

PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.

PROGRESS

The research magazine of Parkinson's UK
Issue 16 Winter 2014/15



Parkinson's. It's time to get personal.

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WELCOME

This issue our welcome comes from our Chief Executive Steve Ford who shares his thoughts on an exciting new chapter for Parkinson's UK research.

In every issue of *Progress* we fill you in on promising areas of research that we all hope will lead us to a cure for Parkinson's. But clinical trials are just part of the challenge.

To enable people to live their lives free from the symptoms of the condition we need to make sure that a massive leap takes place – that pharmaceutical companies believe in and invest in the discoveries that are made.

Connecting everyone involved in the development of a cure and better treatments is a key part of the new strategy for Parkinson's 2015-2019. To do this takes vision and leadership, which is why Arthur Roach has joined us as our new director of research and development.

As you'll see on page 20-21, his experience will enable him to bring together partners at every stage of the drug development process to tackle the roadblocks slowing our progress and capitalise on opportunities.

It's not only about connecting people – it's about inspiring them too. We need to make sure the most urgent challenges are being addressed by people who are 100% committed to finding the answers as soon as possible.

At our conference the end of 2014, we brought together some of the biggest names in the Parkinson's research community and some of the most passionate people who are living with the



condition. Both groups are equally important to the success of Parkinson's research.

Over the next year we'll be making sure there are even more opportunities for people affected by Parkinson's to get involved.

If you'd like to be a part of our exciting research do join the Research Support Network by visiting parkinsons.org.uk/rsn to stay up to date with opportunities. And thank you for all your support in the meantime.

INTERNATIONAL NEWS ROUNDUP

There have been some exciting developments in Parkinson's research over the last few months. Here's a summary of some of our favourite news stories.

Anti-inflammatory drug shows promise for Parkinson's

US researchers have discovered a new drug, called XPro1595, which may be able to protect brain cells from dying in Parkinson's by blocking inflammation.

We know that inflammation may be involved in the death of cells which cause Parkinson's. So drugs that can reduce inflammation may be able to halt the progression of the condition.

In this study, the researchers tested XPro1595 in rats that had been given a chemical which damages the brain cells affected in Parkinson's. The researchers found that the drug entered the brain where it was able to stop cells from dying and reduce movement symptoms in the rats.

This new drug may have the potential to stop the condition in its tracks, but it is still very early days and much more research is needed. The next step is to translate these findings into a safe and effective treatment for people with Parkinson's.

parkinsons.org.uk/researchnews29jul2014

Parkinson's dementia - it's in the genes

Parkinson's UK-funded researchers in Cambridge and Newcastle have discovered changes in three genes that may affect memory and thinking in people with early Parkinson's.

Unfortunately, people with Parkinson's are much more likely to get dementia than people of similar age without the condition. But at the moment we cannot predict who is at risk.

Over 200 people with and without Parkinson's took part in the study. People with differences in 3 genes did less well on tasks testing spatial awareness, memory and decision making.

These subtle changes in thinking – called mild cognitive impairment – may be an early warning sign of dementia.

Finding genes that are linked to early thinking problems will help us understand why some people with Parkinson's develop dementia, and give us clues to develop new treatments.

parkinsons.org.uk/researchnews7aug2014



GDNF Parkinson's trial given major boost by Pfizer

The future of our biggest clinical trial – GDNF – has received a significant boost. Leading pharmaceutical company, Pfizer, has committed to investigating the possibility of a larger study into the potential treatment when our research ends.

This means that if the results are promising, then a much-needed, larger clinical trial could take place – providing the vital support we need to ensure the treatment could be made available to people with Parkinson's.

Currently, our researchers in Bristol, are working with a promising protein called GDNF, which we believe may hold the key to stop Parkinson's getting worse, something which no existing treatment can do.

Our small trial is investigating whether infusing GDNF directly into the brain using a specially designed delivery system could help to improve symptoms and slow down the development of the condition. Results are expected towards the end of 2016.

parkinsons.org.uk/researchnews16sep2014

Smartphone apps to spot early signs of Parkinson's

One day smartphones could be used as 'pocket doctors' to spot early signs of Parkinson's, by measuring subtle changes in speech and movement.

Researchers at the University of Oxford are testing whether a smartphone can sense tiny changes in voice, walking behaviour and manual dexterity in 2,500 people with Parkinson's.

This research is a welcome step forward. Parkinson's is a very complex and fluctuating condition – so effectively managing it is a real challenge.

Smartphones offer huge potential as they continuously capture information, and can monitor subtle changes – such as an increase or decrease in someone's tremor.

Arming doctors and people with Parkinson's with this technology could revolutionise the way the condition is managed.

parkinsons.org.uk/researchnews9sep2014

News in brief

Wearable technology to manage Parkinson's

We are helping bring an innovative medical device designed in Australia – which is worn like a watch and captures information about movement – to people with Parkinson's in the UK.

Electrical brain stimulation boosts memory

Exciting a specific part of the brain with electromagnetic pulses could boost our ability to remember certain facts, a study in Science suggests. The US trials involving 16 volunteers found the non-invasive procedure could boost our ability to remember certain facts.

Age may not be a barrier to DBS

Deep brain stimulation is a well-established therapy for Parkinson's but it's not always offered to older people who may be suitable. US research suggests that people over the age of 75 are no more likely to experience complications from the procedure than younger patients.

Bulgarian yogurt: a cure for Parkinson's?

Last year, The Sun reported on research claiming Bulgarian yogurt could help fight Parkinson's. This study was carried out in microscopic worms, so there's a huge amount of work to do before these early findings could lead to a treatment for people with Parkinson's.

Google buys firm behind Parkinson's spoon

Global business giant Google has purchased Lift Labs, a biotech company who make a tremor-cancelling spoon for people with Parkinson's.

David Burn on non-motor symptoms

David Burn, our Clinical Director, has spoken about non-motor symptoms in a global online webcast series hosted by the World Parkinson's Congress. Listen to all the webcasts at:

<http://www.worldpdcoalition.org/webcasts>

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

www.twitter.com/parkinsonsuk and parkinsons.org.uk/researchnews

PARKINSON'S. IT'S TIME TO GET PERSONAL.

If you give 100 people with Parkinson's a drug, half may benefit but the other half may experience severe side effects. Overall your trial has failed, but does this mean your drug is useless? Or does it actually mean that you've actually tested it in the wrong people?

A more personal approach...

Personalised medicine has the potential to transform the way we look at and tackle Parkinson's. The simple concept behind personalised medicine is that we become smarter at identifying the people who will benefit from different treatments.

Currently we treat Parkinson's as if it's one condition. We're starting to realise that there may actually be many different forms. We therefore can't rely on a 'one size fits all' approach to treating it.

Instead of treating all people with Parkinson's the same, a personalised approach would help us give the right treatment, care and support to each individual based on their particular symptoms and how their condition is likely to develop.

Personalised medicine is currently most advanced in cancer. Rather than treating tumours based on where they grow in the body, doctors can now choose the correct treatment based on the genetic fingerprint of the cells inside the tumour.

This has revolutionised the treatment of many cancers and led to much more targeted treatments that not only improve survival rates but also come with fewer side effects than traditional chemotherapy.

One of the first examples is trastuzumab, better known as herceptin, a drug that blocks the HER2 receptor which becomes overactive in some types of breast cancer. Women with breast cancer can have a test to see if they have overactive HER2 receptors and if the drug will be useful.

So how do we make Parkinson's treatment more personal?

The first step towards delivering truly personalised treatments for Parkinson's is to work out how many different types of the condition there are, and how they present and progress.

This requires a huge amount of carefully collected data – and it's exactly what we're doing through two of our largest projects: Tracking Parkinson's and the Oxford Parkinson's Disease Centre. Both projects are studying Parkinson's by closely monitoring people who have recently been diagnosed and collecting information about every aspect of the condition as it develops over time.

Dr Michele Hu is leading a Parkinson's UK team at the University of Oxford which, in 2010 began recruiting participants who'd recently been diagnosed with Parkinson's.

Now there are more than 1,400 people participating – including people with Parkinson's, relatives, unrelated healthy volunteers and people with REM sleep behavior disorder. People with this condition act out their dreams and we know they are much more likely to develop Parkinson's.

Michele comments:

"The special thing about our study, and the Tracking Parkinson's project, is that we're collecting incredibly detailed information from lots and lots of people with Parkinson's. And because we're working extremely closely with our colleagues in the Tracking Parkinson's project,



the two studies are very closely matched which makes them even more powerful.

“We’ve now been collecting data from our participants for a couple of years and it’s already beginning to reveal some fascinating insights into Parkinson’s.

“We’ve discovered that there are differences between men and women who have Parkinson’s. Men are more likely to experience problems with

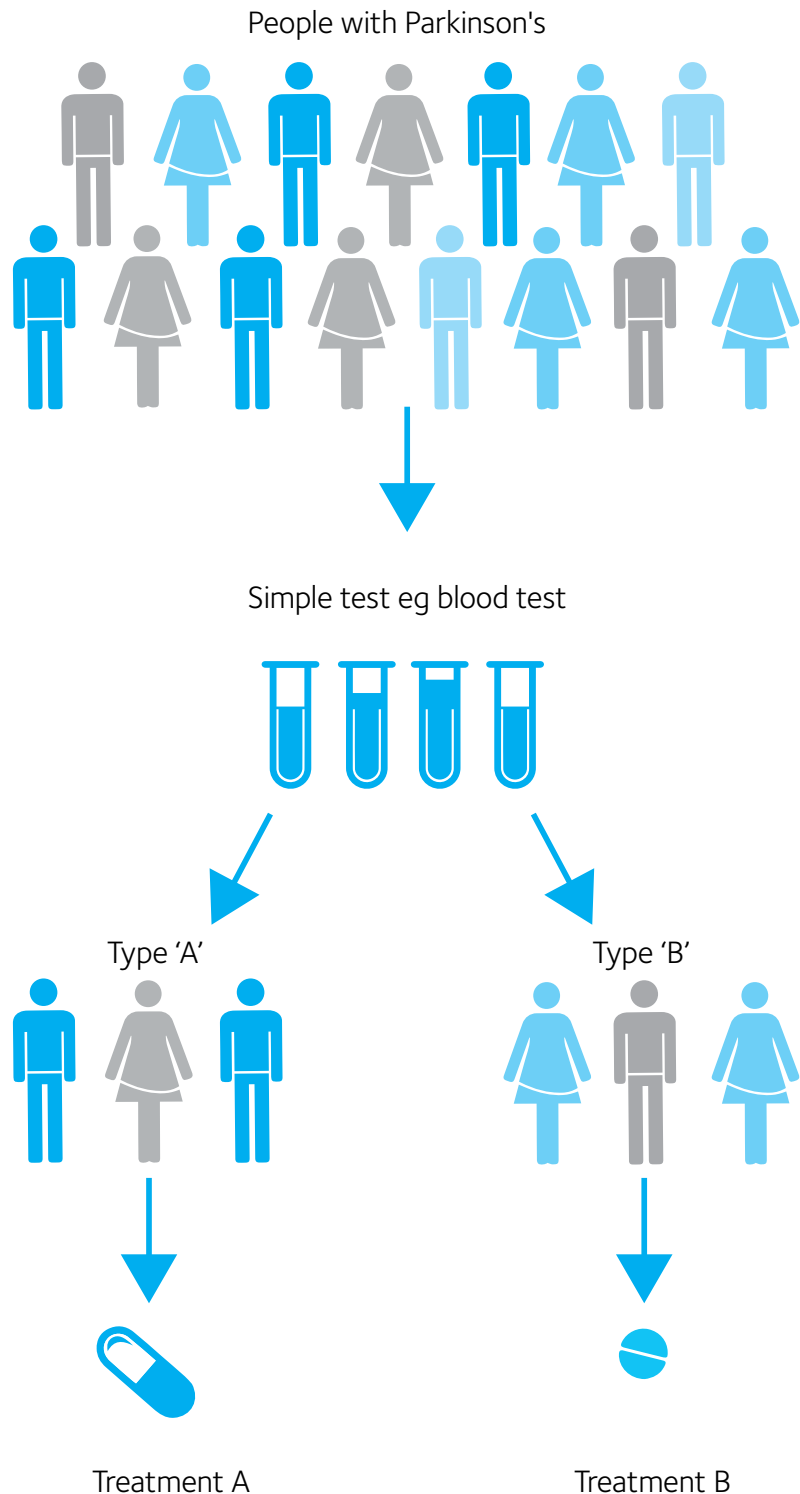
memory, postural hypotension (dizziness on standing) and sleep problems. While women tend to experience more problems with posture and balance.

“Even more excitingly, we think that we are beginning to be able to separate the people with Parkinson’s in our study into distinct groups based on their symptoms and how the condition is progressing.”

How would personalised medicine help people with Parkinson's?

When treatment gets personal everyone benefits.

- People with Parkinson's would receive the right treatments for them, giving them the best control over their symptoms with fewer side effects.
- Researchers will be able to test new treatments in people with Parkinson's who are most likely to benefit - making drug trials faster and much more likely to succeed.
- The NHS will benefit from time and cost savings so doctors can treat Parkinson's more effectively.



PARKINSON'S. IT'S TIME TO GET PERSONAL

People powering research

Without the thousands of people with Parkinson's and their loved ones who take part in this research, personalised medicine would remain an impossible dream.

Lucy was diagnosed with Parkinson's at the age of 38 and moved to Oxfordshire shortly afterwards with her husband Angus and their two cats. Now both Lucy and Angus are taking part in our Oxford study and here they explain what motivated them to get involved:

"I decided to take part in the study because I felt I had an overwhelming responsibility to help. In 30 years' time I don't want to be complaining that there is still no cure for Parkinson's, knowing that I could have taken part and didn't.

"The experience has been fascinating and thorough, and has helped me understand my condition a bit more, as I am still getting used to it. All of the staff were positive and friendly, and having recently moved to the area, taking part provided another means of support."

Lucy

"I didn't hesitate for one minute at taking part in the research study. I now have a far better understanding of Parkinson's and an appreciation of what Lucy has to deal with on a daily, even hourly basis. Not only is the study interesting but it's a journey we can take together."

Angus



A digital revolution

Now researchers are turning to technology to help them study Parkinson's in greater detail than ever before. Michele comments:

"One of the greatest challenges for me as a consultant and researcher is that I generally only see my patients for short windows every six to twelve months."

"Parkinson's is a fluctuating condition, so how can I really know how it affects the individual throughout the day and between visits? And how can I really know how if the treatment I prescribe is right for that individual?"

Technology may provide the solution. Michele and her team in Oxford are now teaming up with UK researcher Max Little. Max has developed a new program that runs on a mobile phone and can monitor vital changes in tremor, balance, walking, and voice in just a few simple tests.

"We're going to be asking some participants in the Discovery study to take one of our mobile phones home with them and complete the tests at different times over the course of a week. This will give us vital information about how their Parkinson's affects them from day-to-day which we've never really had access to before."

In the future these kinds of technologies may become part of the everyday management of Parkinson's.

Many people with diabetes monitor their blood glucose throughout the day by pricking their finger and putting a drop of blood on a testing strip. This can give them a much better idea of when they need to take their medication to manage their symptoms best.

There is currently no simple test that does the same job for Parkinson's, but researchers are working to develop smart wearable technologies that can monitor subtle changes in symptoms, and give people a signal to alert them to take their medication at the right time for them.

The future is personal

Today someone with Parkinson's sees their consultant a few times a year and has their daily medication tweaked by a pill here, a pill there.

But this is changing, and the internet is already transforming the way that we monitor and collect information about our health.

Paul Wicks, vice president of innovation at PatientsLikeMe, a free online network that is open to people with any health condition, explains:



"Our ultimate ambition is to create a world in which personal experience drives the way conditions are measured and medical advances are made, and to empower patients to support one another by sharing their experience.

"We have 9,000 members with Parkinson's from all over the world and have a relatively large group of young-onset patients who first experienced symptoms before the age of 40.

"We started PatientsLikeMe to help people better understand their illness, share information about their condition and treatment, and get the support they need to live better every day.

"Members report on the treatments they're taking (including drugs, supplements, and exercise) share information about their quality of life, symptoms, and a whole range of insights into what it's like to live with their condition.

"What members get in return are three things: through powerful graphs and reports they can see exactly how they're doing day to day so they can make better care decisions, they can share information so that others can learn from their experience, and they contribute data for research so that medicine can improve for all."

These advances in our understanding of Parkinson's as a condition, our ability to monitor subtle changes, and the power of unprecedented amounts of data – mean personalised treatment for Parkinson's could be just around the corner.

Further reading

Find out how you can get involved in research through our Research Support Network:
parkinsons.org.uk/rsn

Find out more about our groundbreaking research at the University of Oxford:
parkinsons.org.uk/discovery

PatientsLikeMe member and person with Parkinson's, Ed, shares their story in this short video: <http://bit.ly/1rFDAhD>

Find out more about PatientsLikeMe here:
www.patientslikeme.com

NEW RESEARCH PROJECTS

We've got an exciting new batch of research projects to share with you that are just getting underway. Find details of our current projects at parkinsons.org.uk/currentresearch

'Get it on time': what's the evidence?

Who?

Dr Rob Skelly

Where?

Derby Hospital

What?

£11,843 over 12 months

Many people with Parkinson's tell us that their medication is delayed or not given at all when they are admitted into hospital.

Rob's previous study funded by Parkinson's UK suggested that when people don't get their Parkinson's medication on time they are more likely to stay in hospital longer.

Now Rob and his team aim to find out if people with Parkinson's recover more quickly and spend less time in hospital if they are given their medication on time.

They will use electronic drug charts which have recently been introduced to hospitals across the UK to accurately record when medication has been given. They will then use this along with information about the length of stay of Parkinson's patients at the Royal Derby Hospital to analyse whether there is a connection.

They will also look to see if medication delays are worse at particular times of the week such as during the night or over the weekend.

When an individual is admitted to hospital it is distressing for both the individual and their family so it's vital that they receive the care they need. For those with a complex condition such as Parkinson's it can be particularly difficult.

If Rob and his team can provide firm evidence of the link between getting medication on time and a shorter stay in hospital, this small study could improve the care of people with Parkinson's in hospitals across the UK and provide further evidence to support our Get It On Time campaign.

Find out more about the Get It On Time campaign and how you can get involved on our website: parkinsons.org.uk/getitontime



Targeting Parkinson's dementia

Parkinson's dementia is a condition that some people can experience as their Parkinson's progresses. It affects thinking, memory and decision-making and can have a huge impact on daily life for people with Parkinson's and those close to them.

Unfortunately, people with Parkinson's are more likely to get dementia than people of similar age without the condition. But we still don't fully understand why people with Parkinson's get

dementia, we can't accurately predict who it will affect, and we do not have any really effective treatments to slow, stop or prevent the onset of dementia.

Dementia is one of the biggest challenges facing the Parkinson's research community, and to address this we're pleased to announce two new projects that will help us to find ways of tackling it.



Developing a simple test for Parkinson's dementia

Who?

Dr Michele Hu

Where?

University of Oxford

What?

£33,300 over 12 months

Michele wants to develop a simple blood test which could help diagnose Parkinson's dementia and predict the risk of someone developing it.

Michele's team have already collected hundreds of blood samples from people with early

Parkinson's through the Parkinson's UK-funded Discovery project which they will now use to search for subtle changes – known as biomarkers – that predict the risk of developing dementia.

If we can find these biomarkers, we could use them to predict, diagnose and monitor dementia in Parkinson's. The test would also improve our understanding of dementia in Parkinson's and why some people develop dementia earlier than others.

A test for dementia in Parkinson's could also help with counselling and future planning. And one day when we have treatment that can slow or stop the development of dementia, this test would allow us to treat people early and potentially prevent it.

Bringing CLARITY to Parkinson's

Who?

Professor Stephen Gentleman

Where?

Imperial College London

What?

£10,569 over 12 months

Although dopamine is often talked about as the key chemical lost in Parkinson's, we're starting to understand that other chemicals and areas of the brain may also be affected.

Recently scientists have discovered that another type of brain cell, which send messages using a chemical called acetylcholine, are also changed in people with Parkinson's, particularly those who have dementia.

In this project, Steve will investigate how acetylcholine producing cells in the brain are changed in people with Parkinson's dementia by studying tissue donated to the Parkinson's UK Brain Bank.

He will use a cutting-edge technique called 'CLARITY' which works by turning tissue see-through so that researchers can look inside without having to cut it up.

We now know that Parkinson's is much more complex than just a lack of dopamine. Understanding how the whole brain and all the different nerve cell types are affected is absolutely crucial to developing better treatments for Parkinson's dementia.



You can find more information and support on living with Parkinson's dementia on our website: parkinsons.org.uk/dementia or by calling our free and confidential helpline on **0808 800 0303**.

Towards a new anti oxidant treatment for Parkinson's

Who?

Dr Paul Tuite

Where?

University of Minnesota

What?

£23,944 over 12 months

Anti oxidants are important as they can prevent damage to cells and help them to stay healthy.

Research has shown that the brain cells lost in Parkinson's don't have enough of a particular anti-oxidant called glutathione, but we don't know yet whether boosting glutathione levels could help protect the brain cells affected in Parkinson's.

Unfortunately taking glutathione pills doesn't increase the level of it in the brain as it cannot pass through the protective blood-brain barrier. But N-acetylcysteine, which is a precursor to

glutathione, can enter the brain and, once there, can be converted into glutathione.

Paul and his team aim to find out if they can raise the level of glutathione in the brain by giving a small group of people with Parkinson's oral doses of N-acetylcysteine twice a day for four weeks.

If this small study successfully shows that an oral supplement can increase the level of glutathione in the brains of people with Parkinson's, this could lead on to larger-scale trials to investigate the benefits of glutathione as a potential new treatment.



Ethnicity and non-motor symptoms in Parkinson's

Who?

Professor Ray Chaudhuri

Where?

King's College London

What?

£33,233 over 12 months

In the largest study of its kind ever attempted, Ray and his team aim to find out more about how Parkinson's affects different ethnic groups.

The team will recruit people with Parkinson's of black African, Caribbean, South Asian and white Caucasian heritage and analyse their experiences of Parkinson's.

Research has already uncovered variations between different ethnic groups living with diabetes, high blood pressure and multiple sclerosis but there has

so far been very little research into how Parkinson's may affect different ethnic groups and how they respond to Parkinson's medication.

The team will gather information from each ethnic group about the range and severity of the motor and non-motor symptoms they experience. They will also investigate whether people of different ethnic background respond to Parkinson's treatments, and assess the impact of the condition on their quality of life.

A smaller group of participants will be invited to have a brain scan and provide blood samples which will be vital for future genetic studies of ethnic groups in Parkinson's.

Ray hopes this research will shed new light on the experiences of Parkinson's in different ethnic groups and help clinicians to provide the right care for individuals of different backgrounds.



A worm model to find drugs that can slow Parkinson's

Who?

Dr Lorraine Kalia

Where?

Toronto Western Hospital, Canada

What?

£35,000 over 12 months

If this project is successful it will identify existing drugs with exciting potential for people with Parkinson's that can rapidly be taken forward to be tested in people with Parkinson's.

Lorraine has previously developed a new model of Parkinson's using *C. elegans* – a type of tiny worm. Now her team will use their worm model to test 240 different drugs see if they may be able to slow the progression of Parkinson's.

The team will be specifically be looking to see whether any of the drugs target alpha-synuclein – the protein which forms sticky clumps known as Lewy bodies inside the brain cells that are affected in Parkinson's. Drugs which target alpha-synuclein may have the potential to slow or stop the progression of Parkinson's – but as yet there are no new treatments have been successfully developed that can do this.

Crucially, all these drugs are already clinically licensed and are used in other conditions – this means we already know they are safe for human use.

Finding new uses for drugs that are already used for other conditions has great promise for quickly bringing new treatments to people with Parkinson's. These drugs are already widely used so they can speedily enter clinical trials. And this approach has already been successfully used to identify diabetes drugs with potential for Parkinson's.



Find out more: browse all our active projects at parkinsons.org.uk/currentresearch

A vaccine for Parkinson's: what are the chances?

You may have read recently about some important advances in the development of a vaccine treatment for Parkinson's. Here we explain how a vaccine could work for Parkinson's and what progress has been made so far.

Vaccines explained

When we think about vaccinations, we generally associate them with infectious conditions like meningitis and tuberculosis rather than Parkinson's.

Using vaccination, over the last 100 years we've been able to almost entirely wipe out conditions such as smallpox and polio. Vaccinations are a simple way of preparing our bodies to tackle unwanted infections.

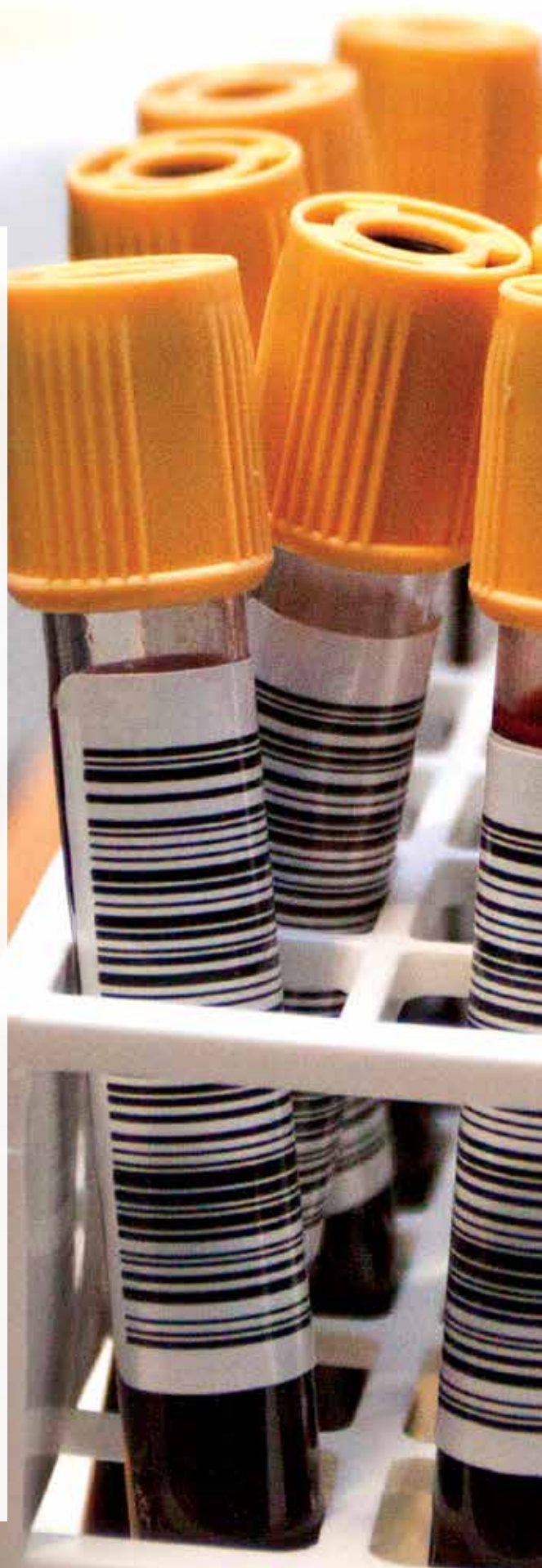
When we have a vaccination, we are injected with tiny fragments of the virus that causes the illness. These fragments are not enough to make us ill. But they do allow our bodies to generate antibodies.

Antibodies are the special proteins that help our immune system identify foreign or unwanted invaders and trigger other cells to come and destroy them. They act as our immune system's memory so that if our body is invaded in future, we can defend ourselves.

How could this work for Parkinson's?

Parkinson's is not an infectious illness. So how could a vaccine help?

In the brain cells which are lost in Parkinson's, research has shown that there is a build-up of a sticky protein called alpha-synuclein. These sticky proteins form clumps called



Lewy bodies which may play a crucial part in the death of these vital brain cells.

Scientists have designed antibodies that recognise sticky alpha-synuclein as a foreign invader. The hope is that these antibodies could help our immune system to identify and remove the alpha-synuclein protein and stop brain cell death in Parkinson's.

Will it work?

Dr Patrick Lewis, University of Reading explains:



"Most of the early work on vaccines for brain disorders comes from research into Alzheimer's.

"Scientists investigated ways to clear lumps of protein (called amyloid beta), which accumulates in clumps called plaques, in the brains of people with dementia.

"They were able to show that vaccinating mice, engineered to develop some of the plaques seen in Alzheimer's led to a decrease in the accumulation of amyloid in their brains."

"This gave researchers hope that using a similar approach in Parkinson's might be beneficial. In 2004, they treated mice engineered to develop these clumps of alpha synuclein with a vaccine designed to generate an immune response. This seemed to clear some of the protein.

"In the meantime, drug companies had started to check whether using vaccines in patients with Alzheimer's could slow down the condition. The results were disappointing, mainly due to a severe side effect called an autoimmune reaction – essentially the body attacking itself.

"This halted research into vaccines for neurodegenerative conditions for a number of years, and still makes companies very cautious about going down this road."

Where are we now?

Affiris, a biotech company based in Austria working with the Michael J Fox Foundation, has recently published results of a vaccine they

have been testing in early stage trials in people with Parkinson's.

Affiris have developed a vaccine that will reduce the possibility of the body attacking itself. The trial involved 24 people with Parkinson's. Eight were given nothing, eight received the active vaccination and eight were given a placebo or dummy vaccination.

None of those given the vaccine went on to develop the severe side effects seen in the Alzheimer's trial.

Dr Lewis comments: "Although this was a small, preliminary trial and the results need to be treated with caution – there was also some evidence that the vaccine slowed down the progress of the condition."

What's next?

It's important to emphasise that trials of the vaccination are at an early stage. Affiris will need to conduct much larger and longer trials to be sure that the vaccine really is safe and beneficial for people living with Parkinson's.

The next step for Affiris is a follow-up trial where they will give people from the original trial a booster vaccine to check for long term safety. Depending on the results of this phase we hope this will lead to a larger trial with more participants.

Dr Lewis comments: "This is a long, slow process – even if all of the follow-up trials went perfectly and they see real benefits for patients, it would be six to eight years before the vaccine would be available generally.

"But these results mark the first step on this journey, and as such provides a glimmer of hope to people affected by Parkinson's"

This is a really exciting area of research and we will keep eye on any further developments. We share any news or opportunities to get involved in this research through our website, publications and Research Support Network.

Find out more about our Research Support Network at parkinsons.org.uk/rsn

Picturing Parkinson's

Last year we challenged UK researchers to give people affected by the condition a unique insight into their research using just as image and an engaging description. Now we'd like to share the results with you.

The competition was inspired by the memory of Dr Jonathan Stevens, who you may remember as Dr Jonny. One of our most dedicated and creative research supporters, Jonathan was passionate about science and photography and shared his talents for both through his online blogs. Sadly, Jonathan passed away suddenly at the age of 34 in December after living with Parkinson's for several years.

We received 37 high quality entries that demonstrated some excellent science photography, as well as some imaginative plain English descriptions that really brought the science to life.

Jonathan's family judged the entries on both the quality of the image and its accompanying description.

Overall winner: Information super nerve-way Rowan Orme

This image is of fluorescently labelled primary rat midbrain neurons that have been cultured for seven days. The large clusters of cells are joined by thick branches of floating axons.

I like to think they are communicating, just as they would in the brain. I imagine the connecting axons are like superfast broadband connections, allowing millions of communications per second. I wonder what they would say to each other? I doubt they would complain about the weather. Or celebrate sporting events. But maybe they would consider their simplistic beauty.

Neurons: such a fundamental part of life, evolved over millions of years, yet so futuristic in their

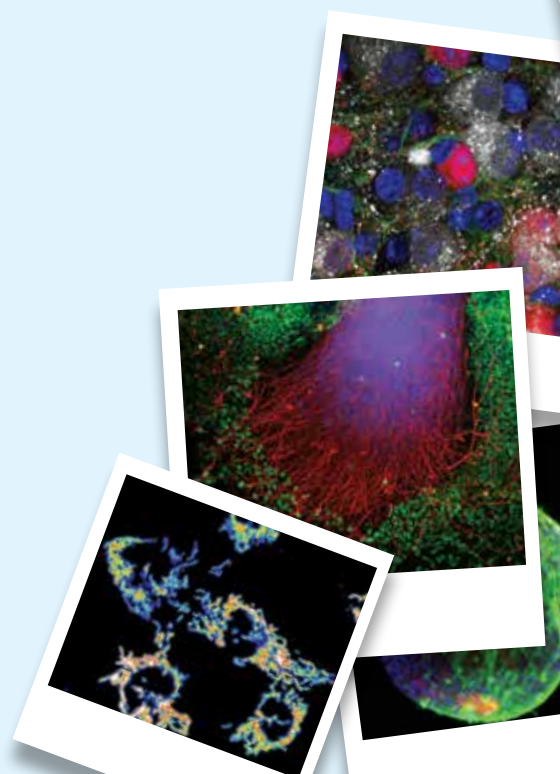
appearance. Maybe, just maybe, neurons like these hold the key to futuristic treatment of Parkinson's.

Brian Stevens, Jonathan's father, who judged the entries with his family, said:

"Judging this extraordinary complex research was a sheer privilege. Jonathan would be honoured that the competition was held in this memory. He was an avid supporter of Parkinson's research, and of communicating its progress to inspire other people with Parkinson's."

You can find all the best entries on our website at parkinsons.org.uk/picturing

You can still enjoy Jonathan's wonderful blogs and photographs at <http://dialoguewithdisability.blogspot.co.uk/>



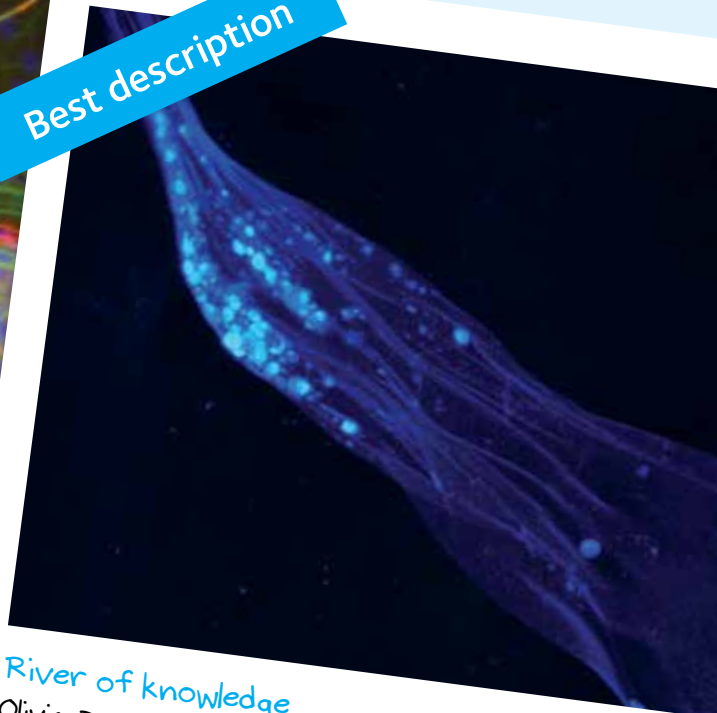
The winner



Information super nerve-way

Rowan Orme
Keele University

Best description



River of knowledge

Olivia Duncan
Kings College London

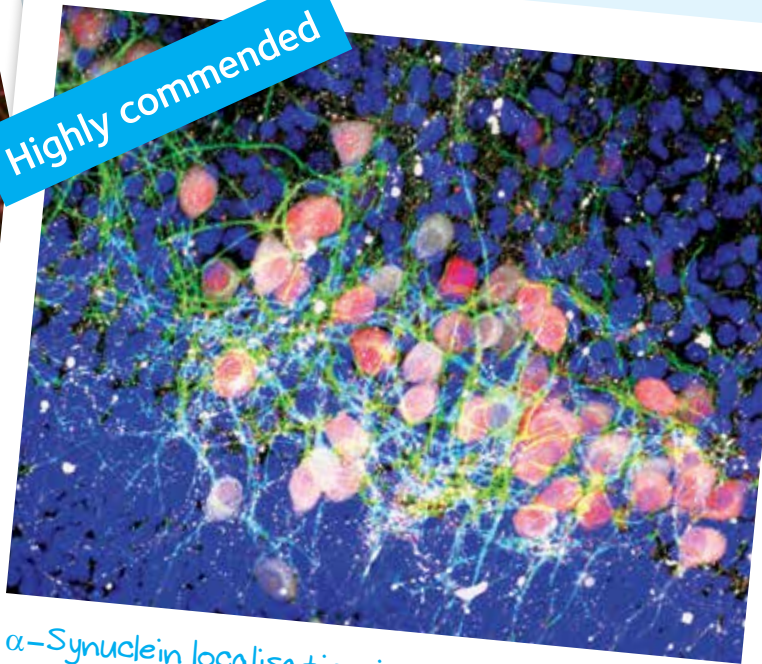
Highly commended



Disease in a dish - the tangled web

Joel Beavers
University of Oxford

Highly commended



α -Synuclein localisation in neurons of the mouse hindbrain

Nicola Drummond
University of Edinburgh

Over to you...

We love to hear your comments, thoughts and opinions on both Parkinson's research and *Progress*, and we use them to shape the content and style of the magazine. Here we share a few of our favourites from the past few months.

TESTING ON ANIMALS

I'm not sure if this topic has been covered before but I was wondering what the views of our forum members are regarding the testing of new treatments on animals. Many people think that all animal testing should cease immediately but I don't think this is either practical or desirable. Many of today's life-saving drugs and therapies would not have been possible without testing on animals. Having said that, I think we should always endeavour to keep testing on animals to a minimum and always make sure that there is no unnecessary suffering. Maybe one day we will develop ways of testing that do not involve animals but for now I think their use is vital. Do others agree?

A post by 'Christo' on our online discussion forum

parkinsons.org.uk/forum

As a charity, we take the use of animals in research very seriously, as do the researchers we fund. We subscribe to the "Three Rs" policy – to reduce, refine and replace the use of animals in research wherever possible. This means we never fund research using animals if there is another alternative.

It's very important to us that our position on this issue is based upon the views of people affected by Parkinson's, and this is reflected by our policy statement on the use of animals which is available on our website:

parkinsons.org.uk/animalresearchpolicy

MONITORING MY PROGRESS

I have had a chart going for many years now which outlines my progress, or lack of it, with Parkinson's, and I am sure that many of you have similar charts as well. I appreciate that there are many different forms of Parkinson's and for that reason the charts will not necessarily always be the same. It is also very difficult to be objective when scoring your progress, but if anyone is interested in joining in on this exercise we can give it a go. The total cost for this project would be exactly zero.

Antony

Hi Anthony, thanks for your comments on monitoring the progress of Parkinson's. We know many other people with the condition keep detailed diaries about their symptoms which can be extremely useful. There are also online tools that you can use to help you keep track of changes in your condition and compare your progress with others.

The most popular of these is called Patients Like Me. It's free to join, the data you share can be used by researchers, and there are already thousands of people with Parkinson's using it:

www.patientslikeme.com/

CONFUSING ACRONYMS!

Thank you to all concerned for the latest Summer 2014 edition of *Progress*.

Since my late husband died, who lived for a long time with Parkinson's and was a brain tissue donor, I have been keenly interested in the possible benefits of stem cell research and found the updates in *Progress* hugely encouraging and informative.

Another purpose of this note is to make a suggestion which I as a very "senior", ie old, reader would find helpful. Even without Parkinson's or dementia, I find it hard to remember the meaning of the sequence of initials to designate a particular aspect of research. For example, that iPS cells are 'induced pluripotent stem cells' or what to remember from GDNF – where I know G and F indicate 'Growth Factor' but I cannot remember what the D and N stand for.

My question is whether in future editions of the magazine there could be a glossary of any acronyms used which could be displayed alongside their full title and the pages on which they appear. For me anyway this would give the quick mental jog that would trigger recollection and further understanding.

**Yours sincerely,
Margaret Little**

Congratulations not only on the work you are doing but also on the reaching out to us via the publications. I am 82 but can, with patience, follow the articles. From ordinary mortals, such as myself, please accept our thanks for the continuing education and encouragement.

Charles

I look forward to the research magazine. The articles are authoritative, well researched and offer hope where hope is due. The more you read, the more complex the subject becomes. I hope this won't be taken amiss but it makes Parkinson's a very interesting condition. I still wish I hadn't got it, or anyone else.

Kieran



What do you think?

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
0207 963 9326



MEET ARTHUR

Arthur Roach joined Parkinson's UK as our new Director of Research and Development in October 2014. Here we ask Arthur what motivated him to join us and what his ambitions are for Parkinson's research over the next five years.

What made you want to work at Parkinson's UK?

There are many reasons, each of which could be sufficient on its own, but together I really had no choice.

First, Parkinson's research is as exciting as any in the field of medicine these days, with an array of truly important insights coming especially from large-scale genetic studies, and the application of new biomarker technologies.

Parkinson's UK has put together an ambitious five-year strategy that increases emphasis on research which will allow us to drive these discoveries into meaningful changes for persons with Parkinson's.

I have always been happiest when working at the interface between academic

science and the business of drug discovery and development, and this role puts me in the middle of that.

Finally, I love London and the UK, and it is a pleasure to be able to live here again.

What do you bring to the role of Director of Research and Development?

I bring many years of experience working in various stages in the drug development process to this new challenge at Parkinson's UK which I hope makes me well prepared to work with all these partners to deliver on our research strategy.

"I'm keen to create new Parkinson's UK-led projects that will encourage collaboration and speed up progress."

I started out in academic neuroscience working at universities in the US and Canada, where I was most recently a faculty member in the Department of Molecular and Medical Genetics of the University of Toronto.

I then moved on to work in biotech and large pharma companies, where I worked for 15 years on discovering and developing drugs for Parkinson's, Alzheimer's and multiple sclerosis, primarily.

I was responsible for the Parkinson's research strategy and partnerships with university scientists at Merck Serono in Switzerland, and recently worked on creating a start-up company addressing a rare, life-threatening neurological disease.

How are we planning to work differently in the future?

I'm keen to create new Parkinson's UK-led projects that will encourage collaboration and speed up progress in key areas, such as bridging the gap between a strong piece of early lab research and drug testing, and repurposing drugs from other conditions for use in Parkinson's.

I hope these projects will help us attract funding from new partners including investors, large and small companies, public grants, and other non-Parkinson's charities.

What real differences do you hope we'll make to the lives of people with Parkinson's?

In the shorter term, I hope we'll identify drugs that are currently used for other illnesses and conditions that can be repurposed to treat debilitating aspects of Parkinson's such as balance and falls, memory problems and dementia, stress and anxiety and sleep disturbances – and see them become widely available to people with the condition.

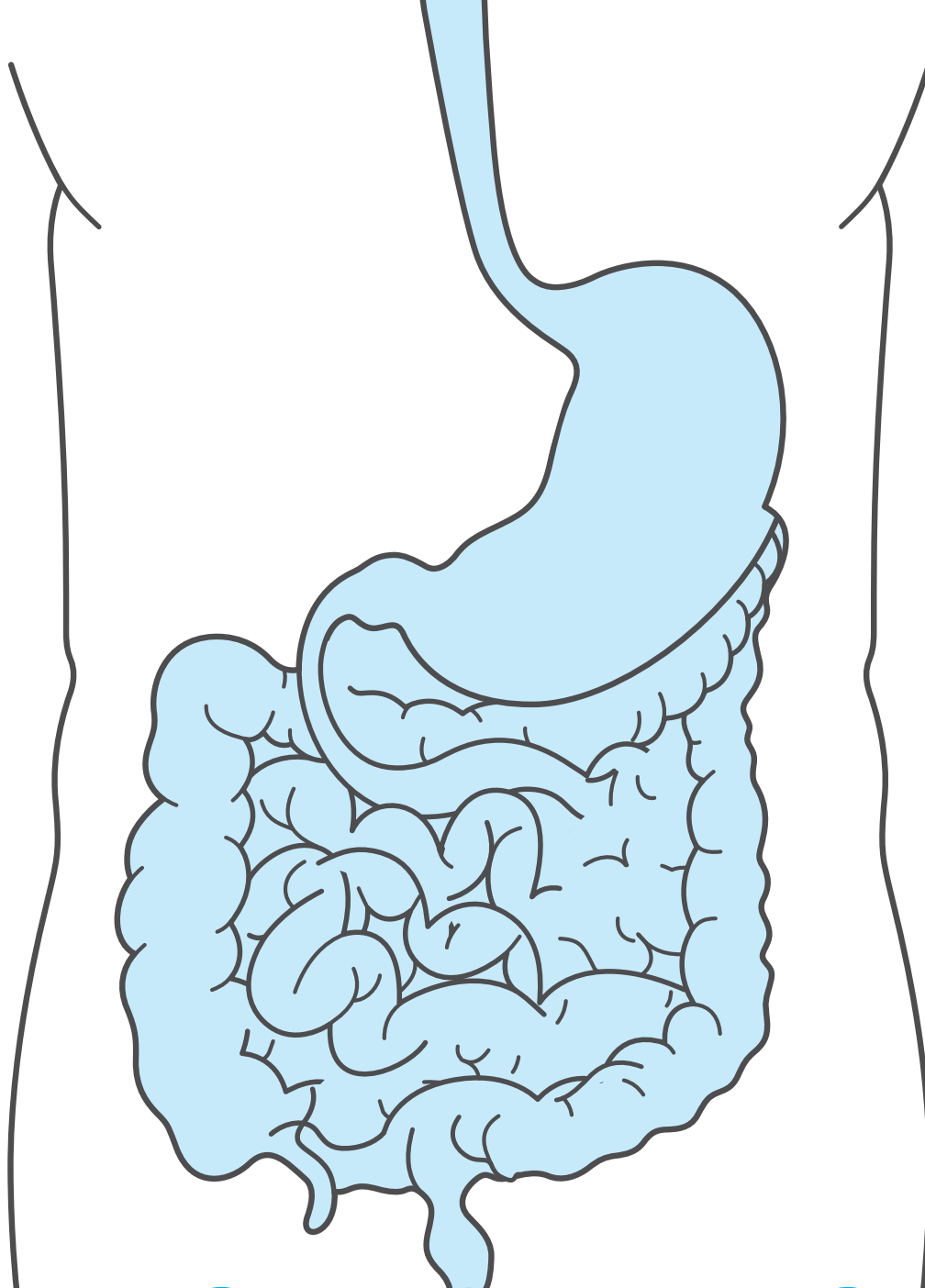
In the longer view, we want to develop new treatments that can slow, stop or even reverse the development of Parkinson's. These new treatments, if given soon after diagnosis – or even better, before the symptoms appear – offer the best hope of developing a cure.

"We will only work on things that we truly believe are promising – we don't have time or money to waste."

And we will be involving people affected by Parkinson's in research in different ways, from strategy to planning to implementation to assessment and communication.

What area of research do you think holds the most promise?

Everything we are doing. We will only work on things that we truly believe are promising – we don't have time or money to waste.



Bowel changes in Parkinson's

Many people with Parkinson's notice changes in their digestion – for example, digestive and bowel problems – and recent research has been looking into how the gut may be involved in the condition. This research is leading scientists to believe changes in the gut may play an important role in Parkinson's, and communication between the gut and the brain may be key.

A healthy digestive community

Inside us all is a complex community of micro-organisms – called a microbiota – that don't cause us any problems and actually help keep us healthy. The average person can have up to 2kg of microbes living in their gut helping to digest their food, make vitamins and fight bad bacteria and infection. In most people the microbiota is fairly stable but changes are known to affect our whole bodies, including our brains.

Over the last decade, researchers have become interested in the tiny micro-organisms that live in the gut – you may have heard of *Bifidus digestivum* that probiotic yogurts market as a “good” bacteria.

The gut microbiota has already been linked to Parkinson's. Smoking and drinking coffee are both habits which very slightly decrease the risk of Parkinson's. One theory is that they may help protect against the condition by encouraging the growth of a healthy community of micro-organisms in the gut.

A GUT FEELING ABOUT PARKINSON'S

When someone says “gut feelings” it can call to mind the butterflies you get before a big occasion such as your first day at a new job. When we are excited or anxious about something, it does feel like the brain is sending messages to the stomach. But what if the stomach is also sending messages to your brain?

Where does Parkinson's start?

But the importance of the gut in Parkinson's may not end there – some scientists now believe that the first changes in Parkinson's may actually happen in the gut.

Researchers have discovered sticky clumps of a protein called alpha-synuclein, which is known to be involved in Parkinson's, in nerve cells that connect the gut and the brain. And more importantly these alpha-synuclein clumps can be found in the gut early on in Parkinson's.

These clumps of proteins are important in Parkinson's because they affect the dopamine – producing nerve cells that are lost in the condition. But finding these clumps in the gut early on in the condition may mean they don't originally come from the brain.

This discovery could mean that changes that cause Parkinson's may sometimes start in the gut, or somewhere else in the body, and travel up the body towards the brain and the substantia nigra – the part of the brain which is affected in Parkinson's.

Could infection contribute to Parkinson's?

Recently researchers have been trying to find out more about how changes in the micro-organisms living in the gut could be linked to Parkinson's. One of the theories is that common stomach infections caused by bacteria such as *Helicobacter pylori* may be involved.

When we get an infection our bodies fight back and recruit cells from the immune system that cause inflammation. This is a natural response that plays an important role in helping our bodies repair themselves. But sometimes the body's inflammation response can go into overdrive and when this happens it can do more damage than good.

We know that inflammation in the brain can damage nerve cells and new drugs are being developed to reduce this inflammation. The hope is that these drugs will protect precious nerve cells that are lost in Parkinson's. What we don't know is if inflammation in the gut can actually cause changes in the brain, but if it can, maybe we can target inflammation to tackle Parkinson's.

Future research

Scientists are only just starting to learn about how inflammation, and other changes, in the gut may be linked to Parkinson's. If Parkinson's really does start in the gut, future research may find ways to stop the condition spreading to the brain.

Further reading

Derkinderen P et al (2014) 'Gut feelings about smoking and coffee in Parkinson's disease' *Movement Disorders*; 29(8):976-9

Parkinson's disease may start in the gut - <http://bit.ly/ZCkBOM>



RESEARCH RESULTS

We keep a close eye on all our research and over the next few pages (p24-29) we share important results from six projects. To keep up with all the latest findings visit parkinsons.org.uk/researchresults

Preventing activity-related falls in Parkinson's

Researchers at the University of Southampton have discovered that strategies that help people slow down and concentrate could prevent people with Parkinson's falling.

Staying active can benefit people with Parkinson's by improving fitness and mobility, providing companionship and positively contributing to quality of life. But the challenge of staying active is that most falls happen during leisure activities. Health professionals and researchers want to help people be active as possible without putting themselves at unnecessary risk of falling.

What the team did

Dr Emma Stack's team investigated why people with Parkinson's fall and what the consequences were. They also looked at what motivated people to continue with leisure activities or deterred them to the point that they gave up.

"I wanted to uncover the strategies people use to continue onward and upward. We are all told to take more exercise – but that's not always possible, and fatigue can limit enjoyment and increase fall risk."

Emma has used the results from this study to create strategies to help prevent falls and keep people with Parkinson's active and safe. This study was made possible by a Parkinson's UK grant of £182,799 awarded in 2010.

Emma answered these questions for Parkinson's UK in her final report.



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

"I listen to what people with Parkinson's tell me! Health professionals and researchers want to help people be active as possible without putting themselves at unnecessary risk of falling. So, we need to find and share tips that will make sense to most people.

"I wanted to uncover the strategies people use to continue onward and upward. We are all told to take more exercise – but that's not always possible, and fatigue can limit enjoyment and increase fall risk.

"I wanted alternatives – techniques to keep people with Parkinson's moving happily and safely!"

What were your goals for the project?

"My project was about the challenge of staying active, as most falls happen during activity. I wanted to find out what happened to people with Parkinson's who fell in the world outside their homes – what caused the fall and what the consequences were.

"And I wanted to know what motivated people to continue with leisure activities or deterred them to the point that they gave up.

"At every stage, I was looking for information that could be useful to other people living with Parkinson's today and that could steer researchers in the right direction in future."

What have you found?

“Leisure makes a positive contribution to quality of life, and companionship, fitness and fun motivated most of the people with Parkinson's we surveyed.

“We found that paying insufficient attention might contribute to nearly half of falls beyond home. Slowing down and concentrating may help avoid tripping. These strategies may help:

- walk carefully from A to B
- keep your hands free
- don't rush
- don't try to remember other things or chat en route.

“Another piece of advice is to pay attention to how tired you feel – be flexible about when you start activities and when you take a break. And remember Parkinson's can fluctuate, do what you enjoy but give yourself time and adapt to your abilities on the day.”

What are the next steps?

“I want to look further into the benefit of adopting a balanced approach to fitness and fatigue. I believe the movement difficulties of Parkinson's might be overcome by devoting as much time to rest and relaxation as to striving to stay active and take exercise (if not more).

“Exercise can cause more physical and psychological fatigue in people with Parkinson's. Research needs to focus on finding a solution.”

How will your research help people with Parkinson's?

“Advice to slow down and concentrate could be used by most people with Parkinson's – however long they have had the diagnosis and whatever their type of Parkinson's.

“Elite athletes train and rest – and I advocate people with Parkinson's do the same! If people do this, they may continue to enjoy and reap the benefits of many important activities.”

References

Roberts HC et al (2013). Slow Down and Concentrate: Time for a Paradigm Shift in Fall Prevention among People with Parkinson's Disease?. *Parkinson's disease*.



RESEARCH RESULTS

Recycling – searching for new Parkinson’s drugs

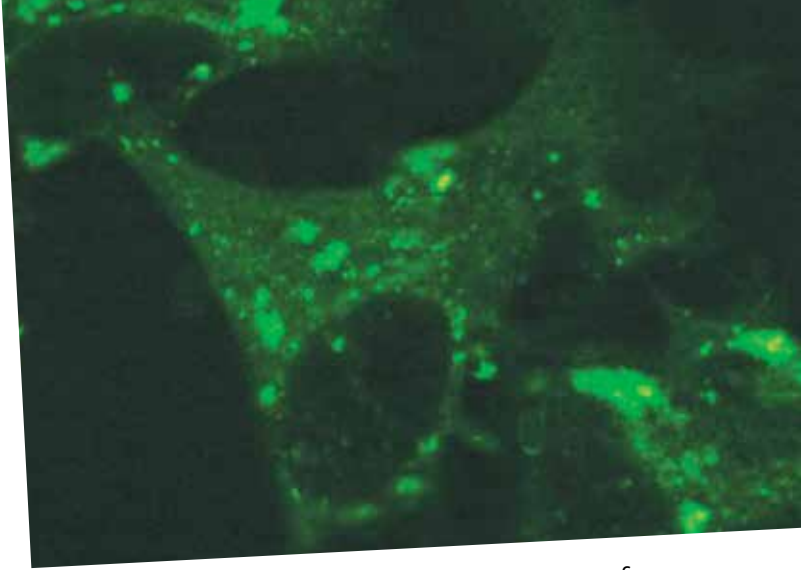
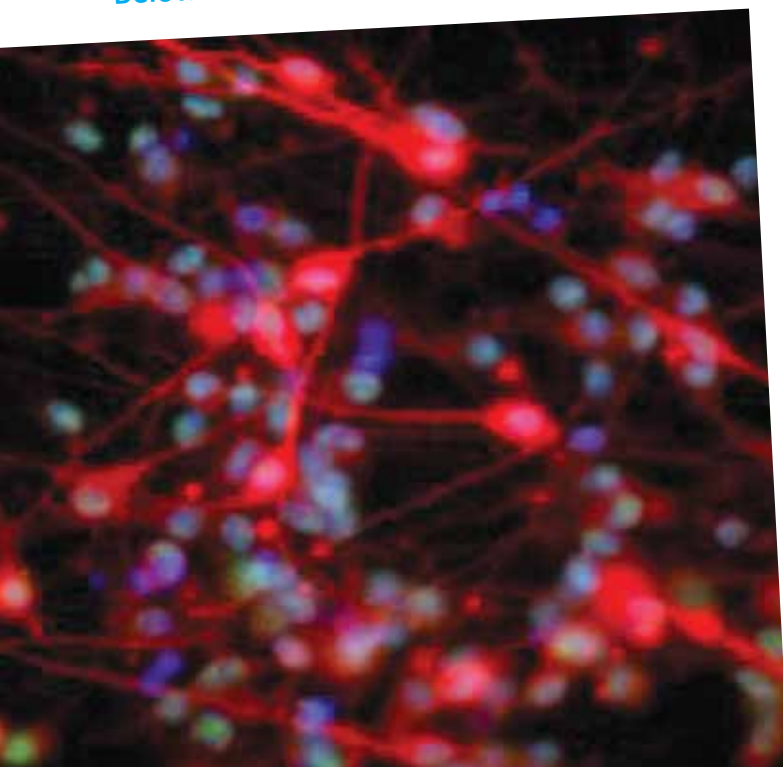
Our researchers at the University of Leeds have made progress identifying potential drugs that promote recycling in the brain cells affected by Parkinson’s. This research could lead to a new treatment for Parkinson’s.

Every cell in our bodies is powered by mitochondria. These tiny power stations produce the energy the cell needs for its essential functions. Mitochondria produce toxic by-products and, over time, they become damaged and less efficient – producing less energy and more toxic waste.

Parkin is a protein that identifies damaged mitochondria, so that they can be taken away, broken down and recycled into healthy new mitochondria. But if Parkin doesn’t work properly, this recycling doesn’t happen and damaged mitochondria build up and start producing too much toxic waste. The research team in Leeds believe this could cause the death of the dopamine-producing cells in Parkinson’s.

The team are testing 10,000 chemicals that may affect the recycling of mitochondria. They have

Below: stem cells stained with fluorescent dye.



Above: Mitochondria maybe tiny but they perform a vital function. In the image below we've lit them up so that we can see how they move around.

already identified more than 150 chemicals which show potential, many of which have already been approved for safe use in people.

The next step is to explore how these chemicals work and if they can be developed into new treatments for Parkinson’s. This exciting study was made possible by a project grant of £154,988, awarded in 2012.

Developing dopamine-producing nerve cells from skin cells

In 2010 we awarded the University of Bristol a grant of £87,476 in 2010 to support PhD student Peter Barbuti’s work in Dr Maeve Caldwell’s stem cell research group. Here, Peter explains how his PhD has helped launch his career in research.

Studying dopamine-producing nerve cells from people with Parkinson’s gives us a unique window into the Parkinson’s brain – helping us to understand the condition better. Working with these cells from people with different inherited and non-inherited forms of the condition could help us move towards ‘personalised treatments’ which can be tailored to the individual depending on their genetic makeup.

In my PhD project, I took skin samples from people with both inherited and non-inherited forms of Parkinson’s and reprogrammed them into stem

cells. Stem cells have the potential to make any cell in the body and using a new technique I was able to make dopamine-producing nerve cells, like those lost in Parkinson's, from these cells.

Generating large numbers of these precious nerve cells will allow researchers to study these cells and how they behave in great detail, and to test new and existing drugs to see if they have potential for slowing or stopping nerve cell death.

I am currently preparing to publish the results of my project in a peer reviewed journal. Thanks to the studentship support from Parkinson's UK, I'm now beginning a new position at the University of Luxembourg. I'm proud to be working at the forefront of stem cell research, and I hope my findings could one day contribute to a cure for Parkinson's.

Using worms to understand Parkinson's

We awarded scientists at the University of Dundee a £191,322 grant in 2010 to learn more about why cells die in Parkinson's by using a worm model of the condition.

Research using *C.elegans* worms has played a vital role in uncovering key mechanisms in many conditions. The research team, led by Dr Anton Gartner, wanted to use a worm model of Parkinson's to look at how proteins help protect nerve cells.

What the team did

The research team investigated the function of a protein called LRK-1 which is present in nerve cells inside worms. LRK-1 is related to the human LRRK2 protein which is known to play a part in some rare inherited forms of Parkinson's. But scientists don't understand the role of LRRK2 inside the nerve cells affected in Parkinson's.

What they found

Anton's team found that LRK-1 is involved in controlling the movement of molecules in and out of nerve cells. They also identified a protein called TPS-17 – which seems to play a crucial role in protecting dopamine producing nerve cells – and found this

protein is involved in the release of the chemical messenger dopamine.

Anton comments:

"Currently, all known treatments for Parkinson's target the symptoms of the condition but cannot slow down or stop its progression.

"To find a cure for Parkinson's, we need to understand why and how the dopamine-producing nerve cells are lost in Parkinson's. Our research aims to do exactly this."



Did you know?

Some fascinating fact about *C.elegans* worm:

- They have just 302 nerve cells making them one of the simplest organism we can study to help us understand conditions like Parkinson's.
- They are approximately 1mm long and transparent – so can only be studied under microscope.
- In the wild they live in soil and eat bacteria.
- *C.elegans* are blind and deaf-but rely on smell, taste and touch.
- Finally, despite their humble origins, *C.elegans* worm have been involved in two Nobel prizes.

You can find out more about the weird and wonderful world of worms in research through Dave the Worm.

Visit www.davetheworm.org



How genetics can affect deep brain stimulation

Our researchers at University College London have discovered that differences in our genes can affect how quickly the symptoms of Parkinson's progress.

Parkinson's affects different people in different ways. Some people develop the condition earlier in life, some later. Some people respond to Parkinson's drugs better than others, and some develop side-effects earlier than others. This variation between individuals may be due to differences in their genes.

We awarded Dr Tom Foltynie an innovation grant worth £14,845 to investigate how changes in key Parkinson's genes may influence the development of symptoms.

What the team did

The research team investigated how changes in genes known to be associated with Parkinson's may influence the development of involuntary movements known as dyskinesia. They also looked at how these genetic changes may affect how well people respond to deep brain stimulation (DBS) surgery.

What they found

They found that around 1 in 4 people with Parkinson's who have deep brain stimulation have a change in one of the known Parkinson's genes – including GBA, LRRK2 and parkin. And people with a change in their GBA gene appeared to have a more aggressive form of Parkinson's and so need DBS at an earlier stage.

Tom comments:

"In the future, research like this could help clinicians give people with Parkinson's more accurate information about how their condition will progress. A better understanding of the complex genetics behind Parkinson's could influence how we decide who is most appropriate for DBS and even help find appropriate people to take part in clinical trials for new treatments."

"It has been life-changing for the better, but not without its ups and downs.

"For me the period directly after deep brain stimulation was a real rollercoaster. There is no doubt in my mind that post op, the tremor was worse, but when you think about what your brain goes through during the procedure it is hardly surprising.

"I was programmed after eight weeks and for four days I had a fabulous time, it did not matter what I did, I had no tremor, and believe me, we pushed the envelope really hard! On day five the tremor came back with a vengeance, but another trip to hospital, this time for two nights and three days saw me totally reprogrammed. It has been 12 days since reprogramming and all is really well. I have played golf three times this week and although parts of my game need work, my putting has improved hugely!"

"007" on parkinsons.org.uk/forum



Good quality social care for people with Parkinson's

A study commissioned by Parkinson's UK has shown how important social care is for the health and wellbeing of people with Parkinson's. This new evidence will help us make the case to people who plan and deliver social care services to reflect what people affected by Parkinson's want and need.

Social care services help people with daily living tasks to remain safe and independent. They usually help people in their own homes, for example with personal care, preparing meals, giving medication, or getting out and about.

We know that good-quality social care can make a big difference to the lives of people affected by Parkinson's, but often people don't get social care support until they reach crisis point.

This research, which has been sent to the Journal of Neurology, Neurosurgery, Psychiatry for publication, was carried out by a team of researchers at Sheffield Hallam University.

What the team did

The researchers interviewed people with Parkinson's, carers, social care providers and health care professionals to find out how good-quality social care can affect health and quality of life.

What they found

The team found that when people with Parkinson's have good-quality social care it gives them more control and choice, and helps them maintain their independence. This can have a positive impact on people's overall health by preventing infections, putting people in control of their symptoms, and combating mental health problems. And this can ultimately reduce the overall costs of care.

But to deliver quality social care, providers need a better understanding Parkinson's, how it is treated, and how important the timing of care is to people living with such a complex and fluctuating condition.

How will the research help people with Parkinson's?

We'll use the research to educate those who plan and deliver social care to make sure it is more



'Parkinson's aware' so that it really meets the needs of people living with the condition. And to boost our campaign for people to get the information and support they need at the start of their diagnosis rather than having to reach a crisis point before accessing care.

Find out more

Visit parkinsons.org.uk/socialcarereform

"Paid care enables [him] to live his life and social care makes it worth living." – Friend

"There's times when I'd like more help, but then again as I say I cherish my independence." – Person with Parkinson's

"There might be a whole raft of things out there that could benefit Mum and Dad or help them that I don't know about, because there's no one telling us what there is" – Daughter

THANK YOU FOR YOUR SUPPORT!

Every penny we spend on Parkinson's UK research is the result of voluntary donations. Thanks to your generosity, we've raised over £800,000 through your cash donations to research in the last two years, helping us to fund three crucial projects that are taking us closer to a cure.

Investigating a new 'iron-handling' drug for Parkinson's

**£240,180
RAISED**

Dr James Duce,
University of Leeds

If this project is successful it will bring us a step closer to testing a new 'iron-handling' drug in clinical trials - a treatment that could benefit the lives of people with Parkinson's.



Investigating a 'shortcut' to dopamine release

**£230,101
RAISED**

Dr Stephanie Cragg,
University of Oxford

This project could bring new insights into how dopamine-producing nerve cells work, and may ultimately lead to new treatments with fewer side effects.



"It's especially nice to be funded by Parkinson's UK because it's such an active community of people who care. It's a real privilege and when our application for funding was successful we were elated."

Dr Stephanie Cragg

Delivering RNAi to the brain to reduce alpha-synuclein

Professor Matthew Wood, University of Oxford

Matthew's project aims to develop an exciting new treatment which has the potential to slow or stop the progression of Parkinson's.

"I know I speak for all my colleagues involved in Parkinson's research when I say how much I appreciate and value your support. You are enabling us to continue to push at the boundaries of our present knowledge and move closer to stopping, preventing and potentially even curing Parkinson's."

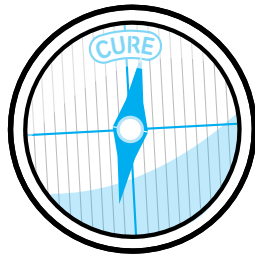
Professor Matthew Wood

**£324,335
RAISED**



A new way to support our research

In 2013 we launched a whole new way to support our scientists cutting-edge research. Our Pathfinders are supporters who have signed up to give a regular monthly donation to support our research.



Here's what some of our Pathfinders have to say about why they've chosen to support our work:

"I became a Pathfinder because my husband has Parkinson's, and I think that research is the way forward to eventually finding a cure for this dreadful disease. My husband has had deep brain stimulation and his life is much improved. But to think that there could be a cure that can only be achieved by research, this work is so important."
Margaret

"My wife has gallantly fought Parkinson's for over 30 years which is reason enough to be a Pathfinder. However over the past eight years she has been cursed with dementia with Lewy bodies, which I understand is associated with Parkinson's. If I can support research which hopefully one day will prevent other people suffering, it will all be worthwhile being a Pathfinder."
Mr Ridpath

"We decided to join Pathfinder as my husband has Parkinson's. It has affected him cognitively which has changed his life dramatically. Parkinson's is such a complex disease and we are passionate about research and hope that a cure can be found so that future generations maybe even our own family members, will be protected from the symptoms of Parkinson's."
Mike and Sonia

"For many years my younger brother has had to live with serious effects caused by Parkinson's disease. In the last 18 months, I too have been diagnosed with this same disease. Funding research is very important, as it gives hope that a cure will eventually be found. I plan to keep up-to-date with current scientific research and to do all I can to encourage others to do the same. My brain may be affected by the disease, but I am still part of the scientific team!"
Leonard

"We have a family history of Parkinson's (father and grandfather). My father is in a care home and has Parkinson's. As a scientist himself, he really appreciates reading the research updates and it keeps him hopeful and interested. From my perspective, it is good to know where the money is going and see the names of researchers and details of the research."
Liz

You can become a Pathfinder by giving £5 a month

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

- an exclusive, limited-edition Pathfinder pin badge
- regular feedback report on key areas of the Parkinson's UK research programme
- invitations to Pathfinder research events



Brain Bank researchers

THE REALITIES OF BRAIN DONATION

Last year our Brain Bank team successfully coordinated the collection of brain tissue from 78 donors who had Parkinson's and 13 people without the condition. That's well over a brain a week.

However, during the same period, there were 23 occasions where registered donors passed away but the team were unable to collect their precious tissue.

I've just read my new copy of *Progress* magazine and read, with interest, the article on the Brain Bank. My father-in-law was on the donor list and very keen to donate his brain as I have Parkinson's and he wanted to do something to help.

Tragically, he passed away on a Saturday morning at 5am. I was with him when he died and, after phoning the local surgery to get a doctor out to verify death, I phoned the emergency number for the Brain Bank. I spoke to a wonderful gentleman, a professor whose name I'm ashamed to admit I've forgotten (but it was a very traumatic time). He warned me that it was highly unlikely that my father-in-law would be able to donate as nothing can be done without his GP signing the death certificate and, as it was a Saturday, it was highly unlikely that we would get it signed until Monday - too late for the donation to take place.

Sadly, he was proved correct and the donation couldn't go ahead, despite my ringing the surgery, NHS Direct and anyone and everyone else I could think of. My father-in-law's GP had assured us that she would be available any time of the day and night but omitted to say that didn't include weekends.

Those who find themselves in the position where a donor is seriously ill and may not die on a weekday between the hours of 9-5 needs to be aware that this situation exists and do everything they can to secure the mobile number of the GP to ensure the donation will be able to go ahead. The lovely, nameless, professor told me that they lose many, many donations every year for this reason. My father-in-law would have been devastated to know that he couldn't do his bit to help research into this awful disease.

Jane Cromey-Hawke

My father died on 21 December last year. His absolute last wish was that his brain should be used for Parkinson's research purposes. We had everyone geared up to make the relevant calls as soon as he died. However, in spite of this, we were told it would not be possible.

Unfortunately I had just landed in New Zealand as he died, otherwise I would have phoned everyone I could think of to make this happen for my Dad. Instead, I am left feeling that I failed him in his last wish.

Alison

Dr David Dexter, Scientific Director of the Parkinson's UK Brain Bank

"We're on call 24 hours a day, 365 days a year. But sometimes delays mean we cannot collect tissue in the 48-hour window when it is suitable for research."

The top five reasons why brain donation cannot take place are:

1. No mortuary staff. The Brain Bank work with local hospitals to arrange for tissue to be collected. However, sometimes there are no mortuary staff available to remove the tissue. This can be a particular problem at the weekend when hospitals have fewer staff on duty.
2. No death certificate. Mortuary staff usually require a signed death certificate before they will agree to remove tissue for donation. Hospital doctors often prefer to wait for the individual's GP to sign the certificate – and if the GP is unavailable, this can cause delays which prevent donations.
3. Coroner's case. If the cause of death is unknown the hospital may decide that they need to perform a full post-mortem to investigate. If this is the case, the delay means we cannot retrieve tissue within 48 hours.
4. Confounding pathology. If the donor has another illness that makes their brain tissue unsuitable for research, such as a tumour, or makes removing tissue dangerous, such as HIV – we are unable to collect the tissue.
5. Informed too late. It's actually quite rare, but occasionally a donor's family either fail to inform us that the donor has died, or sadly, inform us too late.

"The process of brain donation is complicated and requires lots of coordination. We do our very best to work with families and local health professionals to make every donation possible, but sadly sometimes we are unsuccessful.

"We know that this can be extremely distressing for donors families when their loved ones wishes cannot be fulfilled. It's vital that we highlight the kinds of barriers and hurdles we face, so that families are aware that donation can never be guaranteed."

Top tips for donors and their families

There are a number of things you can do to improve your chances of a successful donation:

- Discuss your wish to donate with your family, friends and health professionals. The more people who are aware of your wishes, and what to do when the time comes, the better.
- Always carry your Brain Bank donor card with you.
- Contact the Parkinson's UK Brain Bank as soon as possible. You don't have to wait until the donor has passed away. If someone is likely to die in the coming few days, contact us and we can make preparations to make sure things go smoothly when the time comes.

Contact the Parkinson's UK Brain Bank
020 7594 9732
parkinsons.org.uk/brainbank
brainbank@imperial.ac.uk
Emergency number: **07659 104 537**
(please only use this number in the event of an emergency)



MY LIFE IN RESEARCH

By John Whipps

10 years ago I was a successful research scientist and a professor at the University of Warwick. My area of research aimed to reduce the use of pesticides by finding biological methods to fight plant diseases. How ironic.

I worked hard, travelled the world collaborating with other research groups and lecturing. In my early 50s I began to stumble on my daily run, my back ached, my arm was stiff, I was getting old. The final straw was having to use two hands to brush my teeth: "Like you do when you get old." Oh yes, and don't forget the comments from my students about my poor, indecipherable handwriting.

Eventually, having ignored these symptoms for more than a year, I visited my GP, largely to keep my wife happy (quiet), and was immediately referred to a neurologist. After a series of physical tests and scans, I received the blunt diagnosis: "Parkinson's, go away and look it up on the internet."

I was stunned. I had been at the top of my career and now, according to some websites, I was about to enter a period of rapid decline ending in full blown dementia and death. Hmmm!

Thank heavens I discovered the Parkinson's UK website. It gave me the information I needed about Parkinson's, an introduction to the research going on in the field, and most importantly, hope. I could see that people were working to find a cure and if there's one thing I understood, it was research. So I joined the Parkinson's UK Research Support Network (RSN) and got involved. This has resulted in me commenting on grant applications as a layman, attending research meetings, writing articles about research in my local newsletters



Above: John and his wife Sue.

and providing my opinion on experiment studies. I've also been lucky enough to have gone to two International Parkinson's Congresses in Glasgow and Montreal. I'm now the Research Champion for the Mid Cornwall branch of Parkinson's UK.

I have been very fortunate to come through the early years of Parkinson's so well. This is largely due to health professionals that listen to me, a supportive family and my wife, Sue, also known as my "don't carer". Much of what I have mentioned above has only taken place because of her enthusiasm and encouragement. Research involvement has enabled me to feel that I can make a difference, if not for me, for others in the future.

My previous life made me suited to what I do, but it is possible for anyone to get involved. Every consultant and Parkinson's nurse should be able to tell you about research opportunities in your area, so why not ask them? Through my consultant, I joined the ProDeNDRoN – an NHS register of people willing to get involved in neurological research and this started my direct involvement in a number of research projects.

Research does not always involve taking pills and going to hospitals. Much of the research I have been involved in was done at home! Researchers clearly need people affected by Parkinson's to do research and they try to facilitate it as best they can. We need their results so I hope in the future people affected by Parkinson's will come forward readily and get involved.

Join the Research Support Network
Visit parkinsons.org.uk/rsn

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215 Vauxhall Bridge Road, London SW1V 1EJ

020 7931 8080

hello@parkinsons.org.uk

parkinsons.org.uk

Helpline

0808 800 0303 (freephone*)

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

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 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 or call our helpline.

Parkinson's UK local groups

For details of your nearest group visit

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 or by getting

in touch with us at rsn@parkinsons.org.uk.

Publications

Available online at parkinsons.org.uk/publications

or by getting in touch with us on **0845 121 2354**.

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

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