But these scans are not currently used in clinical trials to rule out people who don't have Parkinson's.

Critical Path for Parkinson's will bring all the evidence together to persuade regulators that brain scans should be used to select people who take part in clinical trials – making trials more likely to succeed.

# SOLUTION

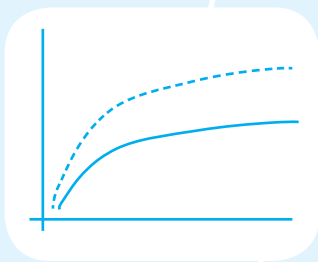


## 2 PROBLEM

### PREDICTING PROGRESSION

Many new treatments being developed for Parkinson's aim to slow the course of the condition.

But it's notoriously challenging to predict how Parkinson's will progress over time. Because we can't predict how Parkinson's would have progressed without treatment, it's tricky to say whether or not a treatment has made an improvement.



### SOLUTION

The Critical Path for Parkinson's will gather information from all over the world to develop a model for predicting the progression of Parkinson's in clinical trial groups.

Using this model, researchers will be able to predict how Parkinson's symptoms would develop for a group without treatment over a set time and compare with actual progression. This will provide proof that the new treatment works.



## 3 PROBLEM

### CHOOSING THE RIGHT PARTICIPANTS

Scientists increasingly believe that Parkinson's is not a single condition, but rather a large number of different conditions with similar symptoms. This means that a drug that helps one person may have no effect on someone else. But for a treatment to be approved it must be effective on a certain proportion of people involved in a clinical trial.

To give a clinical trial the greatest chance of success, we need to be able to choose the right people for the right trials.

Data from previous studies will be used to produce computer simulation tools that will help researchers recruit people that have the type of Parkinson's that is most likely to respond to the new treatment.

### SOLUTION



# Over to you...

We love hearing your feedback on *Progress* magazine and Parkinson's research in general. Here are some of your latest comments, thoughts and opinions on our work.

## FAITH AND PARKINSON'S

I really appreciate receiving the *Progress* magazine and learning about all the work going on into trying to find a cure for those of us who have Parkinson's. I was diagnosed four years ago at the age of 51 and it has been hard to come to terms with.

I was particularly interested in the article on faith in the last issue as I am a Christian and I definitely feel that has helped me to keep going. About two years in I told people at church as my tremor was much more noticeable. Most people are helpful and that makes a difference. Just something like carrying a cup of tea without having to be asked makes a difference when juggling stick, bag, etc.

**Alexis Hardy**

## PRAISE FOR PROGRESS

I just wanted to drop you a quick line to say how brilliant I think *Progress* magazine is! Seriously, I think it's amazing and makes the often somewhat intangible world of research much more accessible to the average layperson like me. Ever since I was 17 (I'm 32 in two weeks), I have lived knowing that a 'cure' for Parkinson's was a long way off and wasn't going to happen in my dad's lifetime. That didn't stop me wanting research to progress so other people don't have to go through what my dad did. I know we're still a long way off from controlling, stopping and maybe even reversing Parkinson's but this latest edition of *Progress* magazine helped to fill people with hope, whilst not over-promising anything.

**Jenny Pearce**

I felt I had to write to congratulate the team for the autumn issue of *Progress* – it really is excellent, a model of clarity and right on the nail!

**Ken Bowler**

## PARKINSON'S IN THE GUT

I found the Autumn 2015 *Progress* extremely interesting. One article questioned whether Parkinson's originated from the gut and I wonder if this could be connected with hernia operations of which I have had several and due for another in a week?

**Mal**

We are pleased to hear you found *Progress* interesting. At the moment, there does not seem to be any evidence of a connection between hernia operations and Parkinson's. However, research into the connections between the gut and Parkinson's is still in its very early stages so there may still be something in this.

### Have something to share?

You can find out how to get in touch or fill in our *Progress* survey on page 30.

# DRUG REPURPOSING IN ACTION

How long do clinical trials take? In the case of nilotinib (Tasigna), the leukaemia drug, it is already in the market. So how long should that take – all going well of course?

## **Post from JB78 on our online discussion forum**

There is no standard length of time for a drug to complete clinical trials. It varies depending on both the drug, and the types of trials needed to confirm that it is safe and effective.

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

We're convinced there are already drugs on pharmacy shelves with hidden benefits for Parkinson's – and nilotinib is great example.

It has already been through clinical trials and is available for the treatment of leukaemia, so we know a lot about this drug already.

Back in October, an exciting study suggested the potential for this cancer drug to help with the symptoms of Parkinson's.

There still needs to be further trials to demonstrate nilotinib is safe and effective in Parkinson's. But if it all goes well, this drug may be available within two to five years.

Repurposing drugs for Parkinson's means they can be moved more rapidly into clinical trials, and could be made available much more quickly, easily and cheaply.

We are currently working with other charities government and regulatory bodies to help make repurposed drugs available to those who need it as quickly and safely as possible.

Find out more about how you could help us find new prospects for repurposing by filling in our survey: [parkinsons.org.uk/repurposingsurvey](https://parkinsons.org.uk/repurposingsurvey)



# NEW RESEARCH PROJECTS

We introduce some of our very latest research projects. You can find all our projects on our website at [parkinsons.org.uk/currentresearch](https://parkinsons.org.uk/currentresearch)

## Exploring anxiety in Parkinson's



Developing treatments

### Who?

Professor Richard Brown

### Where?

King's College London

### What?

£140,616 over two years

Everyone feels anxious from time to time, but severe anxiety can be distressing and interfere with sleep and daily activities. Around half of people with Parkinson's have trouble with anxiety, and for one in four it is severe enough to require treatment. Current treatments for anxiety are far from perfect. Many people prefer not to take medication, and psychological therapies such as cognitive behavioural therapy (CBT) are often difficult to access.

In this project, Richard and his colleagues will investigate whether people with Parkinson's could benefit from an innovative new computer-based therapy for anxiety. This type of therapy has been shown to be effective for other people who experience anxiety. It would be much easier for people with Parkinson's to access than current treatments for anxiety, and much cheaper for the NHS. If Richard's project is successful, he hopes it will lead to large-scale trials of this promising new therapy for people with Parkinson's.



## Astrocytes – a route to better treatments for Parkinson's?

**Who?** Dr Laura Ferraiuolo

**Where?** University of Sheffield

**What?** £50,000 over 20 months

The majority of research in Parkinson's is focused on dopamine-producing cells – the particular cells that are lost in the brains of those who have the condition. These cells play a vital role in coordinating movement, and as they gradually stop working and die, the symptoms of the condition worsen. But Laura believes that astrocytes – helper cells inside the brain whose main role is to provide nutrients and support to other brain cells – may have been unfairly overlooked.

Research in other similar conditions has shown that if astrocytes don't do their job properly, other brain cells die more quickly. Recent research in animal and cell models suggests this might also happen in Parkinson's.

So Laura is going to investigate how astrocytes may interact with the brain cells affected in Parkinson's in detail – and look for opportunities to use these helper cells in developing better treatments. Laura hopes the results will inform future strategies for therapy – should we focus all our efforts on dopamine-producing cells or could targeting astrocytes provide added benefits to people with Parkinson's?

## Taking positive steps to prevent falls

**Who?** Dr Katherine Baker

**Where?** Northumbria University

**What?** £38,592 over two years

Staying physically active may help to reduce the risk of falling for people with Parkinson's. But people with the condition tend to be less active than people of the same age without Parkinson's.

Katherine's project will explore the barriers that prevent people affected by Parkinson's from engaging in physical activity.

She will recruit 20 people with Parkinson's who have experienced problems with their balance or falls in the previous year, as well as 20 people of a similar age who do not have Parkinson's.

After some initial walking, balance and thinking tests, participants will wear an activity monitor to record their movement and a small body-worn camera for five days.

Finally, each participant will be interviewed to help the team explore what factors may prevent them from taking physical activity.

Katherine hopes her study will shed new light on the complex relationship between physical activity and falls in Parkinson's. And better understanding will empower people to manage their condition more effectively and reduce their risk of falling.



## Engineering beetroot to combat Parkinson's in Africa



**Who?**

Professor Cathie Martin

**Where?**

University of East Anglia

**What?**

£16,834 over three years

Fewer than 15% of people in Africa diagnosed with Parkinson's have access to drugs. This is either because they are unavailable or unaffordable. Professor Cathie Martin is a plant scientist and believes there may be an unexpected solution to the problem in beetroot. Beetroot contains a natural form of the Parkinson's drug levodopa but it is usually broken down into pigments.

These pigments give beetroot its characteristic deep purple-red colour. By turning off the genes that convert levodopa into pigments, Cathie aims to make a modified beetroot plant that could provide a natural source of levodopa. This could one day provide a low-cost medicine that could be produced locally and sustainably in Africa and improve access to Parkinson's treatment in the developing world.

## Sniffing out biomarkers for Parkinson's

**Who?** Professor Perdita Barran

**Where?** University of Manchester

**What?** £49,459 over two years

You may have heard about this exciting and unusual project when it hit the headlines last year. What makes this research project really intriguing is that it all started when Parkinson's UK member Joy Milne noticed a subtle change in her husband's smell. Her husband Les was diagnosed with Parkinson's at the age of 45 but Joy actually noticed he started to smell more 'musky' about six years before that.

But it wasn't until Joy joined Parkinson's UK and started meeting people with the same distinct odour that she started wondering if there might be more to it.

"So when I attended a Parkinson's UK research event I mentioned that I thought I could smell Parkinson's to one of the scientists from Edinburgh University – who was very surprised and intrigued. So much so, that they decided to put me to the test!"

Dr Tilo Kunath, a Parkinson's UK fellow at the University of Edinburgh, was the first scientist Joy spoke to.

"I was definitely a bit sceptical so we tested Joy's sense of smell by using T-shirts which had been worn by six people with Parkinson's and six without the condition. We had them all wear a T-shirt for a day then retrieved the T-shirts, bagged them and coded them – so Joy wouldn't know whose was whose but we would. We were pretty impressed when she identified 11 out of 12 correctly just through sense of smell."

Dr Kunath adds: "Joy got the six Parkinson's correct but then she was adamant one of the 'control' subjects had Parkinson's.

"To our amazement, eight months later the gentleman informed me that he had been diagnosed with Parkinson's. So Joy's nose had actually managed to 'diagnose' Parkinson's before any of the usual symptoms of the condition had appeared. That really impressed us and we felt we had to dig further into this phenomenon."

### Searching for a simple diagnostic test

In this new project, Professor Perdita Barran along with colleagues in Edinburgh and London, hopes to identify differences in chemicals present on the skin surface of people with Parkinson's.

The research team will study about 200 people with and without Parkinson's to help them find the chemicals responsible for the odour Joy can smell. If this project is successful, it could lead to the development of a simple test that could be used to diagnose Parkinson's accurately in the very early stages.

This would mean an end to the uncertainty so many people experience when they are waiting for a diagnosis. It would also mean that the new treatments currently being developed and tested could be used earlier – when they have the best possible chance of slowing or even stopping the progression of Parkinson's.



## Mapping the 3D structure of the PINK1 protein



### Who?

Dr Miratul Muqit

### Where?

University of Dundee

### What?

£68,137 over 12 months

The PINK1 protein is important for keeping our mitochondria healthy and producing energy. The mitochondria are often affected in Parkinson's so developing new treatments that target PINK1 could be beneficial for everyone with Parkinson's. In this project, Miratul aims to work out the 3D structure of a protein called PINK1 that is of huge significance in Parkinson's. If he's successful this 3D structure could be used by scientists all over the world, almost like a template, to develop new treatments for Parkinson's that interact with PINK1.

## The genetics of inherited and early-onset Parkinson's

**Who?** Professor Huw Morris

**Where?** University College London

**What?** £48,972 over 12 months

Huw and his team will coordinate the collection and sequencing of the genes of around 1,500 individuals with early onset and inherited forms of Parkinson's, and their close relatives.

The team hopes it will be able to identify differences in the genes of those with and without the condition.

Although genetic forms of Parkinson's are rare, identifying changes in our genes that cause or increase risk of Parkinson's provides vital information that can be used in developing treatments and genetic testing.

## Understanding how genes are involved in dementia with Lewy bodies

**Who?** Dr Jose Bras

**Where?** University College London

**What?** £50,000 over two years

Dementia with Lewy bodies is the second most common type of dementia after Alzheimer's. It is diagnosed when someone has the symptoms of dementia either before or at the same time as developing Parkinson's-like problems with movement. It's very rare for dementia with Lewy bodies to be inherited, but researchers are beginning to uncover genes that may provide crucial clues to how and why it develops.

Jose is looking for differences in the activity of genes that are involved in dementia with Lewy bodies, which he hopes will aid the development of new treatments that could slow or stop these conditions progressing.

## Using brain scans to study cell transplants in Parkinson's

**Who?** Professor Paola Piccini

**Where?** Imperial College London

**What?** £76,893 over three years

The TRANSEURO study is the largest and most ambitious transplantation trial ever attempted for Parkinson's. The hope is that this trial will prove that cells transplants can work safely and reliably for Parkinson's.

Paola's new Parkinson's UK project will support this crucial study by analysing the results of brain scans participants have throughout the trial in greater depth and detail. Ultimately, the findings could help us better understand how cell transplants work for Parkinson's, and accelerate progress towards making this type of treatment a reality for people living with the condition.

# EXERCISE AND PARKINSON'S

Exercise is often seen as a miracle cure for many conditions by stopping them developing in the first place. However, what happens if you already have Parkinson's? Can exercise still help you? Here, we take a look at the suggested benefits of exercise in people with Parkinson's.

## How can exercise help Parkinson's symptoms?

Both the motor and non-motor symptoms of Parkinson's can make exercise difficult. However, a regular exercise routine is thought to have physical and mental benefits for people with Parkinson's. Research suggests that exercise can:

- **Improve motor symptoms**

Researchers have shown that several different forms of exercise can help movement in people with Parkinson's, improving balance and gait (how a person walks).

- **Improve memory and thinking**

Studies suggest that physical activity may improve activities such as thinking, learning and remembering in people with Parkinson's. Exercise has also been shown to delay the onset of dementia. We do not yet know, though, if this is also the case for the types of dementia associated with Parkinson's.

- **Improve general wellbeing**

Exercise has been shown to improve depression and anxiety. As around half people with Parkinson's experience anxiety, exercise could be an effective treatment for this non-motor symptom of Parkinson's.





## Exercise and me

Lionel has Parkinson's and is a keen weightlifter. He shares some of his tips and experiences of exercising with Parkinson's.

### 1. Plan your exercise regime

Timing and degree of effort are very important and can be the difference between being able to do a workout and not.

Try to schedule exercise for when you are 'on'. Also, make sure you work hard but not 'too hard'. If you find out your workout was not enough you can always try a bit harder next time – this is safer than risking over-extending yourself unnecessarily.

### 2. Don't skip exercise

If you are tired don't skip exercise but take an easier workout instead. As people with Parkinson's we often feel tired, so if we missed exercise because of that we would eventually quit altogether.

### 3. Find what works for you and your Parkinson's

While a common rule of exercise is 'not to exercise too often', for me, my exercise works better with short workouts performed once or occasionally twice every day.

And, remember, your Parkinson's is continuing to progress. Over time, you may have to modify what you do as some exercises may become too awkward or even dangerous. Whatever you do though, keep trying.

## Can exercise help the brain?

### • Protecting brain cells

People with Parkinson's don't have enough of a chemical called dopamine as some nerve cells in their brains have died. Studies suggest that exercise may help to protect the cells affected by Parkinson's.

### • Using dopamine better

Most people with Parkinson's don't get diagnosed until at least 50% of dopamine-producing brain cells are lost. Research has shown exercise may help the brain cope with the loss of dopamine in Parkinson's, by making the best use of what dopamine is left.



### Julie Jones, a Parkinson's physiotherapist, shares some advice for exercising with Parkinson's:

"Keeping active is important for people with Parkinson's. I know many people find using a pedometer smartphone apps is useful for monitoring their movements and making sure they are active daily.

"Many different exercises – such as t'ai chi, cycling and walking – can help Parkinson's symptoms. However simpler movements such as stretches and muscle-strengthening exercises can also be beneficial and done at home.

"Many local groups run Parkinson's-specific exercise classes which offer a great opportunity to both exercise and socialise.

"If you are unsure about what exercise is right for you, speak to your GP, specialist or Parkinson's nurse (if you have one). A physiotherapist will also be able to provide advice."

# PICTURING PARKINSON'S

In December last year we held the second Picturing Parkinson's competition for researchers to send in images celebrating the beauty and art in the research we fund.

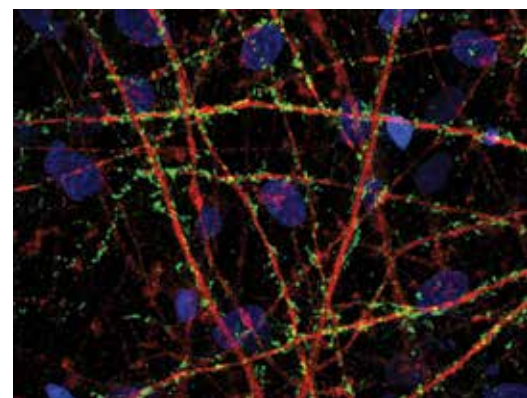
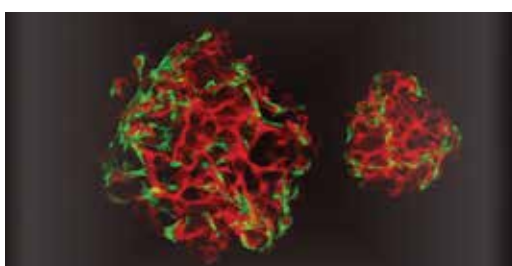
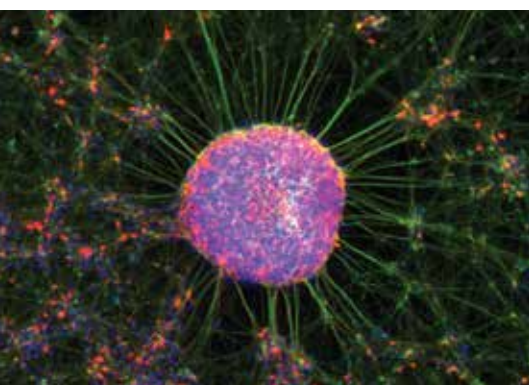
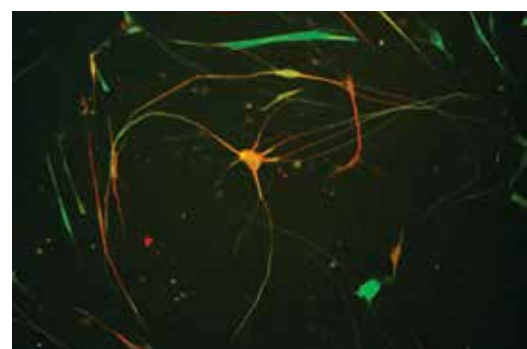
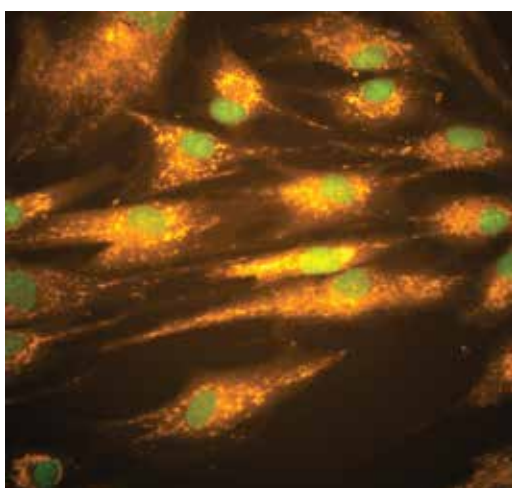
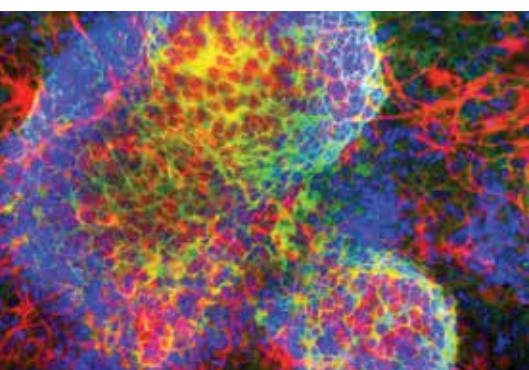
Dr Arthur Roach, Director of Research at Parkinson's UK, introduces the competition: "We held the competition in memory of scientist Dr Jonathan Stevens, who had Parkinson's and passed away at the age of 34 in December 2013.

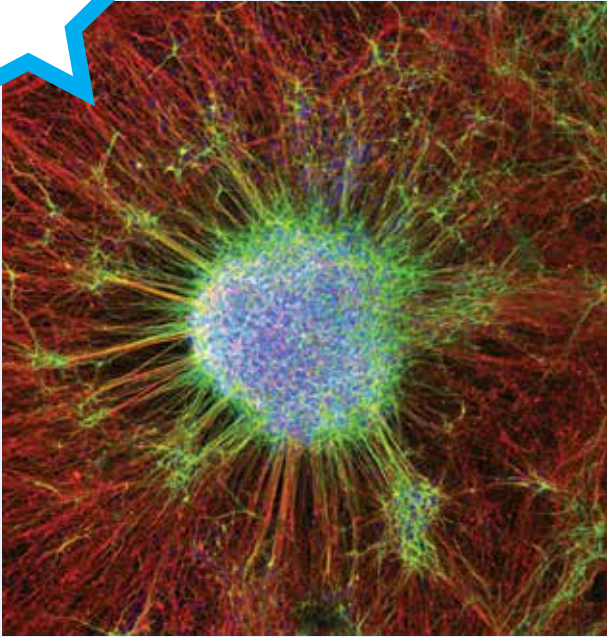
"The remarkable images entered, taken during cutting-edge Parkinson's research, reveal the complexities of the millions of nerve cells that make up our brains. Irish writer Jonathan Swift once said: 'vision is the art of seeing what is invisible to others'. This is what our Parkinson's researchers are doing each day in the lab, discovering new scientific breakthroughs and taking us closer to a cure. It's great that they can unpick the complexities of Parkinson's science and provide images that give us a different perspective on how we're working to develop new and better treatments. They are proving that science is beautiful."

"It's a privilege to judge this competition, which showcases the complexity of Parkinson's research in a unique way. Jonathan was passionate about making research accessible and easy to understand, and we're honoured that this competition helps to do this. As a scientist, Jonathan was an avid support of Parkinson's research and communicating the advances in the area to help inspire other people with Parkinson's."

**Brian Stevens, Jonathan's father**

You can find all the entries at [parkinsons.org.uk/picturingparkinsons](http://parkinsons.org.uk/picturingparkinsons)





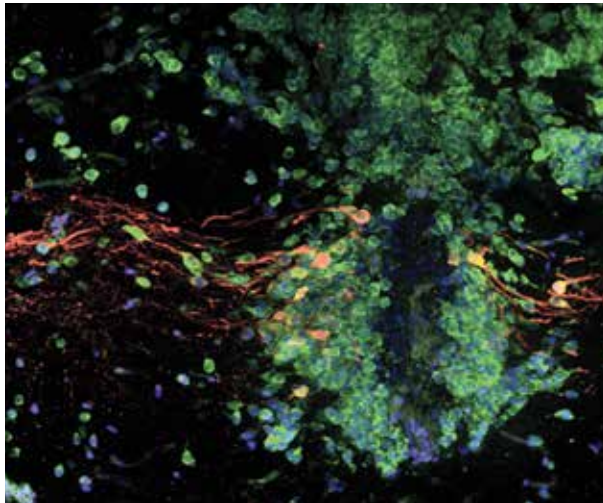
## OVERALL WINER

### Supernova

Philipp Berg

University of Cambridge

“Stem cells allow us to investigate the genetics involved in Parkinson’s. Stem cells from a person with Parkinson’s can be turned into a basic brain cell. These cells, with a little time, can produce millions of densely connected adult brain cells. We can see the cell bodies – in blue – and the long tendril-like processes, which the cells use to reach out and communicate with other parts of the brain, in red and green.”



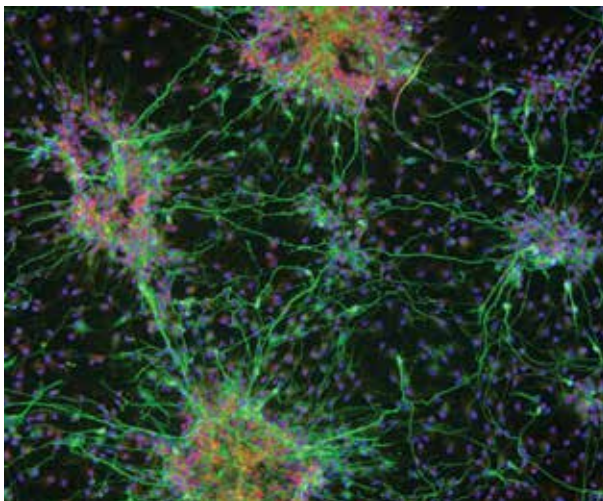
## RUNNER-UP

### Fire in the forest

Sarah Brown

University of Sheffield

“This is a section of a Zebrafish brain. Using these fish, we can see how the alpha-synuclein protein, which plays an important role in Parkinson’s, may affect the survival of brain cells.”



## RUNNER-UP

### The culture web

Dr Shi-Yu Yang

University College London

“This picture shows what brain cells grown in a dish look like under the microscope. The different colours and shapes represent important features of these cells that are also present in the brains of people with Parkinson’s.”



# COMPLEMENTARY THERAPIES – WHAT’S THE EVIDENCE?

Complementary therapies are treatments used alongside conventional medicine. Around 40% of people with Parkinson’s use at least one type of complementary therapy. But do people really benefit? Here we look at the scientific evidence supporting some of the best-studied complementary therapies.

## Acupuncture

Acupuncture is an ancient Chinese treatment. Fine needles are inserted into specific points on different parts of the body. Studies in a rat model of Parkinson’s suggest that acupuncture can promote the survival of dopamine-producing brain cells, the type of cell lost in Parkinson’s. However, evidence of the benefit of acupuncture in people with Parkinson’s is inconclusive.

“My husband saw an acupuncturist many years ago and we feel that although nothing was going to cure the Parkinson’s, it did stop it getting worse for quite a long time.”

**Amc on the forum**

## T’ai chi

The Chinese martial art, t’ai chi, combines relaxation and deep breathing with gentle movement. Research suggests that people with Parkinson’s who practise t’ai chi for six months have better balance and are less likely to fall. And one study found that t’ai chi may reduce falls because people develop a better reaction time – so that when they feel unsteady they are able to recover quickly.

“I find t’ai chi very beneficial. It teaches you how to breathe correctly, how to stand and move correctly uses both left and right hemispheres of the brain, improves muscle tone and relaxes mind, body and soul.”

**Tootsie on the forum**



## Dance

While most people take up dance for their own enjoyment, research suggests that mental and physical benefits of dance also exist. Tango has been shown to improve movement in people with Parkinson's. And, more recently, research in collaboration with the English National Ballet found ballet classes can improve balance and stability in people with Parkinson's.

## Massage

Massage is one of the most popular complementary therapies for people with Parkinson's. Some studies suggest that several types of massage can improve non-motor Parkinson's symptoms and quality of life. Research investigating neuromuscular therapy also found positive effects on motor symptoms of Parkinson's – particularly tremor. In some conditions, massage has also increased dopamine levels in the body. However, this increase has not been seen in Parkinson's.

.....  
"I find sports massage really helps with stiff muscles and I now have a massage about once a month or so (I'd have them more often if I could afford it!)."

**Tabbycat on the forum**  
.....

## Mindfulness

Mindfulness therapy helps people adjust to living with long-term conditions by focusing on the present. It has already been shown to improve both mental and physical health in long-term illnesses such as multiple sclerosis.

We are currently funding research to develop and investigate the benefits of a short mindfulness course for depression and anxiety in people with Parkinson's. But you don't have to have Parkinson's to benefit from mindfulness. Many people use colouring as a mindful activity – you can find an adult colouring book in our online shop.

## What do we think about complementary therapies?

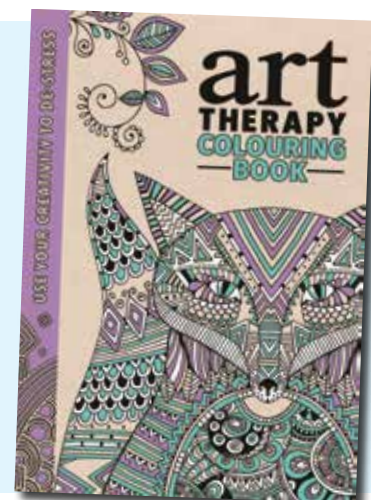
The research evidence to support the use of complementary therapies for Parkinson's is patchy but we know that many people with the condition use and benefit from these therapies. As with so many aspects of Parkinson's, different things work for different people so we encourage people who are interested in complementary approaches to explore what works for them. We always recommend that people use qualified therapists and discuss their choices with their Parkinson's specialist.

You can find out more on other complementary therapies here: [parkinsons.org.uk/complementarytherapies](http://parkinsons.org.uk/complementarytherapies). And share experiences on our online discussion forum at [parkinsons.org.uk/forum](http://parkinsons.org.uk/forum)

Get hold of your very own Art Therapy Colouring Book (PAUK1066, £12.99) from our online shop. Go to [parkinsons.org.uk/shop](http://parkinsons.org.uk/shop)

Why not explore our Daily Living Aids range while you're shopping? From stylish waterproof bedding to practical kitchen wear, our collection is designed to help make life that little bit easier.

For a copy of our free Daily Living Aids catalogue, simply email [shop@parkinsons.org.uk](mailto:shop@parkinsons.org.uk) or call **0844 415 7863**.





# HAVE YOUR SAY IN PARKINSON'S RESEARCH

You may have heard about opportunities to take part in research, but did you know there are many other ways to be involved? We explain what Patient and Public Involvement (PPI) is and how it's different to participation and engagement.

## What is involvement?

**INVOLVEMENT** is a two-directional partnership between researchers and people affected by Parkinson's. For example, working with a researcher to improve their study.

**PARTICIPATION** refers to when people with Parkinson's take part in a study or trial.

**ENGAGEMENT** is when a researcher tells people affected by Parkinson's about their research, such as giving a talk at a local group.

## Improving research through involvement

At Parkinson's UK, we know that people affected by the condition are the experts in living with Parkinson's. This wealth of knowledge can help at all stages of research – in the planning, design, management, evaluation and dissemination of findings.

We believe in involving people affected by Parkinson's in all stages of research. This is known as Patient and Public Involvement. We also believe that partnerships between researchers and members of the public produce higher quality, more relevant research, and ensure that the benefits are felt by the people who need it most.



Mark Mikkelsen from the University of Cardiff tells us about how he involved people affected by Parkinson's to develop his research into a new potential biomarker for Parkinson's:

"During the drafting stage of a funding application we met with a group of six people affected by Parkinson's face to face to discuss our project. We gave out distributed draft copies of our application to the group who then, after reading it, gave us their feedback. We followed up with everyone after the event and continued a dialogue via email about how our application could be further improved.

"The volunteers commented on the length of the brain scanning sessions and helped highlight to us some of the jargon in our application that made the proposal less clear to a lay audience. The volunteers' feedback was immensely beneficial in making our research aims more relevant for those affected by Parkinson's. We found the whole experience was incredibly positive and it gave us a whole new perspective of what clinical research is and what it should be about."





### How can I help?

Here are just a few ways that people affected by Parkinson's have already helped through patient and public involvement or PPI:

**Prioritise and drive research.** In December 2014, we announced our top 10 research priority areas in Parkinson's to help researchers focus on the most important issues. Using questionnaires and workshops, we asked people affected by Parkinson's, carers and health and social care professionals to come up with 10 priority areas for improving everyday life with Parkinson's. The top 10 is now being used to inform, guide and drive future Parkinson's research.

**Promote and improve research studies.** Through opportunities to work in partnership with researchers, people affected by Parkinson's have helped to highlight practical issues researchers might not have considered. For example, they highlighted that speech difficulties could cause people with Parkinson's difficulties in long telephone interviews. People affected by Parkinson's have also helped develop information sheets and consent forms, which can be easily understood by others, that will help researchers recruit and retain participants. And, with their perspective of what it's like to live with the condition, they've helped researchers to understand the answers on questionnaires.

**Inspire a new research area.** The super-sniffing skills of Joy Milne have inspired researchers to investigate whether there are subtle chemical changes in a person's odour that could help to diagnose Parkinson's. The research project is due to start later this year, and Joy will be lending her nose to help progress Parkinson's research.



One of our volunteers, Anne Ferret, worked with Lorna Rixon from City University, on her project that is investigating ways to help people with Parkinson's report non-motor symptoms:

"At our initial meeting, Lorna told me about her research, described her materials and asked me about my experiences of reporting non-motor symptoms. She listened to my 'story' and seemed to value what I had to say. I drew on how things had been with my mum (who has Parkinson's) and also on my work with small children with communication difficulties.

"She then emailed me her materials that she had been working on for me to review, which I did and then we spoke later over the phone to talk about the changes I had suggested.

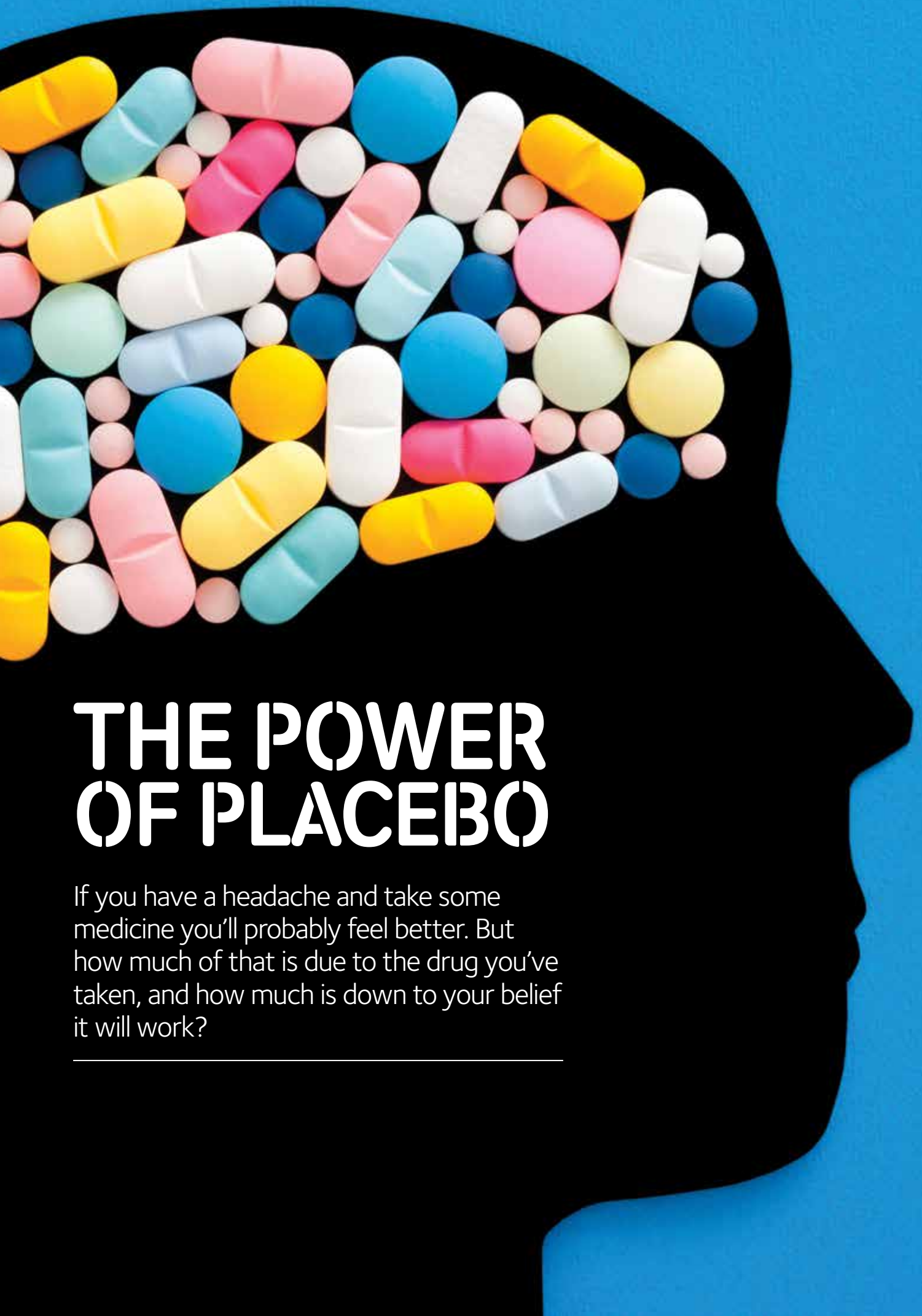
"I felt listened to and valued, but was also aware that whatever ideas I had were then hers to manipulate into her intervention in the way she felt would work best."



### How can you get involved?

Find out about upcoming opportunities to work in partnership with researchers to improve Parkinson's research. Please email us at

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



# THE POWER OF PLACEBO

If you have a headache and take some medicine you'll probably feel better. But how much of that is due to the drug you've taken, and how much is down to your belief it will work?

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## What is the placebo effect?

The placebo effect is a remarkable phenomenon in which an inactive substance, such as sugar or water, can sometimes make us feel better simply because we expect it will. It's a phenomenon that we don't completely understand. But we can see it working in all kinds of ways, and all kinds of circumstances.

Placebos are most often given to people participating in clinical trials – studies that test the effectiveness of new treatments. In a 'placebo-controlled' trial, some participants will receive the real treatment and some a placebo. The participants don't know whether they are getting the real deal or the placebo, and neither do the researchers running the study. When the study finishes, all is revealed and the researchers can look to see if the people who received the real treatment have done better than those who received the placebo.

## The placebo effect in Parkinson's

The placebo effect can be surprisingly potent, and several studies have revealed the powerful effect placebos can have on people with Parkinson's.

In 2010, Canadian researchers carried out a study to see how differing expectations of receiving the active treatment affects the strength of the placebo effect. Participants were told that they either had a 25%, 50%, 75% or 100% chance of receiving levodopa, a Parkinson's medication that increases dopamine levels in the brain. All of the participants actually received a placebo. Fascinatingly, though, only those who believed they had a 75% chance of getting levodopa experienced significant improvements.

Last year, US research showed that how much we think a treatment costs can also affect the power of the placebo response. People with Parkinson's given what they believed to be an expensive drug experienced significant improvements compared to those who thought the drug they were taking was cheap.

Understanding the placebo response in Parkinson's is of critical importance to improving the way clinical trials are designed. We need to be able

test new treatments in a way that minimises the placebo effect and helps us see their true value.

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“We often hear of the placebo effect in Parkinson's. Usually it is seen as a problem, because it makes it difficult to interpret the results of clinical trials. I see it differently. Placebos could be used as therapies in their own right, after all clinical trial after clinical trial has found that they work. We could even engineer them to maximise their effectiveness. And if they lose their effectiveness over time, there's an infinite number of new placebos to move to.”

**John from the Parkinson's UK forum**

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## Could placebos be used to treat Parkinson's?

The use of placebos in medicine is a bit of an ethical minefield, especially where any deception is involved. It can also have serious consequences. Antibiotics have been over-prescribed to people with viral infections where antibiotics are not effective and act as no more than a placebo. This over-use has contributed to the rise of antibiotic resistance.

Surprisingly, even when you know the treatment you're receiving is a placebo it may still make you feel better. This was reflected in a recent survey that suggested many people are open to the idea of using treatments that may boost the placebo response. However, rather than be deceived, they wish to have open and honest discussions with their doctors about their use.

The placebo effect is powerful, but it does have limits. It cannot stop the progression of Parkinson's or the loss of cells in the brain. It may also vary a lot from person to person, and also over time. So while it may be a useful tool for developing therapies that can ease symptoms like pain and anxiety, we know we ultimately need to develop treatments that tackle the underlying biology to provide the real solutions.

# RESEARCH RESULTS

In the last five years we have funded more than 136 research projects worth nearly £25million. We keep a close eye on all our projects and here we look at some of the latest results from four of them. To keep up with all the latest findings visit [parkinsons.org.uk/researchresults](http://parkinsons.org.uk/researchresults)

## Tracking Parkinson's – an interview with Dr Donald Grosset

We launched our ambitious Tracking Parkinson's study, the world's largest study of Parkinson's, four years ago in April 2012. By studying participants in detail over time, we hope to learn more about how the condition develops and progresses, and ultimately develop biomarkers. These will allow us to diagnose and monitor Parkinson's accurately.

A total of 2,240 people with Parkinson's are participating across 70 hospitals in this extraordinary project. In this section, we talk to leader of the Tracking Parkinson's project, Dr Donald Grosset, who reflects on the progress made so far.

### What progress have you made?

"Over the past four years, we have been overwhelmed by the commitment and dedication of our participants, and the professionals who have been supporting the study. So I'd like to say a huge thank you to anyone reading this who has helped us make this project such an amazing success. After four years of carefully collecting blood samples and

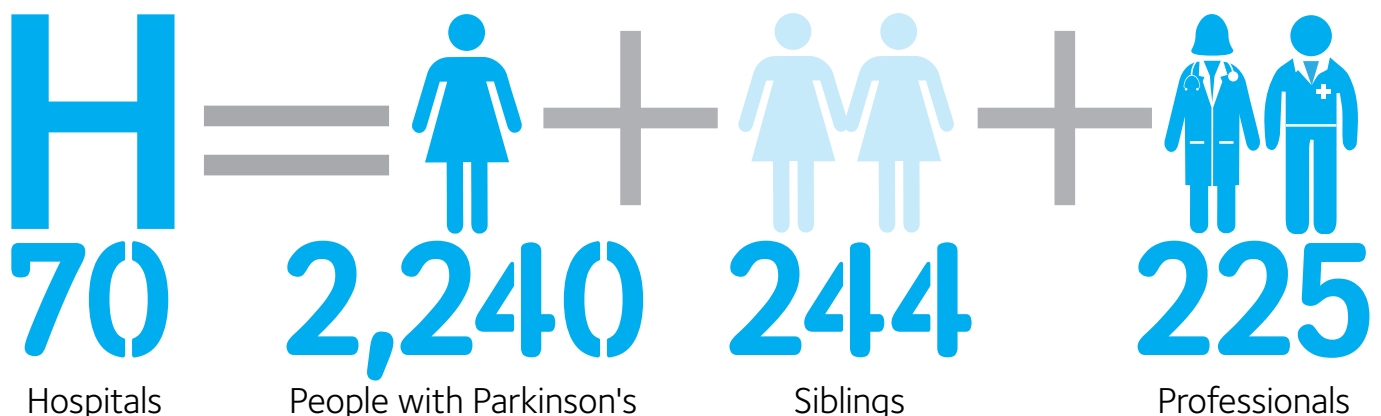
information about people's symptoms, we are now beginning to analyse the data and see the fruits of our labour.

"We have uncovered a really interesting – and previously unknown – relationship between Parkinson's and cardiovascular health which we believe could have really important implications for treating Parkinson's."

### What's been your biggest achievement?

"Perhaps the most exciting and pleasing achievement we've made through Tracking Parkinson's so far is the number of other projects we are now collaborating on.

"We have also developed an incredible relationship with the Oxford Parkinson's Disease Centre which is carrying out a similar project in well over 1,000 people in Oxford and the surrounding areas. Finally, we're delighted that the data we're collecting through Tracking Parkinson's is going to be used in the Critical Path for Parkinson's project to improve clinical trials across the world."



Tracking Parkinson's helped lay the foundations for three vital spin-off projects which are also funded by Parkinson's UK:

- **The largest ever study of pain**  
Led by Dr Monty Silverdale, the study aims to help us understand why people with Parkinson's so often also experience chronic pain, and to come up with better treatment strategies.
- **Searching for biomarkers**  
Professor Simon Lovestone is using cutting-edge technologies to analyse the blood samples we're collecting in Tracking Parkinson's to try and develop a simple blood test.
- **Developing better brain scans**  
Professor Dorothee Auer is carrying out advanced MRI brain scanning with 300 Tracking Parkinson's participants and healthy volunteers.

### What next for Tracking Parkinson's?

"We are now in the final year of our five-year grant from Parkinson's UK but we're not slowing down. As well as continuing to analyse our data, and follow up with all our participants, we're starting to plan where we can take the study next. To help us do this, we're working closely with Parkinson's UK. I recently met with volunteers who are directly affected by the condition to discuss plans for the next phase of Tracking Parkinson's.

"There were a number of key findings for me on the day but the overarching theme is that we should develop the next phase of our research in partnership with our study participants. We're really excited about what the future holds for Tracking Parkinson's, and I look forward to sharing more news with you very soon."

### We're still looking for siblings!

We've recruited all the people with Parkinson's we need but we still need their brothers and sisters to participate. If you are participating in Tracking Parkinson's and have a brother or sister who might be interested please get in touch: [research@parkinsons.org.uk](mailto:research@parkinsons.org.uk)

Margaret is taking part as a sister of someone with Parkinson's.

"My brother has Parkinson's and participated in this study. When I heard they were looking for sibling participants, I agreed to take part. I wanted to help others with Parkinson's and I know participating in research is important to improve our understanding of the condition. The study involved two visits to Southern General Hospital. The first consisted of several questionnaires and tests which checked things such as my memory and sense of smell. The second visit was optional and involved an MRI scan. As I have had strokes in the past, I was happy to have an MRI as it allowed me to get a full examination and check my existing condition. The hospital staff couldn't have been more friendly and put me at ease while participated in these tests."

Dr Donald Grosset is pictured below, far right, discussing the next steps of Tracking Parkinson's with volunteers.



## The development of Parkinson's in the brain

Recent research has suggested that Parkinson's may start in the gut and spread to the brain. Alpha-synuclein is a crucial protein in Parkinson's that is thought to be involved in this process. So, understanding how the protein changes and spreads is critical for developing better treatments that can slow or stop the progression of Parkinson's in the early stages.

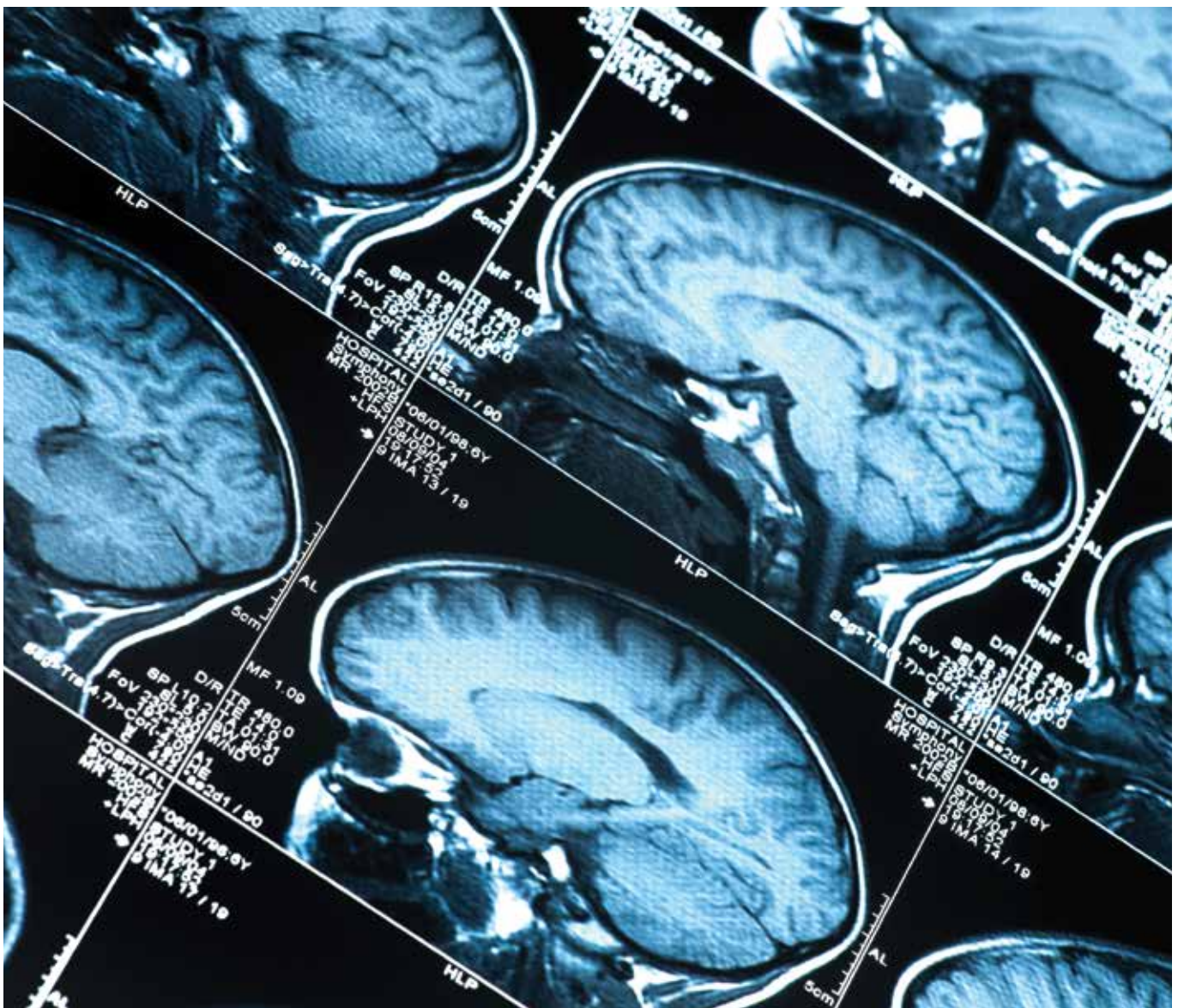
In 2012, Parkinson's UK awarded a £248,000 project grant to Professor Roger Barker and Maria Grazia Spillantini, at the University of Cambridge, to investigate how Parkinson's spreads in the brain.

The team created a new genetically-modified mouse that can be used to investigate how alpha-synuclein may spread from the gut to the brain.

They discovered differences in the way the alpha-synuclein protein in Parkinson's and other closely related conditions, such as multiple system atrophy or dementia with Lewy bodies, affects and spreads throughout the brain.

"This new mouse model is an excellent tool for studying alpha-synuclein in the gut. We hope this work will ultimately lead to a much better understanding of the early changes that happen in the gut in Parkinson's."

**Professor Roger Barker**



## Does Parkinson's make it harder for people to learn new skills?

The ability to learn and remember new motor skills is an important part of daily life. It means we can adapt to changes in our environment, for instance learning to type or use a computer mouse. Learning new motor skills is also vital to the success of physiotherapy and speech and language therapy.

Our researchers at the University of Oxford, led by Peter Brown, have investigated if people with Parkinson's have difficulties learning these skills.

The team used two learning tasks to test whether skill retention is affected in people with Parkinson's. The first task tested people's ability to learn and remember a new motor skill. The second tested their ability to learn a complex mental skill.

The team discovered that people with Parkinson's were able to learn new motor skills as well as people without the condition but have problems retaining them.

.....  
"Understanding the problems with remembering new skills will pave the way towards finding way to overcome these difficulties. Improving retention of new skills could make treatments like physiotherapy and speech and language therapy more effective for people with the condition."

**Peter Brown**

.....  
The team also tested a therapy called transcranial direct current stimulation (TDCS) to see if it could improve learning. The therapy uses a type of electrical stimulation which painlessly passes a small electrical current through the scalp. The team has shown this therapy works for people without Parkinson's, but they believe it may also help people with the condition to remember new skills. Ned Jenkinson, one of the researchers from Peter's lab, received a grant to continue this work at the University of Birmingham. The research project, 'Learning new movements with rewards', started in October 2015.



## Closing in on new treatments for dyskinesia

Levodopa is the main drug used to treat the symptoms of Parkinson's. But up to 90% of people with Parkinson's who take levodopa for a number of years will go on to develop dyskinesia. This symptom refers to uncontrolled jerky movements that seriously affect quality of life and can lead to social isolation.

Animal studies suggest that a protein called PDE-10A is involved in dyskinesia, and that drugs that block PDE-10A activity may be helpful. Now, our researchers at Imperial College London have found that levels of PDE-10A protein are decreased in the brains of people with Parkinson's. They also discovered that lower levels of PDE-10A are linked to more severe dyskinesia. The team, led by Dr Marios Politis, also discovered that PDE-10A levels are linked to the progression and severity of Parkinson's. Lower levels were seen in people who had had Parkinson's longer and who had worse motor symptoms such as slowness of movement and stiffness.

.....  
"We hope that improved understanding of why dyskinesia develops will lead to new and better treatments for Parkinson's, which have fewer side effects. The next steps are to test if drugs that target PDE-10A could potentially have a therapeutic role in Parkinson's by reducing symptoms and complications."

**Dr Marios Politis**



## YOUR LEGACY COULD BE A CURE FOR PARKINSON'S

Gifts in Wills are hugely important to Parkinson's UK – they account for a third of our annual income. This means much of our progress in research has been, and will continue to be, thanks to those who remember us in their Will.

Large or small, all gifts make a difference. Your gift can help bring us closer to finding a cure and help ensure that, because we are here, no one has to face Parkinson's alone.

Once you've taken care of loved ones, we'd like you to consider leaving a gift to Parkinson's UK. To find out more or request our free Will-making guide, please call our legacy manager Christopher Brodrick on **020 7963 9344**, email [cbrodrick@parkinsons.org.uk](mailto:cbrodrick@parkinsons.org.uk) or, alternatively, visit our website [parkinsons.org.uk/legacy](https://parkinsons.org.uk/legacy).

### A legacy to help our work

Florence Phoebe Mary Pite, known to her friends as Jill, was a long-term supporter who chose to include a wonderful gift in her Will to enhance the lives of people with Parkinson's.

Born in Wokingham in 1929, Jill was diagnosed with Parkinson's in May 1995 and later became a member of Guildford and South Surrey Branch. An active volunteer, she hosted coffee mornings to raise funds for Parkinson's UK.

"Jill had a particular interest in research and education. She would be very happy to know that her legacy is to be used to enhance our work to improve the lives of people with Parkinson's, both by the hunt for new and better medication and the important commitment to research and sharing of knowledge through the annual lectures."

**Mary Brown, Parkinson's local adviser for Waverley and North West Sussex**

Her gift of more than £1 million will help fund many areas of our work, including the Parkinson's UK Royal College of Surgeons research lecture for the next five years.

It will also make Jill a founding funder of the Critical Path for Parkinson's – a project which aims to help deliver new and better treatments in years, not decades. As well as contributing to large-scale projects her legacy will help people with Parkinson's in her local area.

"We are pleased that Jill had the foresight and commitment in our work to donate such a wonderful gift that will help fund many areas of our work. It is a fitting tribute to Jill that the lecture series will be renamed the Florence Pite memorial lecture."

**Steve Ford, Chief Executive at Parkinson's UK**

# YOUR THOUGHTS ON *PROGRESS*

*Progress* has changed a lot over the past 18 issues but we can only continue to improve if we get your feedback.

You can fill in our survey online at [parkinsons.org.uk/progressfeedback](http://parkinsons.org.uk/progressfeedback), email us your comments at [research@parkinsons.org.uk](mailto:research@parkinsons.org.uk) or call **020 7963 9313**. Or return the completed survey to **Research Team, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1 1EV.**

1. How interesting do you find *Progress* magazine?

- Very interesting     Quite interesting  
 Some articles are more interesting than others     Not interesting

2. How easy to read do you find *Progress* magazine?

- Very easy to read     Quite easy to read  
 Some articles are easier than others     Not easy to read

3. What do you find most interesting in the magazine?

4. What do you find least interesting in the magazine?

5. Do you have any other comments about *Progress* magazine?

## Get more from research

If you are not a member of the Research Support Network and want to find out about news, local events or opportunities to get involved or participate in Parkinson's research, share your details to join.

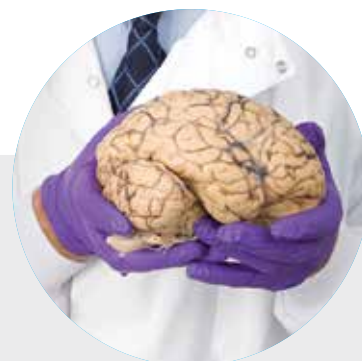
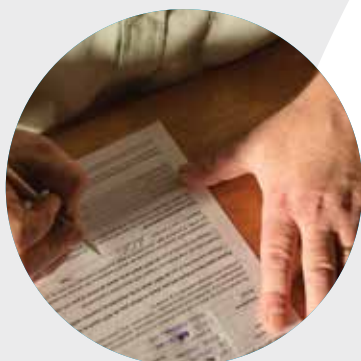
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# JOURNEY OF A BRAIN DONATED TO PARKINSON'S RESEARCH



## 1. BECOME A DONOR

To become a donor, you first need to register. This means completing a donor consent form and health information sheet, as well as an agreement from your next of kin.

Once the Brain Bank team has received your completed forms they will send you a donor card.

## 2. WHEN A DONOR DIES

When a registered donor dies the Brain Bank team should be contacted as quickly as possible on their 24-hour emergency number.

The Brain Bank team will work with the donor's next of kin, medical professionals, funeral directors and mortuaries to organise the tissues to be removed at a local hospital with mortuary facilities.

## 3. COLLECTION

The Brain Bank aim to collect tissue within 24 hours but they can accept tissue up to 48 hours after death. A member of the Brain Bank team will travel to the hospital to collect the precious tissue and take it back to the Brain Bank, making sure they keep it cold and in the best possible condition.

If the tissue is travelling over a long distance, it may be kept in a chemical preservative called formalin to allow more time for transport.

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"When my husband was diagnosed in 2003 it was thought he may have Parkinson's or possibly multiple system atrophy. To have a conclusive diagnosis we were told required a postmortem examination. This was why he agreed to donate his brain tissue. As well as providing research material, it was valuable for our family to have a diagnosis confirmed. Thank you for providing us with that final piece of information."

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The Parkinson's UK Brain Bank is one of the largest national tissue banks. It's a vital resource for Parkinson's researchers both within the UK and worldwide. But how does our brain tissue go from our bodies to a researcher's laboratory bench? We guide you through a timeline of brain donation, describing events both before and after donation.



#### 4. DISSECTION

Before the brain can be dissected, it is first carefully examined. This means photographing and weighing the brain, as well as noting any obvious changes to the surface of the tissue.

Dissecting the brain and spinal cord may take up to two hours. The brain is first cut in half. Half is kept in formalin and used for the diagnosis of the tissue (see next step). The remaining half is cut into very thin slices and frozen to provide samples for research.



#### 5. DIAGNOSIS

The only way to be 100% sure that someone had Parkinson's is by looking closely at the brain after death.

Every brain donated to the Parkinson's UK Brain Bank is examined for signs of Parkinson's by looking at sections of the brain under the microscope and using staining.

The results of the diagnostic examination are shared with the donor's family by letter and with any researchers who use the tissue.



#### 6. RESEARCH

One brain provides around 250 samples which means it can be used in a large number of different research projects.

Researchers from around the world apply for tissue from the Brain Bank. Each application is reviewed by scientific experts and people affected by Parkinson's to ensure that the research is both a good and ethical use of tissue.

Tissue from the Brain Bank is supporting projects across the world, which are helping us understand the condition better and drive us towards better treatments.

If you're interested in registering as a donor, please contact the Brain Bank:  
[parkinsons.org.uk/brainbank](https://parkinsons.org.uk/brainbank)  
Email: [brainbank@imperial.ac.uk](mailto:brainbank@imperial.ac.uk)  
Call: 020 7594 9732

# MY LIFE IN RESEARCH BY JANISHA PATEL

As a carer, I witness firsthand what living with Parkinson's is like. Mum and I are desperate for a cure, and until then better treatments and ways of improving daily life would be fantastic.



Every day, we learn a little more about the illness and we have always wanted to share our experiences, so when I found out about the Research Support Network (RSN), I signed up straightaway.

Most recently, I filled in an online survey about extra living costs faced by people with Parkinson's.

Previously, I took part in the quest to find the top 10 unanswered questions, which began with a survey regarding three aspects of Parkinson's – the symptoms, day-to-day life, and treatment.

The results were analysed and 94 unique questions identified. This was further reduced to 26 questions that research has yet to answer. The final stage was a day workshop to rank the questions, before which we were sent an agenda, each participant's biography, and the list of 26 questions.

During the day we discussed the 26 questions in small mixed groups of people with Parkinson's, carers, and health professionals. We had the opportunity to voice our opinions if we felt something should be higher or lower in rank and



explain why, if the group agreed we changed the ranking.

I felt very strongly about the question "What treatments are helpful for reducing dyskinesias?" because mum is affected by this in many ways.

This includes the pain and fatigue caused by the constant uncontrollable movements, not wanting to go out because of people staring all the time, and injuries from falls or bumping her head and limbs (she once knocked a container of batter from the worktop, it went everywhere including over me and I was left, quite literally, battered!).

While discussing this question it was useful to learn about a drug (apomorphine) from a Parkinson's nurse who had found it to be effective in helping patients in her clinic.

Lastly, all participants were put together and we had a chance to dispute any final thoughts on the top 10 ranked questions. It felt great to participate and to meet so many different people – I even made friends with another carer!

I'm grateful for RSN as it makes it easy to get involved. The emails keep me informed and reassured of all the research being done and the various seminars held by researchers, which allows me to see where I can contribute. I look forward to being involved in future research.

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

# MORE PROGRESS?

*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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**Dr Beckie Port (Editor)**

Senior Research Communications Officer

**Gabs Abrahams**

Graphic Designer

**Isabelle Abbey-Vital**

Research Involvement Officer

**Claire Bale**

Head of Research Communications and Engagement

**Jill Gallagher**

Clinical Development and Regulatory Manager

**Amelia Hursey**

Senior Research Participation Officer

**Sophie McLachlan**

Research Communications Officer

**Dr Arthur Roach**

Director of Research

**Anna-Louise Smith**

Research Support Network Manager



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To find out more, go to [parkinsons.org.uk/texttodonate](http://parkinsons.org.uk/texttodonate)



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**Helpline**

**0808 800 0303** (freephone)

**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–7pm, Saturday 10am–2pm

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