

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

# PROGRESS

The research magazine of Parkinson's UK  
Issue 14 winter 2014

Clinical trials  
explained



# CONTENTS

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Welcome.....	3
From Richard Hill, Parkinson's UK research supporter	
International news roundup.....	4
Keep up to date with Parkinson's research from around the world	
Clinical trials explained.....	6
We take you through how clinical trials work and how you can get involved	
New research projects.....	14
Introducing some of the latest Parkinson's UK-funded projects	
Over to you.....	18
Your letters, comments and opinions on Parkinson's research	
World Parkinson Congress.....	20
Kieran's round-up from a busy and inspiring week in Montreal	
Is there a Parkinson's personality?.....	22
Blogger Amanda explores the current research	
Finding a cure for Parkinson's.....	24
To help explain our research we've put together some infographics	
Research results.....	26
The latest and most important findings from Parkinson's UK research projects	
The Parkinson's UK Brain Bank.....	32
Lifting the lid on a busy year at the Brain Bank	
"I've got nothing to lose by trying it".....	34
Or have you? Research supporter Jonathan investigates unproven therapies	

# WELCOME

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In this issue, our welcome comes from research supporter Richard Hill. He's involved because a close family member has lived with the condition for nearly 30 years. Richard's part of the team that formed the Research Support Network, which now involves hundreds of people passionate about Parkinson's research and the search for a cure.

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When we set up the Research Support Network we wanted to maximise opportunities for people affected by Parkinson's to learn more about research, and to play an active role. Most importantly we wanted it to be a partnership. Rather than relying on Parkinson's UK to create the opportunities, we wanted the network to help volunteers to develop their own by working closely with Parkinson's UK staff and researchers.

To achieve all this we quickly realised that the Research Support Network would need some steering and support. And this too would be a task for volunteers and staff working together.

So the 'Development Team' was born: nine volunteers, all directly affected by Parkinson's and passionate about research. We meet quarterly and work alongside staff to guide the network and make sure that people with Parkinson's stay at the heart of the charity's research. The team's task is a steering one. We're not here to tell supporters what to do, but to give them the scope and opportunities to develop their own activities in support of research.

We're also here to review and monitor the progress of Research Support Network across the UK, to

make sure successful projects are supported and shared, and any problems or gaps are identified and addressed.

It's an ambitious vision, but I hope that those of you who have joined the network in the last couple of years will see that the ambition is becoming reality. There are a wide variety of opportunities to get involved including taking part in clinical trials and surveys, visits to research labs, help with organising conferences, and much more.

Even more encouragingly research supporters are starting to take the lead, organising their own research events, forging relationships with Parkinson's researchers, and writing local newsletters to spread the word.

It's fantastic to see how much we've already achieved and I'm excited by what the future holds. Everyone can play a part, so if you're interested in getting involved please visit [parkinsons.org.uk/researchsupportnetwork](https://parkinsons.org.uk/researchsupportnetwork) and join us!



# INTERNATIONAL NEWS ROUNDUP

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What a few months it's been for Parkinson's research. Here's our take on the some of the most interesting developments from around the world.

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## A drug for all neurodegenerative conditions?

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UK researchers have identified a chemical that can stop nerve cell death in the brain which could lead to a treatment that works for several conditions including Parkinson's and Alzheimer's.

In neurodegenerative conditions, proteins that are the wrong shape, or misfolded, build up inside the affected brain cells. The cells respond in the same way as they do when they are invaded with

a virus – they shut down the production of all new proteins. This starves viruses, but shutting down protein production for too long also starves the nerve cells. Without the proteins they need, they stop working and die.

In this new study, researchers at the University of Leicester studied mice with a condition where misfolded proteins spread through the brain.

When untreated, the mice developed severe memory and movement problems and died within 12 weeks. But mice given a chemical that prevented the shut-down of protein production showed no sign of nerve cell death.

This research is promising but still very much in the early stages. The next step is translating these findings into a treatment that is safe and effective for people – and this will require a lot of further research.

[parkinsons.org.uk/researchnews10oct2013](http://parkinsons.org.uk/researchnews10oct2013)

## Link between depression and Parkinson's

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People with depression are slightly more likely to develop Parkinson's than those without the condition according to a new study carried out in Taiwan.

The link between mood problems and Parkinson's is well known, but it's still unclear whether having depression increases the risk of Parkinson's, or if it's an early symptom of the condition for some people.

The team, from Taipei Veterans General Hospital in Taiwan, studied the medical records of 4,634 people with depression and 18,544 people without and looked at their risk of Parkinson's over a 10-year period.



After factors like age were taken into account, people with depression in the study were more than three times more likely to develop Parkinson's than those without.

But even among those with depression, the risk of developing Parkinson's was still very low.

The relationship between Parkinson's and mood is complex, and further studies are needed to fully understand it.

[parkinsons.org.uk/researchnews3oct2013](http://parkinsons.org.uk/researchnews3oct2013)

## 'Mini brain' grown from human stem cells

In a major breakthrough for stem cell research, researchers in Austria have grown tiny brain-like structures in the lab, which could open up new avenues for studying complex conditions like Parkinson's.

The team used both embryonic stem cells and stem cells made from adult skin cells to grow 'mini brains' that share several regions found in our fully-developed brains, including areas known to be affected in Parkinson's.

Transforming stem cells into nerve cells has already given scientists a window into the human brain.

These mini brains mimic some of its complexity more closely than ever before.

The human brain is the most complicated structure known. So while this is an exciting step forward for stem cell research it's still a long way from the real thing.

But new tools like this are helping us understand how our brains work and will ultimately help us unravel the mysteries of conditions like Parkinson's.

[parkinsons.org.uk/researchnews29aug2013](http://parkinsons.org.uk/researchnews29aug2013)

## Parkinson's UK Twitter news

We share research news from around the world on Twitter. Here are a handful of our favourites from the last few months.

- **How to live longer – the experts' guide to ageing**

In an article from the *Guardian*, experts explain why having good friends, lifting weights and learning languages can lead to a longer life.

<http://bit.ly/169YPII>

- **Going on a health kick reverses ageing**

This story from *BBC News* highlights research from the University of California which has found the first evidence that a strict regime of exercise, diet and meditation can help cells stay young.

<http://bbc.in/18tc5Eq>

- **Unfavourable results from medical trials are being withheld**

Drug companies and medical researchers are putting patients' lives in danger by failing to publish negative results from clinical trials, MPs have warned.

<http://bit.ly/1grTO9r>

- **Fruit flies: a very distant cousin**

Researchers have found that fruit flies, often used in Parkinson's research, are genetically closer to us than we previously thought.

<http://bit.ly/1eUgka4>

- **Pill linked to long life in mice**

More evidence that drugs for diabetes may have hidden talents. This time a drug called 'metformin' has been found to have anti-ageing effects and extend the life of mice, according to recent research.

<http://bbc.in/158WUHy>

Keep your finger on the pulse by following us at [www.twitter.com/parkinsonsuk](http://www.twitter.com/parkinsonsuk) and [parkinsons.org.uk/researchnews](http://parkinsons.org.uk/researchnews)



# CLINICAL TRIALS EXPLAINED

Clinical trials are the way we test medical treatments and therapies. They tell us whether a treatment works, help us to identify and understand the risks and potential side effects, who the treatment is suitable for and what dose works best.

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The father of modern clinical trials is widely considered to be James Lind who was a Royal Navy doctor in the 18th century.

In those days many sailors developed scurvy when on long expeditions which we now know was caused by a lack of vitamin C. In Lind's day vitamins had not yet been discovered, but he had a hunch that the scurvy was caused by a deficiency in the sailor's diets.

To test his theory, Lind designed the first ever controlled clinical trial. He divided sailors with scurvy aboard his ship into several groups. They all received the same general diet, but different groups received different supplements including cider, vinegar, seawater, nutmeg and (crucially) oranges and lemons.

In just six days, the sailors taking citrus fruits were fit for duty. Lind's simple, but effective experimental design is essentially the same one that we use to test new medicines today.

Clinical trials might seem straightforward – give group A the real drug, give group B a dummy version or 'placebo' and then look for a difference in the two groups. But there are lots of things that can muddy the waters, especially in Parkinson's.

## 1. The placebo effect

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The placebo effect is the belief that a treatment will work. In Parkinson's, the placebo effect is unusually strong. This is because the expectation that you may benefit from a treatment actually causes the release of dopamine – the chemical lost in the brain in Parkinson's.

Many Parkinson's trials struggle to produce a difference between the treatment and placebo groups. But how do we work out whether this is because the treatment doesn't work or because the placebo effect is so strong?

## 2. The many faces of Parkinson's

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Parkinson's is a very variable condition. Every person with the condition is different and responds to treatments differently ... and this makes conducting trials for Parkinson's tricky.

What if half the people taking the treatment in your trial do brilliantly and half don't? Does that mean the treatment doesn't work? Or does it only work for people with a particular type of Parkinson's?

## 3. How do you measure Parkinson's?

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At the moment we don't have any objective test to monitor Parkinson's. This is a problem for health professionals in general but it's a major stumbling block for trials because it means there's no objective way to tell whether a treatment works or not.

Researchers rely on looking at people's symptoms and asking them how they feel, which can vary hugely from day to day and doesn't necessarily tell us if a treatment is working.

This means that clinical trials for Parkinson's are notoriously difficult to plan and the results difficult to interpret.

But researchers are finding ways to design studies around these challenges and a number of important clinical trials are currently underway in the UK.



## Our new guide to clinical trials

The complex world of clinical trials can be a confusing place, and finding clear information and advice is no easy task.

We've put together a simple new guide for people with Parkinson's who are interested in taking part in clinical research. There's a taster on these two pages. The full guide is available on our website at [parkinsons.org.uk/clinicaltrials](https://parkinsons.org.uk/clinicaltrials) or just get in touch and we'll pop one in the post for you.

### What does taking part in a clinical trial involve?

Clinical trials can vary enormously. If you are considering taking part in a clinical trial you will be given full details of what will be involved and the chance to discuss this with the researcher, ensuring you fully understand the process.

**Screening** Depending on what the trial is investigating, the research team will be looking for people who fit specific criteria – called inclusion and exclusion criteria – to ensure you are suitable.

Screening usually involves answering questions about your Parkinson's, your medication, treatment history and checking details such as your age and length of diagnosis. It's possible you may need to have blood tests, scans or other tests as well. If you fit the team's criteria you will be invited to take part in the trial.

**Consent** The research team running the trial must have your permission to enter you into the trial. You will be asked to sign a form to show you understand what is involved in taking part and that you are willing to take part.

Before you give consent, the research team should talk you through in detail what is involved and answer any questions you have. We always suggest you discuss the information with your GP, Parkinson's nurse or specialist and your family as well before you sign the consent.

**Taking part** If you fit the research team's criteria and once you have given your consent, you will be able to take part in the trial. Trials can vary hugely depending on what the team are investigating. Often participants will be asked to complete questionnaires, tests and will need to visit the team regularly to have treatment.

## Campaigning to boost clinical research in the UK

We want every person with Parkinson's to have the opportunity to take part in research, but there are barriers which are holding back clinical research in the UK. We're putting pressure on the Government to:

- create an environment in the UK that encourages and supports clinical research rather than hampering it with red-tape and bureaucracy
- put research at the heart of the NHS and make sure that every patient is told about opportunities to participate in research
- make it compulsory that every clinical trial in the UK is registered, the results reported and new treatments are made available
- share patient data collected through the NHS anonymously with researchers so that it can be used to study Parkinson's

### Myth

**Once I consent to taking part I have to complete the trial.**

### Facts

This isn't true: You can choose to leave a trial at any point and do not have to give an explanation.



## Should I take part in clinical trials?

Here's a post from forum member **Elegant Fowl** from a discussion about taking part in clinical trials on our online research forum.

So far I have done nothing more risky than MRI scans, although I'm open minded about participation in more invasive trials later.

There are many studies that are observational and that carry no significant risk.

Some of these require nothing more than carefully completing a few questionnaires and perhaps being examined by an extra doctor or two. These can add significantly to the knowledge of the condition and its treatment.

There are other options that involve giving fluid samples (saliva, blood or in exceptional cases spinal fluid via lumbar puncture) or spending an hour or two in an MRI scanner (I like them – but maybe I'm strange).

Slightly more invasive than the above are trials of drugs already proven safe for human use for other conditions but which show potential for Parkinson's.

Zolpidem (a drug for insomnia) and exenatide (a diabetes drug) are examples of these. But the more invasive trials like the ones using cell transplants or infusions into the brain are clearly not trivial undertakings.

Finally we can all participate after we are gone. The Parkinson's UK Brain Bank provides an invaluable resource for research. You have to be dead to get in (they insist on it) so it doesn't hurt a bit. You don't even need to have Parkinson's to join – all welcome.

There are loads of different studies that you can participate in and whatever your attitude to risk there is probably one for you.

To read more or join the discussion visit [parkinsons.org.uk/researchforum](http://parkinsons.org.uk/researchforum)

## Myth

Taking part in clinical trials is a last resort.

## Facts

There are clinical trials for those at every stage of Parkinson's. Trials investigate every aspect of life with Parkinson's, from new physiotherapy approaches, to cutting-edge new treatments like gene therapy.

## How can I find out about clinical trials taking place?

**1 Speak to your specialist** If you are interested in finding out about taking part in clinical trials for people with Parkinson's speak to your specialist. They will be able to advise about local studies you could take part in.

**2 Visit our website** We keep a list of Parkinson's research projects including clinical trials around the UK that are looking for participants on our website.

You can browse the list to find studies in your area [parkinsons.org.uk/researchstudies](http://parkinsons.org.uk/researchstudies)

**3 Join our Research Support Network** Our network brings people affected by Parkinson's together to help find a cure and better treatments for the condition.

People who join the network receive frequent emails from us highlighting opportunities to support research, including trials that need participants [parkinsons.org.uk/researchsupportnetwork](http://parkinsons.org.uk/researchsupportnetwork)

## Inside a clinical trial

In October last year, we launched a crucial new study to investigate whether a drug called GDNF delivered directly to the brain can help to improve Parkinson's symptoms – such as stiffness, slowness and tremor – and slow the development of the condition.

GDNF is a growth factor – a special protein that is naturally produced inside the brain and supports the survival of many types of brain cell – including the cells lost in Parkinson's.

However, because GDNF is a large protein it's quite difficult to get it into the brain. So in this trial participants are undergoing surgery to implant a device that can deliver the drug directly to the right area of the brain.

The £2million project is funded by Parkinson's UK, with support from the Cure Parkinson's Trust and in association with the North Bristol NHS Trust. The drug is being provided by Medgenesis, a Canadian biotech company.

**Tom Phipps was diagnosed with Parkinson's eight years ago at the age of 50 and was the first person to have this groundbreaking new treatment as part of our trial. We spoke to Tom about his experiences in the study and why he decided to volunteer.**

"I was diagnosed when I went to the GP about an injury I had that wasn't recovering. He referred me to the neurologist and 20 minutes later I was delivered with a diagnosis of Parkinson's.

"Almost immediately I thought 'I'm going to do something about this'. And since then I've been trying to do just that. I've become very involved in volunteering with Parkinson's UK. I've given talks, organised fundraising events and tried to keep myself fit.

"When the opportunity came to participate in a research trial that seemed particularly interesting I jumped at the chance.

"I first heard about the trial at my Parkinson's UK branch meeting in Bristol when Dr Alan Whone, the researcher leading the study, came to speak to us.

"He told us about the previous trials of the drug GDNF that happened several years ago in Bristol and produced promising results. He also explained the new cutting-edge delivery system, which he believed would address previous problems with delivering the drug to the right nerve cells in the brain.

"I was so keen on it that I approached Lucy, the research nurse for the study, and put myself forward. My wife and I were then invited for an 'interview' and I was assessed for my suitability for the project. We watched a video about the trial and what it meant to be a participant, and then I was asked what I was doing the next week. It all happened much more quickly than I imagined and lo and behold the next week I was having surgery to implant the drug delivery system into my brain. It was quite a leap of faith but I thought 'what the heck, I'm going to go for it'.

"Initially my family was worried. My wife hid it well but I think she was quite nervous because it is quite major surgery. But they were all really supportive and that's been so important, I couldn't have done it without them.

"For me it has been a privilege to be part of the trial. I think the project is absolutely brilliant – I think the team is fantastic. They're really friendly and as a participant you're part of a team, the consultant and the research nurse and the senior consultant surgeon, it's almost first name terms because you're all doing the same thing. You're working towards the same end which is the result of a major trial.



Tom

“To date, I don’t actually know whether I’m receiving the real drug or a dummy version, and neither do any of the research team. It has to be this way to make it a proper scientific test and I understand that. It’s not a proper trial if you don’t have a placebo. But I also know that after my first nine months, which is almost over, I’ll be switched onto receiving the real drug – so all participants do ultimately have the chance to take the ‘real thing’.

“It is quite an intensive study and it is a big commitment, but I believe the trial is worth it and that it’s going to make a difference for somebody – if not for me, then I hope for people with Parkinson’s in the future.”

#### Find out more

Find out more about the GDNF trial by visiting [parkinsons.org.uk/gdnf](https://parkinsons.org.uk/gdnf)

## Behind the scenes

Sharon Erb works at the Clinical Trials Unit in Newcastle and is the Trial Manager responsible for a Parkinson's study called MUSTARDD-PD. We asked Sharon to explain a bit more about this important trial and about her role 'behind-the-scenes'.

"MUSTARDD-PD is a large UK trial investigating whether a drug usually used to treat Alzheimer's, called donepezil hydrochloride, could also benefit people with Parkinson's who are experiencing mild memory and thinking problems.

"It's a double-blind trial so participants are randomly selected to receive either the donepezil hydrochloride or a placebo (dummy drug).

"This means that neither the doctors, the study office, nor the participants themselves know whether they are taking the active medication or placebo.

"Without the placebo group we wouldn't be able to work out whether the drug really works for people with Parkinson's.

"So while taking part in the trial may not directly benefit the people who receive placebo they are essential to making new treatments available to everyone living with the condition.

"Medical care can only advance through research and this simply can't happen without the people who take part in trials like ours.

"As the Trial Manager on this study I have had the responsibility of setting up the study, writing many important documents and gaining permissions for the study from the Ethics Committee and The Medicines and Healthcare products Regulatory Agency (MHRA).

"I work with all of the 22 different hospitals across the UK to make sure they have everything they need to carry out the study.

"On a day-to-day basis I manage the communications across a very large number of people and organisations. These include the different management teams overseeing the conduct and safety of the study, doctors and nurses at each of the research sites, the company providing the medication and the people funding the research.

"Although I now work in an office away from the clinical setting, I find it very rewarding to know that I am helping to conduct an important research study that could answer a question that is so important to people with Parkinson's and their families."

### What would you say to someone who was considering taking part in a new drug trial?

"Ask lots of questions. Ask your doctor about opportunities to participate in research. If there is a study you're interested in, find out as much as you can. Do you fit the criteria they're looking for? What does taking part in the study involve?"

"Knowledge is power and will help you make the decisions that are right for you."



## Diabetes drug trials – the story so far

Professor Clive Bartram is a retired consultant radiologist recently diagnosed with Parkinson's. Here he writes about the work of Dr Thomas Foltynie from the National Hospital at Queen Square, who is leading the trials of the diabetes drug, exenatide.

In 1992, Dr John Eng, from New York, decided to investigate the saliva of the venomous lizard, the gila monster, based on reports of its biological effects.

The compound Eng discovered, exenatide, is similar to the hormone released into the bloodstream when we eat that stimulates the production of insulin. It is now used in the treatment of type 2 diabetes.

More recently, Parkinson's UK-funded researcher Dr Peter Whitton from University College London, showed that exenatide also had an effect on the brain, both protecting and stimulating nerve cell growth in rat models of Parkinson's.

Dr Foltynie undertook a recently published pilot study of exenatide in Parkinson's in 45 participants assigned randomly to either exenatide treatment or a control group.

Exenatide has to be injected using a specially designed device. As a result, producing a 'placebo' version for this small trial was too expensive. So this trial was not a 'double-blind study', the gold standard for proving drug efficacy – and participants and researchers were aware of who was receiving exenatide and who was not.

The participants were assessed using a standardised rating scale for Parkinson's severity.

For the trial these ratings were made by reviewing videos of participants during the clinical examinations, so that the researchers were

unaware of who was on treatment or not. In this way the trial was partially 'blinded'. At the end of the trial the group receiving exenatide had, on average, improved by 2.7 points on the rating scale since the start of the trial.

In comparison, those who did not receive exenatide had worsened by 2.2 points over the course of the study – giving an overall difference of 4.9 points. When the same assessments were repeated two months later after stopping exenatide the difference was still 4.4 points.

Although this trial had limitations, the results are still valuable as they suggest that exenatide may not only slow the natural progression, but might also reverse Parkinson's to some extent.

Most importantly, it provided enough evidence to justify proceeding to a full double blind study funded by The Michael J Fox Foundation.

This will be achieved using specially constructed injection devices containing either exenatide or a placebo, so that all participants will be truly 'blinded' – they will not know if they are receiving treatment or not.

From a patient's perspective let us hope that this upcoming double blind trial confirms a role for exenatide in Parkinson's, as this will be a major step forward in the treatment of the condition.

### Find out more

We'll share the details about recruitment for the next trial as soon as we can. Look out for news on our website, or join the Research Support Network to receive updates.  
[parkinsons.org.uk/researchsupportnetwork](http://parkinsons.org.uk/researchsupportnetwork)



# NEW RESEARCH PROJECTS



In 2013 we've funded 15 new research projects that tackle a whole range of crucial questions for Parkinson's. Over the next few pages we'll introduce you to some of our new grants and the researchers leading them.

## Helping people with Parkinson's talk about non-motor symptoms



### Who?

Dr Catherine Hurt

### Where?

City University, London

### What?

£116,589 over 30 months

Catherine aims to develop an interactive web-based tool to empower people with Parkinson's to report non-motor symptoms to healthcare professionals. 'Non-motor' symptoms include problems with memory, sleep, mood, vision and the bowel and bladder. Most people with Parkinson's experience at least one of these non-motor symptoms, but many do not report them to their doctor and so do not receive the help they need. This may be because people don't realise the problem is related to Parkinson's, they don't think anything can be done to help, or they feel awkward or embarrassed.

Catherine hopes her study will shed more light on the reasons why people don't talk about non-

motor symptoms, and that these new insights will feed into developing practical web-based tools that empower people with Parkinson's.

"Non-motor symptoms can be very distressing. But if people can be encouraged to report symptoms, they will be more likely to receive appropriate care, reducing distress and improving quality of life, for them and their families."

## Bringing together the global thinking on Parkinson's genes



### Who?

Dr Ruth Lovering

### Where?

University College London

### What?

£190,000 over three years

This project will bring together the huge and expanding knowledge of the genetics of Parkinson's and make it accessible free of charge, to researchers all over the world.

In the last 15 years we've identified a range of genetic changes that play a part in Parkinson's. Understanding how these genetic changes affect how nerve cells work is providing vital new insights into why they die in Parkinson's, and how we may be able to protect them.

As techniques for analysing genes become more powerful, researchers around the world are uncovering more about the genes involved – creating a huge amount of information that is difficult to navigate.



Ruth is leading this highly collaborative project involving leading international experts in Parkinson's research who will work together to summarise what is already known about genes linked to Parkinson's and what they do.

"We'll add this information to genetic databases so that the whole Parkinson's research community will be able to use it. This will speed up global research into understanding the causes of Parkinson's, developing new treatments, and the creation of new diagnostic tests."

## Searching for biomarkers



### Who?

Professor Simon Lovestone

### Where?

UK-wide collaboration

### What?

£749,887 over three years

Biomarkers are subtle, but measurable changes in the body that could be used to diagnose and monitor Parkinson's. We already have them for other conditions – body temperature is a well-known biomarker for fever, and blood pressure is used to determine the risk of stroke.

Finding a reliable biomarker would transform the diagnosis and management of Parkinson's. It would also speed up research to find the next generation of treatments, which we hope will be able to slow or stop the progression of the condition.

We've awarded a major new research grant to Professor Simon Lovestone to lead the search

for biomarkers using the blood samples and information collected through the largest ever in-depth study of people with Parkinson's – Tracking Parkinson's, as well as people recruited to the Discovery study in Oxford.

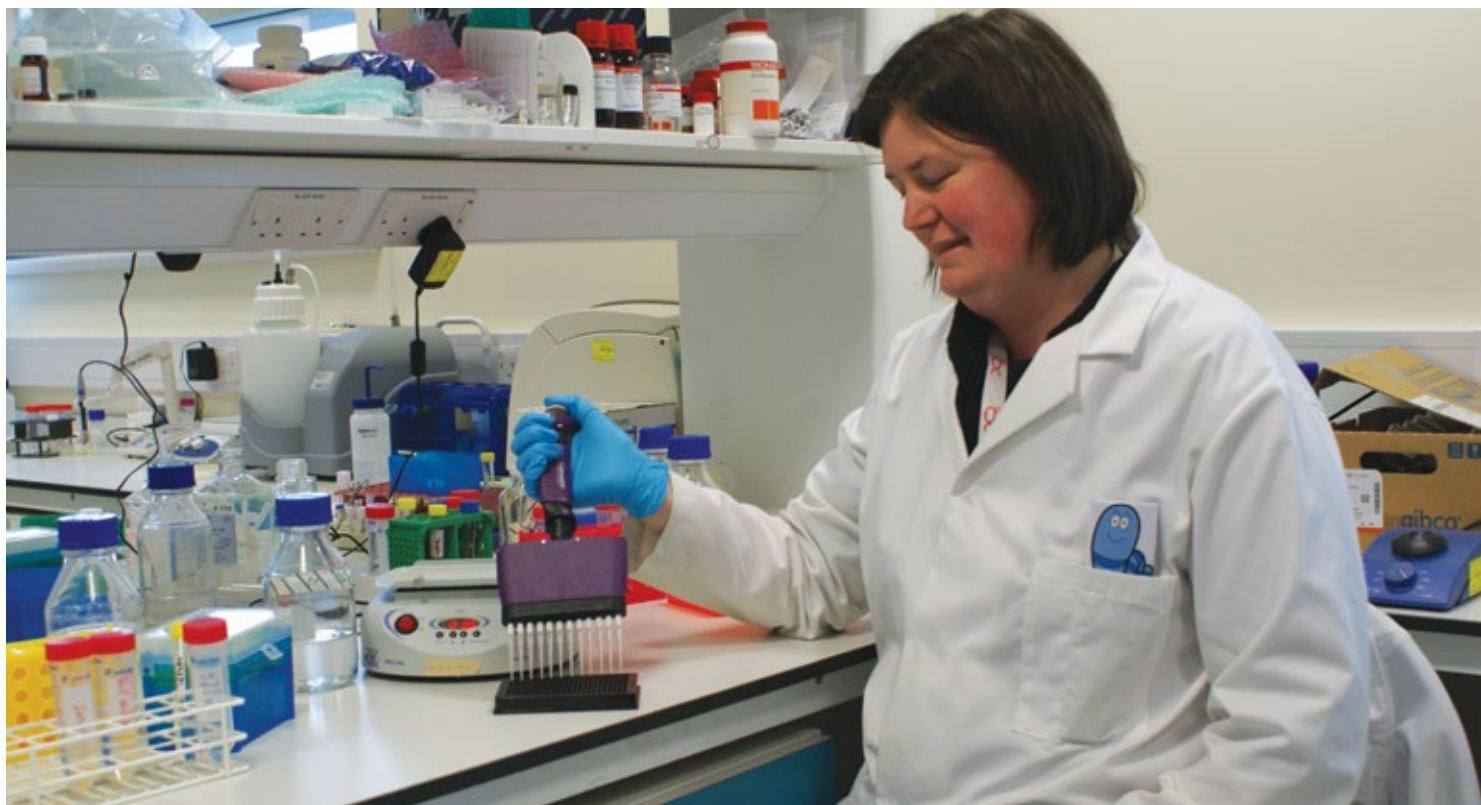
"Our expert team brings together Parkinson's researchers from across the UK who will work alongside biotechnology companies to tackle this major research project.

"I've been involved in the hunt for biomarkers for Alzheimer's over the past few years and now I'm keen to apply what I learnt there to Parkinson's.

"One key thing I've learnt is that simply comparing people with and without the condition is not enough. People with Parkinson's are not all the same. It's a very complex condition, people have varying symptoms, take different medications, have other illnesses and different lifestyles – and all these things need to be taken into account.

"The Tracking Parkinson's study gives us a unique opportunity to do this. We have access to detailed clinical information alongside biological samples, which means we'll be able to compare people with different types of symptoms and different rates of progression, as well as comparing people with and without Parkinson's.

"At the end of our three-year grant we hope to be in the position to develop a reliable test that can tell us if someone has Parkinson's, and more importantly, can tell us how severe their condition is. This is a really ambitious project, but I'm confident that we've come up with the right approach to close in on a biomarker for Parkinson's."



## Better drug screening – finding new uses for old drugs

**Who?** Dr Heather Mortiboys

**Where?** University of Sheffield

**What?** £249,565 over three years

We've awarded Dr Heather Mortiboys at the University of Sheffield a Career Development Award worth £249,565 to find existing drugs with potential for Parkinson's.

We've been talking to Heather about what inspired her interest in Parkinson's research and her hopes for her new three-year project.

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

I first became interested in Parkinson's while doing my first degree in Biomedical Science after an inspirational lecture in the third year.

Parkinson's is a condition that affects lots of people, which we've known quite a lot about for a long time and yet things have not progressed as quickly as people would have hoped. I wanted to find

out why it was so difficult a problem to solve and decided to do my PhD in Parkinson's research.

During my PhD I became fascinated by the mechanisms that lead to Parkinson's and how we can use our knowledge about these mechanisms to find better treatments for people living with Parkinson's – they are the reason I do research.

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

We are in very exciting times in Parkinson's research with several areas coming to the fore at the moment.

Powerful new techniques for DNA sequencing mean we can gain huge amounts of information about changes in genes, both the genetic code, but also subtle changes in how they behave.

This level of detail was not possible before and could provide us with vital clues to what is going on at different stages of the condition.

Progress is also being made in the hunt for biomarkers. Scientists are getting closer to finding ways to monitor the progress of the condition with simple tests. This would be a huge breakthrough,



allowing us to diagnose Parkinson's earlier and test new treatments more accurately.

But for me, the most exciting avenue for Parkinson's research is the new techniques available to carry out fast and accurate screening to find new drugs for the condition.

This used to be led by the pharmaceutical industry, but the advances in this area mean this is now something that university researchers like me can do.

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

I was the first person to discover problems in the tiny energy-producing batteries (called 'mitochondria') in skin cells from people with a rare inherited form of Parkinson's – which is probably my most important scientific achievement.

But my proudest achievement is being awarded the Career Development Award by Parkinson's UK.

I have dedicated my research life to Parkinson's and this award will enable me to do that. It came as a culmination of lots of hard work and determination.

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

I'm really very excited about this award as it allows me to explore many of the ideas I have been developing over my career to date.

The focus of my project is using drugs that are already used to treat other illnesses and seeing if they will be useful for people with Parkinson's – a strategy called drug re-purposing.

Unlike many drug screens I'll be focusing on drugs which are already in clinical use. This means the lengthy and expensive safety testing has already been done.

I am also weeding out any drugs which cause side effects which would make them unsuitable for people with Parkinson's. This means that any drugs we find should be able to move through to clinical trials quickly and safely.

To find out which drugs have potential for Parkinson's I'll be testing them in skin cells from people with three different forms of the condition:

- people with early onset Parkinson's caused by a mutation in a gene called 'parkin'
- people with late onset Parkinson's caused by a mutation in a gene called 'LRRK2'
- people with Parkinson's who don't have a family history of the condition

I hope this will help me identify drugs that will be of benefit to as many people with Parkinson's as possible.

I'll be looking specifically at how the different drugs affect energy production and waste disposal inside the cells.

These are both things that go wrong inside the nerve cells lost in Parkinson's, so any drugs can help cells do these tasks better may have exciting potential as new treatments.

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

The ultimate goal of the project is to find a drug that will have a beneficial effect for people with Parkinson's, hopefully even slowing the progression of the condition.

This is a pretty big goal, but I hope I've designed my project to avoid most of the pitfalls that will hopefully give me the best chance of success.

Becoming more involved with Parkinson's UK over the last year has given me the chance to meet with more people with Parkinson's and carers.

This has been immensely inspiring and makes me more motivated than ever to achieve something that can make a difference for the people who deal with the condition on a daily basis.

# 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.

## PERSPECTIVES ON POSTURE

In the last issue of *Progress* we shared the results of Parkinson's UK-funded researcher Dr Karen Doherty's project exploring the complex postural problems that can affect people with Parkinson's. Thanks to Brian and Darryl who both got in touch to share their interesting experiences of this aspect of Parkinson's:

I write having read the article about Karen Doherty's posture research in the last issue of *Progress* magazine.

My wife has Parkinson's with dementia and one of her earlier symptoms was an increasing forward-leaning posture.

This became quite severe, until she had a fall and was hospitalised with a broken hip.

The operation on her hip was quick but the hospital physiotherapists were unable to restore her mobility and she ended up having to stay in hospital for over six weeks.

The result of the long stay in bed was a complete and apparently permanent cure of her stoop, which amazed her doctors, who were not Parkinson's specialists.

Once home I was able to get her walking again with a frame and while she sometimes leant to one side or backwards, or to the left in her chair, the postural problems she had before never reappeared.

**Brian**

I was diagnosed with Parkinson's in 2000. By 2007-2008 I began to find myself less able to walk and photos of me show a growing stoop and lean to the right. I assumed that this was all part of Parkinson's and there was nothing I could do.

But in 2010 my consultant referred me to a specialist Parkinson's physiotherapist. She gave me simple exercises to do, advised me to try using the Nintendo Wii Fit and use a mirror to check my posture and monitor my progress. Another friend recommended I try Pilates.

Since then I have notched up 1,200 days on the Wii Fit and completed two, 10-week Pilates courses. I am still not perfectly upright, but a lot better than before. I can walk one to two miles whereas before I was struggling to manage a few hundred metres. I no longer get the pains in my appendix area, I can dig my allotment, play drums in a band, and I look better in photographs!

**Darryl**

I have received your latest *Progress* magazine and read it from cover to cover. It's so comforting to know so much research is going on throughout the world into finding a cure for this horrible condition. The magazine is easy to read and very informative. Keep up the good work!

**Dave**

## A STATISTICAL ERROR?

Thanks you very much for your lovely summer copy of *Progress* magazine. I think your front cover headline, 'Why do 1 in 500 get Parkinson's?', is incorrect. The chance of a person developing Parkinson's during their lifetime is estimated at one in 40 to one in 50 according to the British Medical Association. They state that between 2–2.5% of the UK population will be diagnosed with Parkinson's at some point in their life, more commonly after the age of 60 or 70.

**Joe**

Hi Joe, well spotted! You're absolutely right. What we should have said on the front cover is 'Why do one in 500 have Parkinson's?' Over the course of our lives everyone's risk of Parkinson's is probably much closer to one in 50.

I've just finished reading the latest issue of *Progress*, and I wanted to write immediately to compliment all involved on an excellent magazine. It's a great read, very accessible and informative without being patronising, and perhaps most importantly of all, it conveys a real sense of justifiable hope. I also very much liked the sense of participation that comes through in the articles on the World Parkinson Congress and the James Lind Alliance. Many thanks and well done to all involved.

**Melinda**

## AS EASY AS RIDING A BIKE...

I was interested in the article in the recent issue of *Progress* about the ability to ride a bike with Parkinson's.

I have used a bike to get around my village for some years as it so much easier and certainly quicker than walking. I have continued to use this mode of transport as it seems unaffected by my Parkinson's of some 15 years.

I believe that it has something to do with the enforced rhythm of the cycling motion. Likewise I find that stairs and steps whether up or down are no problem, and I can run far better than I can walk (although I admit that I ran as a sport for many years).

I also play golf two or three times each week walking behind an electric trolley.

I think all these activities enforce a rhythm on the brain and reduce the effects of Parkinson's. When I have to walk I mostly use walking poles, which once again enforce a marching movement.

They have the added advantages that people keep out of your way while at the same time giving an impression of athleticism that is not conveyed by a pair of walking sticks.

The arm of my dear wife also provides the necessary forward movement when none of the above tricks are practical.

**Alastair**



## Have your say

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

# WORLD PARKINSON CONGRESS: KIERAN'S ROUND-UP

The third World Parkinson Congress in October last year was three hectic days of plenary sessions, workshops, roundtables, posters and networking. But what did we learn from our trip to Montreal?

There was no earth-shattering news announced at the Congress, but it was a time for the global Parkinson's community to take stock of how far we've come and the challenges we need to tackle together. Having been to the previous Congress held in Glasgow in 2010, it was really encouraging to see the clear progress that we've made since then.

## Day 1: Why do nerve cells die?

The central question of what happens inside the brain in Parkinson's dominated the agenda. While we still do not fully understand why certain nerve cells die in the brains of people with the condition we have made important steps forward since 2010.

In particular, we've begun to tease apart the role of a protein called 'alpha-synuclein' in the spread of nerve cell death. It seems that this sticky, mis-shapen forms of this protein build up inside nerve cells causing all sorts of problems. More importantly, clumps of this rogue alpha-synuclein escape from cells and invade their neighbouring cells – creating a chain reaction of nerve cell death.

This recent discovery may give us an exciting new opportunity to create drugs that can stop the spread of alpha-synuclein and of Parkinson's in its tracks. We're currently funding a wide range of innovative projects investigating the behaviour of this crucial protein and developing strategies to prevent its destructive effects.

## Day 2: More than a movement disorder

Our focus turned to a very different issue – the complex array of non-motor symptoms that affect people with Parkinson's.

These include everything from sleep problems and constipation to depression and dementia, and they can have a devastating impact on people living with the condition. Having a whole day dedicated to non-motor symptoms is in itself a huge leap forward from 2010.

Despite their impact, it's only relatively recently that these symptoms have begun to be recognised as a core part of Parkinson's. I'm proud to say that the UK really is a world leader in this area of research.

This was demonstrated by fantastic talks from Professor Ray Chaudhuri from King's College London on the spectrum of non-motor symptoms, and by Professor David Burn from Newcastle University, who expanded on this in his talk on dementia and psychiatric problems.

Non-motor symptoms are often the most challenging to treat because we don't fully understand them and we don't have good quality evidence for what treatments work best. Both Ray and David currently hold grants from Parkinson's UK which are helping to fill the gaps in our knowledge and ultimately provide better treatment and care for people with Parkinson's and their families.

### Day 3: Towards a cure

Finally, day three and perhaps the most exciting day of the Congress as it was all about new approaches to treatment. Again a UK researcher, this time Professor Roger Barker from the University of Cambridge, gave us an update on where we've got to so far.

Roger focused on recent progress in cell and gene therapies for Parkinson's that both hold enormous potential for treating the condition in the future. Cell therapies mean using cells – like stem cells – as a treatment, and in the case of Parkinson's, growing healthy nerve cells that can be transplanted to repair the brain. While we haven't yet reached the stage of testing stem cell therapies in people with Parkinson's, there is a trial underway in Europe led by Roger that is testing transplants using foetal cells in people with the condition. If this trial is successful it could provide the launchpad needed to take the next step into stem cell treatments.

Roger explained how gene therapies have also made rapid progress in the past few years. These treatments use genes to change the behaviour of our cells and there are a number of different approaches currently being developed and tested in clinical trials. The most successful so far is one called ProSavin, which was developed by UK company, Oxford Biomedica. ProSavin works by boosting the activity of the three key genes needed for nerve cells to make dopamine.

### Remaining challenges

Of course there were also some major challenges highlighted at the Congress. Finding biomarkers – subtle but measurable changes that can be used to precisely diagnose and monitor Parkinson's – is an urgent need. The fact that we can't tell whether people with Parkinson's are getting better or worse is hampering clinical trials and our efforts to find better treatments. And being able to diagnose Parkinson's at the earliest possible

stage, before symptoms appear, is likely to be very important in future when we do have treatments that can significantly slow Parkinson's or stop it in its tracks.

The lack of suitable animal models was also a strong theme throughout the Congress. Without animal models that truly reflect Parkinson's, it's incredibly difficult to reliably test emerging therapies. As a result, many drugs that initially look promising in animal studies fail when we test them in humans. The opposite may also be happening, meaning promising treatments fail when we test them in animals and never reach the people who need them! Both of these issues are significant stumbling blocks for research – but what I found positive was the commitment from across the global research community towards solving these problems together.

Collaboration is going to be vital if we're going to crack these problems, and one of my personal highlights at the Congress was a meeting we organised to bring people together to discuss how we can best share data. There is a huge amount of brilliant work going on all over the world, but at the moment much of it is disjointed and the data generated is never linked up. Our meeting brought together some of the major players to thrash out how we can share data better and it was really positive to see the commitment from people from across many sectors.

So after three days I was left feeling very positive, not only about the major progress that's been made over the last three years, but also by the clear and important contribution that UK researchers and more importantly Parkinson's UK have made to that progress. In many areas we really are leading the world, and it's been fantastic to see that recognised on the world stage.

### Find out more

News and views from the World Parkinson Congress are on our website: [parkinsons.org.uk/wpc](https://parkinsons.org.uk/wpc)

# IS THERE A PARKINSON

Amanda Bates is a professional technical writer who just happens to have young-onset Parkinson's. She started blogging with Parkinson's when she noticed a relative lack of young-onset-specific material on the internet. She also juggles motherhood, part-time work and what she hopes to be a burgeoning career as an artist.

I've come across the idea that a certain type of person is more likely to develop Parkinson's several times now. One theory suggests that people who are, in some way, driven or obsessed are more likely to get Parkinson's. Another rather vaguely claims that people who develop Parkinson's are inherently more intelligent than average. Is either likely to be true? And is there any credible research on the subject? I was curious enough to go delving into the literature available online. A 1993 article in *Neurology* suggested that we're not usually thrill-seekers:

"Studies suggest that Parkinson's is associated with a particular group of personality characteristics. With relative uniformity, PD patients are described as industrious, rigidly moral, stoic, serious, and non-impulsive."

But that article seemed to be specifically about the current state of people who already had Parkinson's. The characteristics identified here could be an effect of the condition. What about before Parkinson's symptoms appear?

In a review from 2006 of past literature, looking at the pre-Parkinson's personality, the authors commented that:

"Parkinson's cases were more introverted, cautious, socially alert, and tense than controls. [...] the general descriptions of PD patients included nervous, cautious, rigid, and conventional."

It occurred to me to wonder if anyone had done any research specific to the personalities of people with young-onset Parkinson's.

After all, if there is a personality type more at risk of developing Parkinson's, you might imagine that such people might develop the condition earlier.

But I couldn't find anything apart from a note in a 1988 paper that there were "no differences in personality characteristics" between young and old onset Parkinson's.

And I'm sorry to say that I couldn't find the source of the suggestion that we are inherently more intelligent than average.

## Conclusions

The existence of a Parkinson's personality is uncertain. It seems that people have gone looking for it, and found one (which is, in itself, highly suspicious). But nobody is quite sure whether the personality traits that were identified are indicative of a likelihood of developing Parkinson's or an early symptom.

As Parkinson's is thought to begin up to 10 years before diagnosis, it may be difficult to tell whether the common traits are genuine aspects of an individual's personality or whether they are caused by the beginnings of a decline in dopamine in the brain.

# 'S PERSONALITY?



If there truly is a pre-Parkinson's personality then it seems to describe a reserved, well-behaved type with a tendency to depression and possible obsessive behaviour.

I fit some of that description, but not all of it. I do not believe that my personality has changed appreciably within the last 10 years or more, and I don't think my personality has been affected by the condition. I have to say that I'm not entirely convinced by the idea that there might be a pre-Parkinson's personality.

Muhammad Ali and Michael J Fox don't seem to fit the description very well. It's interesting to muse upon, but the whole idea is a bit ... dare I say unscientific? Measuring personality seems a very

difficult thing to do. Probably best left in the realms of anecdote and conjecture.

Read more of Amanda's musings on her blog:  
<http://bloggingwithparkinsons.wordpress.com>

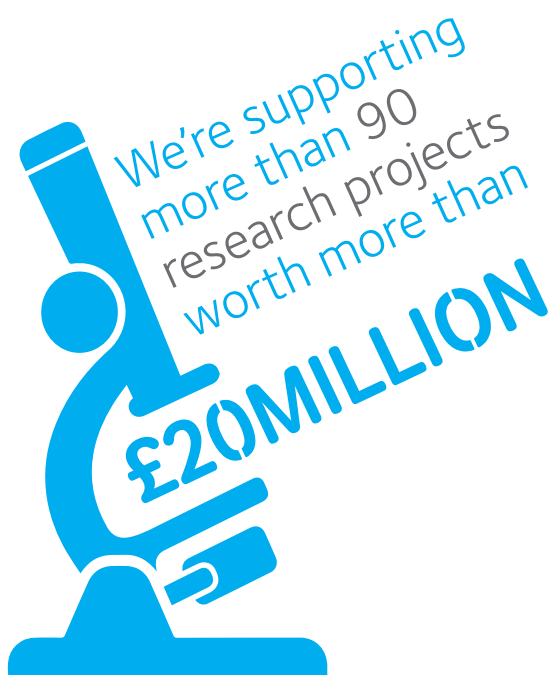
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- Ishihara L & Brayne C (2006) 'What is the evidence for a premorbid parkinsonian personality: A systematic review' *Movement Disorders*; 21:1066.
- Herbelein I et al (1998) 'Personality, depression, and premorbid lifestyle in twin pairs discordant for Parkinson's disease' *J Neurol Neurosurg Psychiatry*; 64:262.
- Gibb W & Lees A (1988) 'A comparison of clinical and pathological features of young- and old- onset Parkinson's disease' *Neurology*; 38:1402.

# FINDING A CURE FOR PARKINSON'S

We're the largest charity funder of Parkinson's research in Europe and we're leading the way to better treatments and a cure. To help explain our research, we've put together these eye-catching infographics and a short animation that you can watch on the website:

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



## Pioneering research

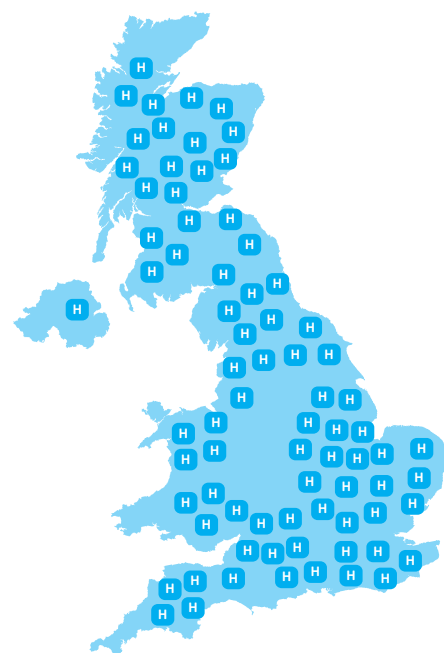
So far we've invested more than **£60million** in groundbreaking research.

Every research project we fund works towards improving life for people living with Parkinson's and a cure. We've already made enormous strides in our understanding of the condition and developed better treatments and therapies. But despite recent progress we are still searching for a cure.

## Thinking big

We're funding the world's largest ever in-depth study of Parkinson's.

Our Tracking Parkinson's project is the world's largest ever in-depth study of people with Parkinson's. This ambitious five-year project, fully funded by Parkinson's UK, aims to speed up our search for a cure by sharing in-depth information about Parkinson's with researchers all over the world.



More than 3,000 people across 70 hospitals in the UK are involved in the world's largest study of Parkinson's



## Connecting the world's best brains

Our research is global. We support Parkinson's research, wherever it is.

Research is a global business and at Parkinson's UK we like to keep a finger on the pulse of research happening across the world. We work in partnership with other international research organisations and encourage our researchers to collaborate and share with colleagues all over the world.



## Double your money

Last year, our researchers gained more than £5million from other funders.

Our funding acts like a magnet and helps researchers attract extra funding for their vital Parkinson's research from sources such as the Government and pharmaceutical industry.



## Bringing people together

Through our network, anyone can get involved in Parkinson's research.

We put people living with Parkinson's at the centre of our research and involve them in every aspect of our work. Our Research Support Network brings together people who are driven to help find a cure and better treatments for Parkinson's.

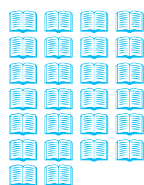
## Growing knowledge

Every project we fund adds a vital piece to the Parkinson's puzzle.

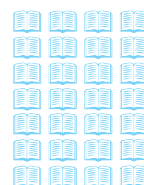
Our researchers deliver results that are paving the way towards better treatments, care and services for everyone living with Parkinson's – and one day a cure for the condition.



**50** investigating the causes of Parkinson's



**26** understanding and improving life



**28** finding better treatments and a cure

Parkinson's UK-funded researchers published **104** scientific papers last year

# RESEARCH RESULTS

Our researchers had a busy year in 2013. Over the next few pages (p26–31) we share exciting results from six projects. To keep up with the results and for more information visit [parkinsons.org.uk/researchresults](http://parkinsons.org.uk/researchresults)

## Online test identifies people at higher risk of Parkinson's

A study led by Parkinson's UK research fellow Dr Alastair Noyce has shown that a simple online test can be used to identify people who may be at higher risk of developing Parkinson's.

This study involved 1,324 people without Parkinson's who were over the age of 60. It involved a combination of an online survey, keyboard tapping test and smell test. The early results were published in the *Journal of Neurology, Neurosurgery and Psychiatry*. The project began with an innovation grant of £35,000, awarded to Alastair in 2010. This paved the way for Alastair's Career Development Award of £246,439, which runs until 2015.

.....  
"I took part to help people like my friend."  
**Participant**  
.....

## Risk factors and early symptoms

By the time the movement symptoms of Parkinson's appear, more than 70% of the precious dopamine-producing nerve cells affected in the condition have already been lost. But problems including constipation and sleep disturbance can start many years before. Other factors can slightly influence our risk of developing Parkinson's. For example, having a close relative with the condition can increase it, and drinking coffee can reduce it. Alastair pinpointed a number of factors like these, which he included in the survey. This gave everyone who took part a risk 'score'.

## Predicting Parkinson's

To test the survey, the team used sense of smell and finger tapping – both of which are affected early in Parkinson's – as physical markers of risk. When they put all the risk scores in order, they found that those with the highest risk scores had significantly reduced sense of smell and finger tapping speed compared to those with the lowest risk scores.

The next phase of the study will help the team refine the survey to make it as accurate as possible. All participants will be asked to complete survey and tests again on a yearly basis. And smaller groups who scored either 'high' or 'low' for Parkinson's risk, as well as some in the middle, will be invited to have full clinical examinations and brain scans. Of the participants currently enrolled in the study, statistically only around 10 are likely to develop Parkinson's.

Alastair comments:

"Researchers around the world are working hard to develop the next generation of treatments for Parkinson's. 'At risk' individuals could be ideal candidates for clinical trials. If we can identify people early – before the onset of movement symptoms – we would be in the best possible position to slow or stop the progression of the condition."

## References

Noyce AJ et al (2012) 'Meta-analysis of early nonmotor features and risk factors for Parkinson disease' *Annals of Neurology*, 72:893–901

Noyce AJ et al (2013) 'PREDICT-PD: Identifying risk of Parkinson's disease in the community: methods and baseline results' *J Neurol Neurosurg Psychiatry*

## Highlighting the impact of non-motor symptoms in early Parkinson's

Results from our funded research at Newcastle University suggest that non-motor symptoms are not only common in people with newly diagnosed Parkinson's, but have a significant impact upon their quality of life.

Non-motor symptoms are those not relating to movement. They include symptoms such as constipation, depression and sleep problems. The study, which was published in the journal *Movement Disorders*, was carried out as part of a much larger project led by Professor David Burn, worth £1.18million over five years.

### What the team did

158 people newly diagnosed with Parkinson's and 99 people without the condition took part in the study.

All participants completed:

- the non-motor symptoms questionnaire
- a health-related quality of life questionnaire
- an assessment of their mobility, mood, sleep, thinking and memory

On average, people newly diagnosed with Parkinson's were experiencing eight non-motor symptoms, compared to people without the condition who experienced three.

Depression, incomplete bowel emptying, anxiety, impaired concentration, memory and sleep problems had the greatest impact upon quality of life.

.....  
"Anxiety stopped me in my tracks last year, so I had sessions of cognitive behaviour therapy. While it didn't 'cure' my anxiety it certainly helped me to recognise the symptoms of an attack so I could try to do something about it."

**Djemm, from our online forum**  
.....

### Non-motor symptoms can appear early

Dr Gordon Duncan, who was the lead author of the study, comments:

"Non-motor symptoms are known to have an impact upon quality of life in people who've had Parkinson's for some time, but our study shows they can also be a significant problem for people newly diagnosed with the condition. Our results emphasise the importance of screening for non-motor symptoms not only in the more advanced stages of Parkinson's, but also at the time of diagnosis."

.....  
"I never had constipation until I started some new medication. I felt awful, but my Parkinson's nurse gave me advice and I feel a lot better now."

**Alun, who has Parkinson's**  
.....

### The non-motor symptoms questionnaire

Our non-motor symptoms questionnaire is for people with Parkinson's to complete to help health professionals assess their non-motor symptoms.

Order free or download at [parkinsons.org.uk/nonmotorquestionnaire](http://parkinsons.org.uk/nonmotorquestionnaire)

### References

Duncan GW et al (2013) 'Health-related quality of life in early Parkinson's disease: The impact of nonmotor symptoms' *Movement Disorders*

**Below:** People with Parkinson's can have trouble getting to sleep.



## Clues about the early stages of Parkinson's from new mouse model

Our researchers have developed a new genetic mouse model of Parkinson's to track the earliest changes that take place in the brain.

The study was carried out at The Oxford Parkinson's Disease Centre, which was set up in 2010 as part of Parkinson's UK's largest ever research project: The Monument Discovery Award – worth £5million over five years.

### Dopamine is affected from the beginning

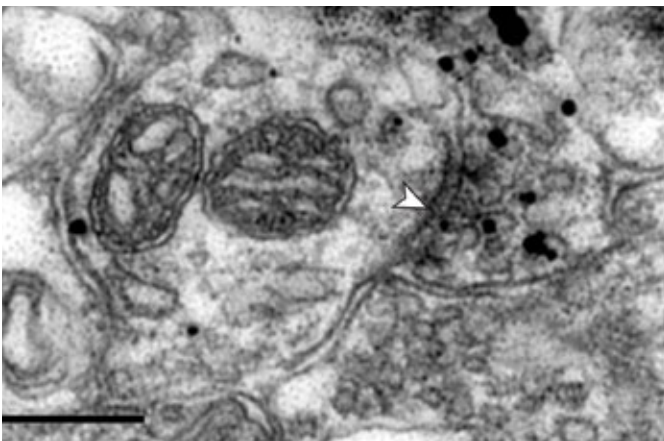
The team genetically engineered mice to produce high levels of the human version of a protein called alpha-synuclein.

Alpha-synuclein is thought to be a key factor in nerve cell death in Parkinson's. It forms the sticky clumps, known as Lewy bodies, found inside the Parkinson's brain. But we don't know exactly how alpha-synuclein is involved in the chain of events that causes nerve cells to die.

This study is the first to show that the way the chemical messenger dopamine is stored and released is affected at the very start of the process – before Lewy bodies appear.

### Animal research is vital

Dr Richard Wade-Martins, head of the Laboratory of Molecular Neurodegeneration and lead



**Above:** under the microscope: dopamine builds up at the junction between nerve cells.

researcher on the Monument Discovery Award, comments:

“Up until now it was assumed that Lewy bodies form first and drive the development of Parkinson's. Our work shows that dopamine-producing nerve cells stop working properly long before they start to die, and before Lewy bodies have a chance to form.

“Parkinson's is a progressive condition that develops slowly over time.

“One of the major barriers to developing new treatments for Parkinson's is that existing animal models don't accurately mimic the changes that take place in the brain.

“This new model will help us understand the condition better, and ultimately find a cure.”

The groundbreaking study was published in the leading scientific journal *Proceedings of the United States National Academy of Sciences*.

### Reference

Janezic S et al (2013) 'Deficits in dopaminergic transmission precede neuron loss and dysfunction in a new Parkinson model' *PNAS*; 110:E4016–25

## Research reveals potential for new Parkinson's drugs

Drugs that may have potential to protect the nerve cells affected in Parkinson's have been identified by researchers at the world-leading Sheffield Institute for Translational Neuroscience (SITraN).

The study, which was carried out as part of Dr Heather Mortiboys' new Career Development Award (see interview on page 16), was published in the top journal, *Brain*.

The team tested more than 2,000 compounds on skin cells from people with Parkinson's. They focused on the effects on mitochondria – the tiny batteries that power every cell in the body.

Problems with mitochondria are thought to play a major role in nerve cell death in Parkinson's.

They identified a group of drugs that improved the ability of mitochondria to produce energy, including one with particular promise called ursodeoxycholic acid (or UCDA) – a drug used for decades to treat certain forms of liver disease.

Because this drug is already widely used, we have a head start in the clinical trials marathon. We are working with the researchers to see how we can bring this forward.

### Reference

Mortiboys et al (2013) 'Ursocholic acid rescues mitochondrial function in common forms of familial Parkinson's disease' *Brain*: 136;3038–50

## Fat – a new source of stem cells for Parkinson's?

Researchers at University College London have successfully isolated stem cells from human fat, and turned them into the type of nerve cells affected in Parkinson's.

Stem cells are like blank cells that can turn into any type of cell in the body. Nerve cells made from stem cells are a vital resource for Parkinson's research, effectively giving us a window into the brain.

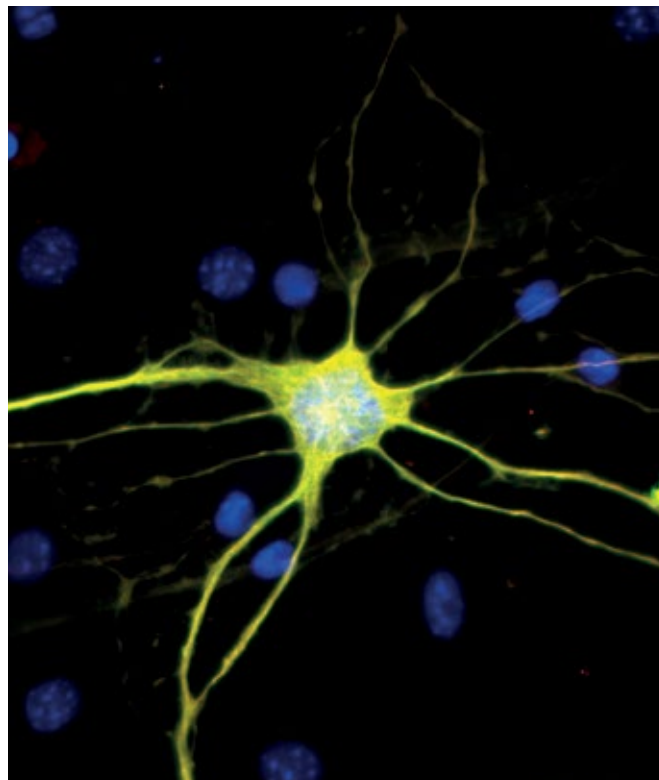
Stem cells taken from embryos (or embryonic stem cells) were the first to be studied. But we can now get stem cells from a few different sources.

The team found they only needed to take a tiny (less than 1mm) skin biopsy to collect enough cells for their experiments.

Now they have shown that their technique works, they plan to use samples from people with inherited Parkinson's, and have collected 15 so far.

They will use these cells – that are genetically destined to develop Parkinson's – to study what happens inside the nerve cells affected in the condition, and as a tool to test new drugs.

This exciting study was made possible by an innovation grant of £15,500, awarded to Dr Jan-Wilem Taanman in 2012.



Above: Nerve cell grown from a fat stem cell.

## Specialist ward improves care for people with Parkinson's

A team at Derby hospital have shown that a specialist unit can make a real difference to people with Parkinson's when they're admitted to hospital.

An innovation grant of £34,996, awarded to Dr Rob Skelly in 2012, allowed the the hospital to set up the unit where:

- all staff were trained on Parkinson's medications – particularly the importance of giving them on time and their side-effects
- Parkinson's medications were available on the ward to reduce delays in administration

“It's very important with people with Parkinson's to carry on the same routine they have at home so they don't lose the benefits of their medication.”  
**Gill Longmate, Ward Sister**

Rob, who is a geriatrician with a special interest in Parkinson's, led this pioneering study. He explained the team's findings in his final report.

# RESEARCH RESULTS

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

"Many people with Parkinson's don't get the care they need in hospital. Sometimes staff aren't familiar with Parkinson's, its complications or drug management. This can mean medication is delayed or not given, and this might reduce mobility and lead to longer stays in hospital.

"It was people with Parkinson's who really highlighted the need to improve hospital care to me. And Parkinson's UK drew attention to the problem with their Get It On Time campaign.

## What were your goals for the project?

"We wanted to set up a specialist in-patient unit, with specially trained staff, for people with Parkinson's needing urgent admission to hospital.

"The aim of this research was to find out if a Specialist Parkinson's Disease Unit (SPDU) could help to ensure people with Parkinson's get their medication on time, improve their experience in hospital, and reduce their length of stay.

"During the study we aimed to collect information to support plans for a larger, multi-centre study.

## What have you found?

"Before setting up the unit we gathered information from general wards which we compared to our findings from the specialist unit.

We found:

- less Parkinson's medication was missed – 13% on the SPDU and 20% on general wards
- more medication was given on time – 64% of medication was given within 30 minutes and 91% within an hour on the SPDU compared to 50% given within 30 minutes and 79% given within an hour on general wards
- people with Parkinson's and carers were more satisfied with the care they received and the average length of stay fell from 13 to nine days

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"It gives the patient far better quality of life while in hospital."

**Owen, whose wife Rosemary has Parkinson's**

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## What are the next steps?

"Although our pilot study is promising, evidence from a bigger randomised trial is needed to convince NHS commissioners that they should



**Above:** Dr Rob Skelly and the team at Derby hospital.

adopt this approach. We're currently planning a larger trial which will include cost-effectiveness analysis.

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

"The team have agreed to continue the project. We're working to make the specialist beds more accessible, as beds are not always available for every person with Parkinson's admitted. We plan to appoint a more senior physiotherapist and will continue to provide training for new and existing staff. We hope that other hospitals in the UK will choose to set up similar units."

#### Get it on time

We launched Get It On Time to make sure that the thousands of people with Parkinson's admitted into UK hospitals each year get their medication on time, every time.

If people with Parkinson's don't get their medication on time, their ability to manage their symptoms may be lost. For example they may suddenly not be able to move, get out of bed or walk down a corridor.

Visit [parkinsons.org.uk/getitontime](http://parkinsons.org.uk/getitontime) for more information.



#### Find out more

Watch Rob talking about the study at the World Parkinson Congress in October last year: <http://bit.ly/1fOh2LQ>







# THE PARKINSON'S UK BRAIN BANK

We're the UK's largest Brain Bank dedicated to Parkinson's. We 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.

This year, the team at the Parkinson's UK Brain Bank have continued their vital work, providing information for those who are considering joining the register and working with researchers who request tissue for their studies.

By working closely with several large Parkinson's UK-funded research studies including 'Tracking Parkinson's' and the 'Monument Discovery Project', the number of registered donors has increased.

- This year the team collected 103 brains from people with Parkinson's, and 17 from people without the condition.
- The total number of brains at the bank now stands at 641 brains from people who had Parkinson's and 154 from people who didn't.
- The current number of registered donors is 5,850 (up 283 from last year). Of these, 1,794 (31%) have Parkinson's and 4,056 (69%) don't.
- The Brain Bank received 40 new tissue requests from researchers around the world this year (25 from the UK, 10 from Europe and five from the rest of the world).

## How donated tissue is working towards a cure

Using brain tissue to unravel the causes of Parkinson's is a vital step towards the next generation of treatments that could slow or stop the progression of the condition. Tissue can also help us to understand the underlying reasons for symptoms often experienced and ultimately help us to improve life for those with Parkinson's today.

Here are some of the latest findings based on research using tissue from the Brain Bank:

**Calcium** A report published in the journal *Brain* provided further evidence that too much calcium may play a part in the loss of the dopamine-producing nerve cells lost in Parkinson's.

**Genetics** A new study published this year found changes to the COMT gene, involved in the production of dopamine, may affect the age of onset of Parkinson's, particularly in men.

**Sleep** The underlying reasons for sleeping problems often experienced in Parkinson's are not well understood. This year research using Brain Bank tissue has shown an association between the presence of Lewy bodies (sticky clumps of protein that form inside nerve cells in Parkinson's) in particular areas of the brain and disturbed sleep.

## Sharing this research

This year the Brain Bank has continued to share it's vital work at several prestigious international scientific meetings including the 11th International Conference on Alzheimer's and Parkinson's. The team have also hosted a number of Parkinson's UK visits for both supporters and staff including their 'Meet the scientists' open day, which were a great success.

[Find out more parkinsons.org.uk/brainbank](https://parkinsons.org.uk/brainbank)

# “I’VE GOT NOTHING TO LOSE BY TRYING IT”

It is completely understandable, when faced with any illness but especially a chronic and progressive one, to reach for any potential treatment. But sometimes you can reach too far into unproven ‘natural’ remedies, as researcher supporter Jonathan explains below.

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This is particularly important when dealing with the issue of cures – the hope for one can make you vulnerable. People with an incurable and chronic illness are predisposed to listen to talk of cures.

However, such talk can give you false hope and lead you down the wrong path. Describing something as ‘natural’ does not make it more likely to succeed. There is no difference between ‘natural’ and man-made ‘chemicals’ because nature is a monumental chemical factory and uses the same atoms as we do to make chemical compounds.

Levodopa, the main drug treatment for Parkinson’s, is a precursor to dopamine, but dopamine is naturally occurring. So why is it ‘unnatural’ – implying harmful – to take it in tablet form?

Most natural remedies are based on the testimony of one person. It often goes something like this: ‘I eat some chocolate and find my symptoms improve – therefore, the chocolate must be helping me get better’.

But this misses many other possible reasons for the improvement such as the normal variation in symptoms, the feeling you are doing something to help yourself, the sugar in the chocolate providing more energy and so on.

In other words, there could be many contributing factors that lead to symptoms improving.

The charity Sense about Science has published a clear and sensible booklet called *I’ve got nothing to*

*lose by trying it* to help people navigate the tricky issue of ‘cures’.

Scientific knowledge is only science if it is supported by evidence – there is no place in science for blind trust.

Therefore, anyone who claims to have found a cure should have a wealth of published evidence to show you. Such evidence is the basis of a scientist’s reputation so they will be proud to share it.

We all have a responsibility to assess the evidence. However, not everyone has been trained in science.

This is where charities like Parkinson’s UK come in. They are in touch with the scientific community and can present the evidence in plain language to enable people to make informed choices.

Parkinson’s can make you feel vulnerable and alone. It is therefore crucial to empower people with knowledge and hope – but it is equally disempowering to give false hope.

## Find out more

Read more from Jonathan on his blog: <http://dialoguewithdisability.blogspot.co.uk>

Download a copy of the guide from the Sense about Science website: <http://bit.ly/zC12m2>. Or request a copy from Parkinson’s UK by calling **0207 963 9313**.

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[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).

## 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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