

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

PROGRESS

The research magazine of Parkinson's UK
Issue 11: summer 2012

New treatments – what's in
the pipeline for Parkinson's?

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Front cover image
Assortment of pills

WELCOME

Hello and welcome to the summer 2012 issue of *Progress* – your twice-yearly update on Parkinson’s research.

I’d like to kick off by saying a massive thank you to everyone who responded to our call for feedback in the last issue of *Progress*. We were delighted that so many of you took the time to tell us what you think about the magazine and to offer your ideas, questions and comments. You’ve really helped us shape the content of this issue, and your influence runs right through the magazine.

As a result of your suggestions we’ve added a round-up of all the latest international news on page 4.

Many of you were also keen to hear about new drugs and clinical trials, so our feature ‘A peek inside the pipeline’ (see page 5) focuses on the next generation of treatments for Parkinson’s.

And on page 32-33 we put the flood of brain donation questions we received to

Dr David Dexter – the scientific director of the Parkinson’s UK Brain Bank.

Finally, if you turn to page 18, you’ll see we’ve included a selection of our favourite letters and comments about *Progress*.

And of course, we’ve a batch of fresh research projects to tell you about, plus news of the latest encouraging results and progress from studies already underway.

I hope that you enjoy the summer issue of *Progress* – but don’t forget to keep the feedback coming, we need ideas for next time!

Best wishes,



Dr Kieran Breen

Director of Research and Innovation



PARKINSON'S RESEARCH FROM AROUND THE WORLD

Are cautious people more likely to develop Parkinson's?

Being cautious may not be always good for your health, according to new research presented at the American Academy of Neurology meeting in New Orleans in April.

Researchers at the University of South Florida found that people with Parkinson's tended to avoid taking risks compared with those without the condition. Even 30 years before symptoms emerged, those who later developed the condition were less likely to engage in risky or exhilarating activities such as riding roller coasters or speeding. <http://bit.ly/J6PsHU>

Good news for berry lovers!

Research published in the journal *Neurology* in April suggests that men with diets rich in flavonoids – found in berries, apples, red wine and tea – may have a reduced risk of Parkinson's.

The researchers analysed diet and risk of Parkinson's in 130,000 people in the US over a 20-year period. They found that men whose diets contained the most flavonoids were 40% less likely to develop Parkinson's compared with the men who ate the least. But curiously, this effect wasn't seen in the women in the study. parkinsons.org.uk/researchnews5april2012

UK breakthrough for neurodegenerative conditions

In May, research published in the scientific journal *Nature* revealed new hope for drugs that can halt nerve cell death.

These could work across a range of conditions, including Parkinson's. In neurodegenerative conditions, misshapen (or misfolded) proteins appear and nerve cells in the brain die – but it

isn't clear how the two are linked. The team at the University of Leicester discovered that when misfolded proteins build up in the brain, cells respond by halting the production of all new proteins. This starves the cells of crucial proteins and ultimately means they stop working and die. But they were able to prevent nerve cell death by preventing this shutdown of protein production. parkinsons.org.uk/researchnews9may2012

Parkinson's UK Twitter news

Positive results for new drug for people with Parkinson's who experience dyskinesia <http://reut.rs/GEm74a>

Simple design changes can help people with dementia stay in their homes for longer – watch the video <http://bbc.in/GCQFIX>

New Scientist: Stem cell brain injections ease Parkinson's in an animal model <http://bit.ly/z5Dhfh>

People with REM sleep disorder may be at greater risk of developing Parkinson's or thinking and memory problems <http://bit.ly/wVTA70>

How (and why) to donate your brain to a brain bank for science <http://bit.ly/xxK1jD>

Having a 'purpose' in life may protect against harmful changes in the brain associated with Alzheimer's <http://bit.ly/KNRuKO>

Follow us www.twitter.com/parkinsonsuk

A PEEK INSIDE THE PIPELINE

Every drug, treatment and therapy available today is the result of a long and expensive development process.

It all starts when researchers identify a promising new drug or therapy. These must first be rigorously tested in the lab to see how effective they might be and, crucially, to make sure they are safe.

This phase of development, called 'pre-clinical testing', may take several years, and the vast majority of these new treatments never make it out of the lab.

Of every 5,000 drugs initially tested, around five make the leap to clinical trials. Clinical trials are the way that new treatments are tested on people. They are conducted in four steps or phases:

Phase 1 trials test whether a treatment is safe, has any harmful effects and tests different doses. These studies are usually fairly small, involving only about 30 participants. Participants can be healthy volunteers or people with the condition to be treated.

Phase 2 trials start to explore how well the new treatment works. These studies are larger and may involve hundreds of people, usually those with the condition to be treated. They aim to identify the best dose and how often the treatment should be taken. Only treatments that produce convincing results in phase 2 make it into phase 3 testing.

Phase 3 trials aim to confirm the best dose and test a new treatment against the existing standard treatment – if it gives better results, it may become the new standard treatment. Most new treatments have to go through a few phase



3 clinical trials before being approved for use. Phase 3 trials may involve thousands of people with the condition and cost millions.

Phase 4 trials are carried out after a drug has been approved for use – they collect more information about the side effects as well as the long-term risks and benefits.

A new treatment may take 10 years to make its way through clinical trials. And only around one in five that start clinical trials is eventually approved for use.

This means that new treatments can come with a price-tag of around £500million – roughly the same as the cost of a space shuttle mission!

It takes years to translate discoveries into treatments that are convincing enough to make the leap into clinical trials. But despite the odds, there are new treatments currently being tested for people with Parkinson's.

Stem cells

Stem cells offer tremendous potential because they are capable of becoming any of the hundreds of different types of cells that make up the human body.

Scientists are working to find ways to grow new nerve cells that could one day be used to replace those lost in Parkinson's.



Above: Stem cell researchers (funded by Parkinson's UK) at work in Edinburgh

These studies are still in the 'pre-clinical' phase so no clinical trials using stem cells for people with Parkinson's have yet been carried out. But several important steps forward have recently been made.

Earlier this year, initial results from the world's first clinical trial using embryonic stem cells to treat eye conditions suggest the treatment is safe.

In November last year, researchers in the US successfully used nerve cells grown from human embryonic stem cells to repair the brain in three different animal models of Parkinson's. The transplanted nerve cells survived, formed new connections and restored lost movement in mouse, rat and monkey models of the condition. Importantly, there was no sign of tumours – a problem seen in previous studies.

Even more encouragingly, the European Health Commission is funding the largest ever trial of cell transplantation for people with Parkinson's. This €12million study is being co-ordinated by Parkinson's UK-funded researcher Roger Barker.

The five-year study brings together leading international experts to test whether transplanting

foetal nerve cells can help repair the brains of people with Parkinson's. If the trial shows that cell transplants work consistently for people with Parkinson's, it will be major step towards future clinical trials of stem cells.

Gene therapy

There are three different gene therapy approaches currently in early stage clinical trials. Many others are being developed in the lab, including several projects funded by Parkinson's UK.

Gene therapies work by inserting genes into cells that aren't working properly. The genes provide instructions that change the way the cells behave.

Gene therapy hit the headlines earlier this year when *Sky News* interviewed Sheila, a lady diagnosed with Parkinson's 17 years ago, who experienced significant improvements in her symptoms in a trial of the gene therapy ProSavin.

ProSavin, developed by a British company, uses three genes that help nerve cells in the brain make their own dopamine – the chemical that is lost in the brain in Parkinson's.

Current treatments for Parkinson's – and why we need better ones

In Parkinson's the nerve cells in the brain, that make a chemical called dopamine and help to control movement, die. These are lost slowly, and it isn't until around 70% are gone that the physical symptoms of Parkinson's – the slowness, stiffness and tremor – emerge.

Since the 1960s, the most commonly used drug to treat Parkinson's has been levodopa. It works by boosting the levels of dopamine in the brain and can help to manage the symptoms.

Many other drugs have since been developed that work in similar ways to increase dopamine levels. Approaches like deep brain stimulation can also provide some relief from the symptoms of Parkinson's.

But, we don't yet have any treatments that can slow, stop or reverse the development of Parkinson's. We cannot stop the death of these precious nerve cells, which means the condition continues to progress, symptoms worsen and side effects such as uncontrollable movements may emerge.

Now the hunt is on to find new and better treatments that do more than mask the symptoms.

ProSavin is still in the early stages (Phase 1/2) of clinical trials. It's currently being tested in a small group of people with the condition to check safety, (which so far looks good), and to find evidence of benefit. If others taking part in the study do as well as Sheila, we hope to see ProSavin moving into bigger clinical studies soon.

Old drugs, new tricks

Finding new uses for old drugs has great promise for quickly bringing new treatments to people with Parkinson's. As these drugs are already widely used for other conditions, we know they're safe. So they have a head-start in the clinical trials marathon.

New uses are emerging as we learn more about the subtle links between different conditions and how the older drugs work. And new technologies, like computer modelling, are helping to spot drugs that may have hidden talents.

Clues from diabetes

There is evidence that people with diabetes have an increased risk of Parkinson's. It turns out that diabetes drugs may also be useful for treating Parkinson's.

One example is exenatide – a drug already used by around 6 million people with diabetes worldwide. Lab studies funded by Parkinson's UK helped to show that exenatide could improve symptoms and even rescue dying nerve cells in different animal models of Parkinson's. Now exenatide is being tested in a small phase 2 study of 40 people with Parkinson's at University College London Hospital.

Below: Current Parkinson's medications help to manage the symptoms



Clinical trials jargon buster

Placebo

A placebo is a dummy treatment, sometimes a sugar pill, which is given to some participants in trials.



Comparing the responses of participants taking the real drug to those taking the placebo helps researchers to check whether new treatments really work.

Blinding

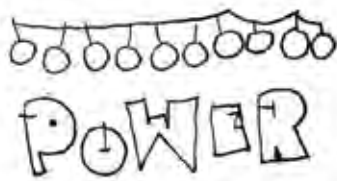
The best clinical studies are called 'double-blind'.



Here neither the researchers nor the participants know who is getting the real treatment and who is getting the placebo. This helps prevent bias and expectations skewing the results of the study.

Power

To produce meaningful results, clinical trials need to involve enough people to prove the benefits of new treatments. This reduces the risk of the results being due to chance.



The larger the study, the higher the power, and the better the chance of achieving conclusive results.

Illustrations by Paul MacDonald, diagnosed with Parkinson's in 2007. Paul uses his drawing skills as a therapeutic tool to focus on the positive side of life with Parkinson's.

Other diabetes drugs under investigation include a group of drugs used to treat type II diabetes, called thiazolidinediones (or TZDs) which have shown exciting potential to protect against nerve cell death.

We're funding Professor Michael Duchen at the University of London to explore whether TZDs can help protect nerve cells grown in the lab – which could lead on to clinical trials.

A new use for nicotine

Nicotine is another drug currently under intense investigation for Parkinson's. Various studies have shown that people who smoke are slightly less likely to develop Parkinson's.

But could nicotine really be used to treat Parkinson's one day?

To find out, we're currently funding pre-clinical studies at the University of Oxford led by Dr Stephanie Cragg.

These are studying the effect of nicotine on the dopamine-producing nerve cells that are lost in Parkinson's.

Early results look promising and suggest that nicotine may boost the amount of dopamine that nerve cells produce.

Phase 2 studies to test whether nicotine patches improve symptoms in people with Parkinson's are now underway – one in France and one in the US funded by the Michael J Fox Foundation.

Investigating insomnia drugs

Researchers are exploring whether a drug called zolpidem, currently prescribed to some people as a treatment for insomnia, may also have benefits for people with Parkinson's.

One of these studies is taking place at Aston University in Birmingham and is funded by Parkinson's UK.

The research team, led by Dr Ian Stanford, has shown that certain brain rhythms – called beta rhythms – increase in people with Parkinson's.

These may be at the root of many of the movement symptoms of Parkinson's.

Low-doses of zolpidem have been shown to reduce these overactive beta rhythms and may help to improve symptoms without side effects.

Protecting precious nerve cells

There's more news on the development of approaches that aim to protect the nerve cells lost in Parkinson's. These have the potential to slow or stop the development of the condition.

One of this new wave of treatments for Parkinson's is a drug called Cogane, which is being developed by a UK-based pharmaceutical company.

Pre-clinical tests suggest that Cogane stimulates the production of naturally-occurring proteins (called growth factors) in the brain, which help nerve cells survive and grow.

Cogane is now being tested in a large phase 2 study involving 400 people with early stage Parkinson's in several different countries (including the UK). Initial results are expected towards the end of 2012.

Another similar approach is being investigated by a company in New Zealand.

But instead of using a drug to boost the levels of protective growth factors in the brain, they plan to use cells.

The treatment involves transplanting pig cells taken from the choroid plexus – an area of the brain that produces chemicals and proteins that help protect the brain and repair damage from disease or injury.

A phase 1 trial of the new treatment is expected to start in early 2013.



The future's looking bright

It's still too soon to know which of the treatments will actually make it through the clinical trials process and become available to people with Parkinson's.

Some will fail along the way, but the variety of different approaches to treating Parkinson's means that the future is looking brighter all the time.

Find out more

Find Parkinson's research studies in the UK that may be looking for participants: parkinsons.org.uk/researchstudies

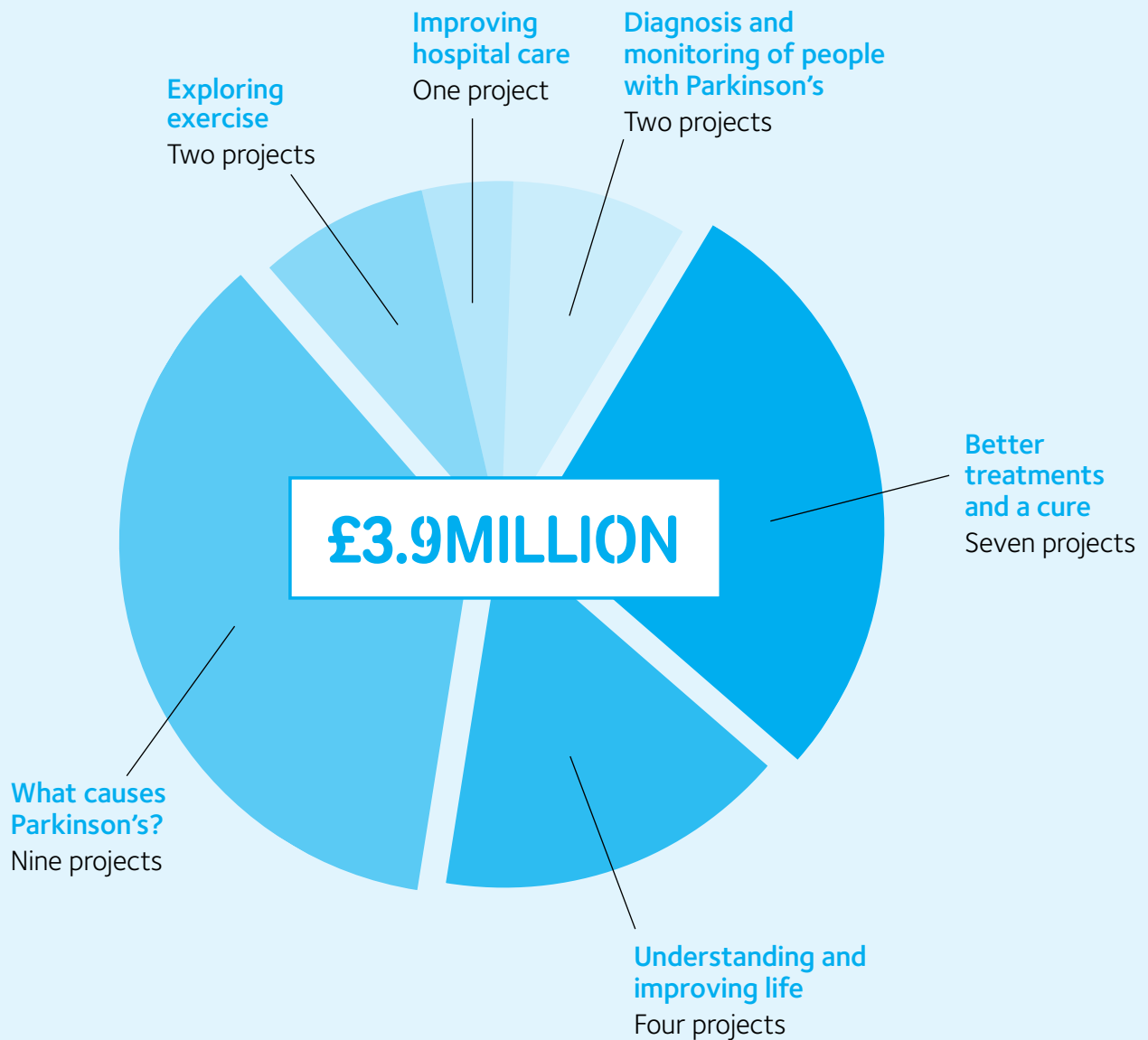
See our booklet *Drug Treatment for Parkinson's*. Our publications can be ordered for free (see p35) or downloaded from parkinsons.org.uk/publications

Browse international research studies at <http://clinicaltrials.gov/ct2/home>. And stay up to date by keeping an eye on the research news feed on our website: parkinsons.org.uk/researchnews

We'll also keep you up-to-date through the *Parkinson* magazine, and of course future issues of *Progress* – so watch this space.

NEW RESEARCH IN 2012

Since the last issue of *Progress* we have approved 25 projects totalling over £3.9million. On pages 11-17 we'll tell you more about some of these.



For more information about some of the projects, you can find the articles on the following pages:

- **Improving hospital care** p11
- **Exploring exercise** p12-13
- **Diagnosis and monitoring of people with Parkinson's** p14-15
- **Understanding and improving life** p16-17

Find out more

You can find out more about all our current research studies by visiting our website at parkinsons.org.uk/currentresearch

Improving hospital care

Dr Rob Skelly and his team investigate whether Specialist Parkinson's Units can make a difference to hospital care.



Above: Rob and the team at Royal Derby Hospital

Many people with Parkinson's don't get the care they need in hospital. Staff don't always know enough about the condition, its complications or drug management. This can lead to medication errors and reduced mobility, as well as longer stays in hospital.

Dr Rob Skelly at Royal Derby Hospital has received an innovation grant of £34,996 for his 12 month project exploring whether Specialist Parkinson's Units can reduce medication errors, improve patient satisfaction, and reduce the length of hospital stays for people with Parkinson's.

Rob's team have set up a Specialist Parkinson's Unit within Royal Derby Hospital where:

- all staff will be trained on Parkinson's medications – particularly the importance of giving them on time and their side effects
- Parkinson's medications will be available on the ward to reduce delays in administration
- people with Parkinson's will be encouraged to manage their own medications
- the unit will be managed by a geriatrician with a special interest in Parkinson's

The team will collect data before and after the new unit is introduced to see whether a specialist unit can make a difference to people with Parkinson's.

Rob explains where the idea for a Specialist Parkinson's Unit came from:

"Medication management is a big problem for people with Parkinson's in hospital – and while Parkinson's UK's Get It On Time campaign is making a difference, I feel there's still more we can do to improve care.

"Other studies have shown that patients with certain conditions do better in specialist units than on a general ward. So I thought this approach might do the trick for Parkinson's too.

"The idea of having a Specialist Parkinson's Unit is a simple one and, if we're successful, could easily be adopted by other hospitals to really make a difference to people with the condition and their families."

Below: A carer and person with Parkinson's at the Edgware Day hospital – the only specialist Parkinson's care centre in the UK



Exploring exercise

Regular exercise is vital for everyone, but research is beginning to reveal important extra benefits for people with Parkinson's.

Various types of exercise may be helpful for people with Parkinson's depending on their fitness, symptoms and types of activities they enjoy.

Recent studies have shown that weight training which helps develop muscle strength may help to manage the movement symptoms in the longer term. And activities like 'Tai chi', an ancient martial art that practises slow, flowing movements and meditation, may help to improve balance.

Studies have even suggested that exercise could help to protect the nerve cells lost in Parkinson's, potentially slowing the progression of the condition. That's something no current treatment can do.

Below: The Xbox Kinect in action



We've already funded a project to explore using the Nintendo Wii as a form of exercise for people with Parkinson's. So we're delighted to announce two new studies that will help people with Parkinson's get the most out of exercise.

Developing movement-based computer games for Parkinson's

We've given Professor Lynn Rochester at Newcastle University £31,836 to fund her nine-month project. Lynn explains why developing movement-based computer games may help people with Parkinson's who have problems with posture.

"It seems that more complex and challenging forms of exercise that use sound and visuals can help make exercise more effective for people with Parkinson's. But this can be difficult to achieve with traditional physiotherapy techniques. So movement-based computer games systems have exciting potential for developing fun and innovative ways for people with Parkinson's to exercise."

In this project Lynn and her team will work with five volunteers who are all at different stages of Parkinson's to design and test a new game to improve posture for the Xbox Kinect.

"I hope the results of this study will lead to bigger projects to develop different games that tackle a range of Parkinson's symptoms, and a large-scale study to test the effectiveness of the games for people with the condition.

"Ultimately this study could lead to a range of computer-based exercise games that people with Parkinson's can use at home with their families to manage and improve physical symptoms – helping people maintain their independence and improve their quality of life."

About the Xbox Kinect

- The Xbox Kinect uses a camera-based controller, which means players can control games through body movement without the need for handheld controllers.
- So far there has been no published research into whether the Xbox Kinect can help people with Parkinson's. But Professor Lynn Rochester believes it has great potential for developing tailored games to tackle specific symptoms of the condition such as balance and posture.
- What's more, because Xbox Kinect tracks the player's body movements, it could also help people and their physiotherapists monitor any changes in their symptoms.

Using exercise to prevent breathing problems

Professor Richard Walker's 12-month project, funded by an Innovation grant worth £15,619, will explore whether exercise can improve breathing problems in a group of people with Parkinson's, and ultimately improve overall health and quality of life. Richard explains:

"Many people with Parkinson's experience breathing problems at some stage.

"These can lead to much more serious conditions like pneumonia, which is one of the most common reasons for people with Parkinson's to be admitted to hospital.

"Exercise has been shown to help improve breathing problems for people with conditions like asthma. So we're keen to investigate if it has similar benefits for people with Parkinson's."

Richard and his team will recruit people with Parkinson's in Northumbria through his Parkinson's clinic and test their breathing and lung function.

He will then invite the volunteers who experience some difficulties with breathing to take part in the study.

Half will be randomly chosen to take part in a 12-week exercise programme, and half will be the 'control group' who continue their normal routine.

Richard and his team will carefully monitor:

- lung function, breathing and exercise capacity
- the effect of exercise on quality of life, anxiety, depression, sleep and thinking
- levels of 'brain derived neurotrophic factor' (or BDNF) in the blood, a protein which may help to boost brain health

"If our project is successful, it could lead to new ways to tackle breathing difficulties for people with Parkinson's.

"This would not only significantly improve peoples' general health and wellbeing, but could also help to prevent potentially life-threatening illnesses like pneumonia."



Above: Regular exercise is vital for everyone – and may have extra benefits for people with Parkinson's



HELP US
FIND A
CURE

Diagnosis and monitoring of people with Parkinson's

We launched 'Tracking Parkinson's' on 16 April, the first day of Parkinson's Awareness Week 2012. And we need thousands of people with Parkinson's across the UK to get involved.

Tracking Parkinson's will be the world's largest ever in-depth study of people with Parkinson's and ultimately aims to speed up our search for a cure by finding 'biomarkers'.

So far, more than 1,500 people have contacted the research team about taking part. But we still need people who've been diagnosed with Parkinson's in the past three years or who were diagnosed before the age of 50 to get involved.

This study, led by Dr Donald Grosset at the University of Glasgow, is happening across a network of more than 40 study centres around the UK and will cost more than £1.6million over five years.

Finding 'biomarkers' – the key to a cure?

Finding biomarkers is a key part of our five-year research strategy because we believe they will be crucial to finding a cure for Parkinson's.

Biomarkers are small changes in the body that can be measured to show how severe a medical condition is, or to help us diagnose it in the first place. But no biomarkers have yet been found for Parkinson's. Without a reliable biomarker we cannot diagnose Parkinson's accurately or measure how it progresses – which is a massive barrier to testing new treatments. Having a biomarker for Parkinson's would also help us diagnose Parkinson's earlier, when people are most likely to benefit from the new treatments scientists are working on.

Dr Donald Grosset, who is leading the Tracking Parkinson's study, said:

"The cure for Parkinson's is a global challenge and all the samples gathered from our thousands of volunteers will be available for analysis by researchers the world over. This, in itself, will speed up our ultimate goal – to develop a cure for Parkinson's. I am very excited to be leading this cutting edge research collaborating with top researchers from Scotland, England, Wales and Northern Ireland."

Find out more

If you've been diagnosed with Parkinson's in the past three years or were diagnosed before the age of 50, you may be eligible to take part in the Tracking Parkinson's study.

Please call our helpline on **0808 800 0303** or visit parkinsons.org.uk/tracking to find out more.

If you're unable to take part in this study but would like to take part in research, you can find a full list of projects around the UK that need volunteers at parkinsons.org.uk/researchstudies



Anne-Marie Wright was diagnosed with Parkinson's in October 2010 and is taking part in the Tracking Parkinson's study:

"A cure for Parkinson's would be like winning the lottery. Life has really changed since I've been diagnosed, so any kind of further treatment or a cure would be just a miracle really. I got involved by coming to the clinic and speaking to my specialist nurse.

"Taking part in the study involves a blood test every 18 months, 6-monthly visits to my consultant and a questionnaire. But everything is built in during my visits so I don't have to spend extra time going along.

"I'm keen to do whatever I can to help the researchers who are working so hard to help people like me. By taking part in this study I'm not getting a new treatment but I'm helping the researchers build a better picture of Parkinson's that will hopefully lead to breakthroughs further down the line – and that's worth doing."

Understanding and improving life: non-verbal communication

Difficulties with communication affect many people with Parkinson's and can lead to frustration and isolation affecting family and carers too.

Dr Ellen Poliakoff at the University of Manchester has been awarded £65,318 for a new PhD student, Stacey Humphries, to investigate how Parkinson's affects peoples' ability to communicate.

But rather than focusing on speech, the three-year study will investigate changes in the non-verbal signals that people use to get their message across. We asked Ellen about her plans for the new study, which will start in October.

What is non-verbal communication?

"When we speak we also use subtle non-verbal signals to get our point across. Body language, facial expression and eye contact all play an important part in helping people understand what we're saying.

"There is some evidence that non-verbal communication is affected by Parkinson's, but there are lots of questions that we need to answer. I'm interested to know what kinds of non-verbal

Below: Non-verbal signals play a big part in communication



communication are affected in people with Parkinson's. And whether people with the condition use non-verbal techniques to help compensate for problems they have with speech."



Above: Ellen (right) and PhD student, Stacey

How will you study non-verbal communication in Parkinson's?

"Non-verbal communication is quite a tricky thing to study, so firstly we're going to video people with and without Parkinson's as they talk.

"Then we'll analyse and show the videos to people without the condition to test how effective the non-verbal signals people with Parkinson's use are, and if they help them to communicate better. finally, we'll investigate whether Parkinson's affects peoples' ability to read non-verbal signals in others."

How will the research help people with Parkinson's?

"I hope that investigating how people with Parkinson's use non-verbal signals when they speak will help us better understand the communication difficulties that people with the condition face. This could ultimately lead to developing therapies and strategies that can help people with Parkinson's communicate more effectively."

Find out more

See our information sheet *Communication and Parkinson's* to find out more. Our publications can be ordered for free (see p35) or downloaded from parkinsons.org.uk/publications

Understanding and improving life: investigating dementia with Lewy bodies

We've teamed up with the Lewy Body Society to support two new Innovation grants investigating dementia with Lewy bodies.

Dementia doesn't affect everyone with Parkinson's, but it's more common in people with the condition and has a major impact on the person affected and those who care for them. But current treatments for dementia are limited so more research is urgently needed.

Tackling dementia is a priority for Parkinson's UK. We're currently funding Professor David Burn's research, worth over £1 million, at Newcastle University which aims to identify people with Parkinson's who are at risk of getting dementia. And now there are two new research projects funded by the Lewy Body Society, which will bring us closer to a future where people can live their lives without the disabling effects of dementia.

Cracking the genetic code

Like Parkinson's, it's very rare for dementia with Lewy bodies to be inherited. But while researchers have uncovered several genes that affect a person's risk of developing Parkinson's, we know very little about the genes involved in dementia with Lewy bodies.

Dr Jose Bras and his team at University College London will use a grant of £35,000 to analyse the DNA of 700 people with dementia with Lewy bodies. Jose hopes to spot subtle genetic changes that will help us understand the condition better.

Nerve cells from stem cells – a window into the brain

We don't fully understand how and why Lewy bodies develop – or how this is linked to nerve cell death. And crucially we don't have any treatments that can prevent Lewy bodies forming or nerve cells dying.

Parkinson's UK Senior Research Fellow Dr Tilo Kunath is already using nerve cells made from

stem cells to better understand Parkinson's and test new drugs. Now we've awarded his team at the University of Edinburgh an extra £18,172 to do the same for dementia with Lewy bodies.

Dementia with Lewy bodies

Dementia with Lewy bodies is the second most common cause of dementia after Alzheimer's. It's diagnosed when someone has the symptoms of dementia either before or at the same time as developing Parkinson's-like problems with movement. But in some cases, no movement problems may develop at all. The name comes from Lewy bodies, which are clumps of protein that develop inside the nerve cells in the brain. These nerve cells go on to get sick and die in both Parkinson's and dementia with Lewy bodies.



Find out more

Visit www.lewybody.org or see our information sheets *Dementia with Lewy bodies* and *Parkinson's dementia* to find out more. Our publications can be ordered for free (see p35) or downloaded from parkinsons.org.uk/publications

Your letters...

In the last issue we asked for your feedback about the magazine. We received so many thoughtful comments, suggestions and questions that we thought we'd share some of our favourites here.

AN INTERNATIONAL FLAVOUR TO PROGRESS

I'd really like to know more about collaborations between the charity and other organisations like Michael J Fox Foundation, Medical Research Council etc and what progress is being made within other research organisations. It's lovely to know all about what the charity is funding but we are a pretty small fry in terms of overall funding and I would find it interesting to know what the big boys are doing (if anything).

Anonymous, feedback submitted online

A lots of people said they were keen to see more international research news in Progress, and we've added 'Parkinson's research from around the world' at the start of the magazine – see p4.

“ Having been recently diagnosed I was amazed at the work going on to find a cure. My father also had Parkinson's so I look to the future with some trepidation. This magazine made me feel more positive. Thank you for the work you do. ”

“

I love reading the magazine and find myself engrossed in it as soon as it pops through the door. Well done to everyone who contributes and works so hard to get it out. ”

”

MAKE IT EASIER TO TAKE PART

The 'Taking part in research' column makes it sound fairly straightforward to participate. However, the website that one is referred to, by the column, is by no means user friendly. It is not clear which studies are still seeking participants and which are closed or only recruit through clinics or in other ways.

As a potential volunteer I can tell you that a clear statement of whether they are still recruiting, whom they are seeking to recruit, and so on, presented in as standardised a format as possible, would be more productive for them and less frustrating for potential participants.

Anonymous, feedback submitted online

This feedback helped us make some important changes to make the list of studies on our website clearer and more consistent: parkinsons.org.uk/researchstudies

**82% OF PEOPLE TOLD US THEY FIND
PROGRESS MAGAZINE VERY INTERESTING**

“

It is just at the right level for me – clear, well-paced without feeling dumbed down for the lay-person. ”

SOLVING SPEECH PROBLEMS

Reading the last issue of *Progress* I couldn't help but notice the idea of using mobile phones to help manage speech quality. I was diagnosed in 2006, and one of the symptoms has been declining voice quality. Last year I had an intensive four week course with my speech therapist. This went well and my voice improved. However, although there are periodic reviews after the course you are, in the main, left alone to both apply what you have learned and sustain the vocal improvements.

I knew I could speak loudly, but I couldn't easily tell whether I was hitting the right volume, particularly in business meetings. So I decided to try and solve the problem by designing my own 'Voice Volume Monitor' to show me how loudly I'm speaking. I now use my monitor every day when I do my speech exercises and the extra feedback makes them much more effective.

Marcus

We're funding research to develop mobile phone apps to help people improve their speech. We've also recently launched Phones for Parkinson's which includes our very first Parkinson's app (see page 20).



71% OF PEOPLE TOLD US THAT
PROGRESS MAGAZINE IS EASY TO READ

WEIRD AND WONDERFUL FUNDING AMOUNTS

The winter issue of *Progress* is very easy to understand and encouraging. But I was puzzled by the figures of the research grants such as £333,229 to Professor Anthony Schapira and to the others. The only grant of a round sum is £15,000 given to Dr George Tofaris. The remaining grants are precise amounts.

Apart from this quibble *Progress* is extremely helpful and optimistic about the future chances of finding a cure. Well done!

Hugh

Great question! When researchers apply for a grant from Parkinson's UK they have to provide a very detailed breakdown of the costs of their research. And when all the specific costs for materials, staff time and equipment they need for their project is added up it often comes to quite an odd number.

*We actually don't include the grant costs to the penny in *Progress* magazine, but some grants are not even rounded up to the nearest pound!*

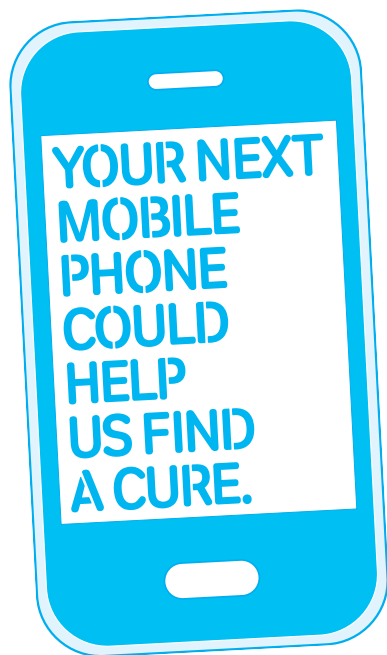
Keep the feedback coming!

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

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

research@parkinsons.org.uk
0207 963 9326

PHONES FOR PARKINSON'S: A GOOD CALL FOR PARKINSON'S UK



In June we launched Phones for Parkinson's, a completely new way of raising vital funds. Here Rachel Backshall, Head of Business Development at Parkinson's UK, answers some of the questions people have asked about the scheme.

What is Phones for Parkinson's?

"Phones for Parkinson's is a new way to raise money for Parkinson's UK. We're now offering ordinary mobile phones with tariffs

from Orange where 45% of the revenue goes to Parkinson's UK. You can also download EasyCall, our very first Parkinson's app, that allows you to make a call with just two clicks, thanks to the large, pre-programmable buttons.

"It's good news for anyone who finds using a smart phone tricky. The app will also give you access to our most popular publications and up to date Parkinson's news via a feed from our website. You can find out how to download EasyCall at parkinsons.org.uk/easycall

How did the idea come about?

"Phones for Parkinson's is a fundraising initiative that was conceived around two years ago and it has taken us this time to make it work for the charity. It's not just a way of raising extra funds for Parkinson's UK – it also allows us to offer mobile apps that are specially designed to help people affected by Parkinson's.

How does it raise money?

"Parkinson's UK raises income by receiving 45% of the profits from both the sales of the phone and then the monthly bills.

Does it cost more than other contracts?

"The contracts that we have agreed with Orange are based on their existing tariffs and are very competitive. You can have one of our four recommended phones and tariffs or you can choose from a wide range that is available.

"The service that you will receive is no different to any you would have with Orange except you know that a large part of the revenue is going towards helping those affected by Parkinson's.

Can anyone be part of Phones for Parkinson's?

"Anyone can have their monthly phone contract through us – whether you are a person with Parkinson's, carer, family or friend or you just want to do something good with your phone payments.

"Like all good ideas it's really simple. You help people affected by Parkinson's with something you would have anyway – your mobile phone contract.

How do I get my phone?

"The details of our four recommended phones and tariffs are on our website parkinsons.org.uk/phonesforparkinsons or you can simply call **020 3476 2626**.

"There are people at the end of the phone who will discuss your needs with you and then recommend the right phone and tariff.

"And when you've made your choice, they will set the tariff up for you and post your new phone to you straightaway."

OUR RESEARCH IMPACT: HIGHLIGHTS IN 2011

We're the largest charity funder of Parkinson's research in the UK. 2011 was another exciting year – here are a few of the highlights.

Turning £1 into £4

Our funding acts like a magnet, attracting extra funding from other sources such as the government, pharmaceutical industry and other charities.

In 2011 we invested more than £4.5million in new research, helping our researchers gain a further £13.2million from other funding bodies.

Sharing new knowledge

In 2011, Parkinson's UK funded researchers shared their research results with the international research community.

They did it by:

- giving 140 presentations at international meetings and conferences
- publishing more than 120 scientific articles in journals
- speaking at more than 100 public events – including one researcher who visited 30 Parkinson's UK local groups

Taking our discoveries forward

Every research project we fund ultimately aims to make a difference to people living with Parkinson's.

And in 2011 our projects helped pave the way for:

- five new clinical trials for Parkinson's
- updates to the NICE guidelines for deep brain stimulation
- discussions with the pharmaceutical industry



“

Our Parkinson's UK grant helped to set up a new research centre at the University of Cambridge attracting external funding of £6million from pharmaceutical company ELAN.

The new centre, called the Centre for Research Innovation and Drug Discovery will focus on finding potential new drugs for neurodegenerative conditions including Parkinson's. ”

Professor Chris Dobson

Find out more

Over the next few pages you can read more about how our research projects are making a difference. And you can also download a copy of the report from our website at parkinsons.org.uk/researchimpact

RESEARCH RESULTS

On p22-28 we tell you about all the latest findings from seven Parkinson's UK-funded projects.

Bone marrow stem cells show promise in the lab

New research led by Dr Alan Whone at the University of Bristol has shown that bone marrow stem cells can protect living nerve cells in a dish. This highlights the potential of bone marrow stem cells as a future treatment for Parkinson's.

Dr Alan Whone is part of a team who are trialling bone marrow stem cell therapy in people with multiple sclerosis.

This exciting discovery, published in the journal *Brain Research*, was made possible by a project grant of £13,130 awarded in 2010.

The research could move forward relatively quickly, because bone marrow stem cells are already being tested for other conditions.



Why bone marrow stem cells?

Bone marrow stem cells produce growth factors – natural chemicals that can reduce harmful inflammation, support damaged cells and help them survive. Crucially, bone marrow stem cells are easy to get hold of, because we all have our own supply.

Bone marrow stem cells can be taken from the pelvis and then put back into the blood through a drip. Once they're in the bloodstream, these cells can travel to areas of damage in the brain.

What the team found

The team showed that growth factors produced by bone marrow stem cells can protect nerve cells against damage caused by exposure to chemicals. These factors not only helped the nerve cells survive, but also kept them working properly.

Their experiments highlighted the importance of a key growth factor called GDNF, because the protection was reduced when they blocked its activity.

Alan comments:

“As a first step towards developing bone marrow stem cell therapy for Parkinson's, we're carrying out experiments in the laboratory to understand exactly how it may help.

“The results from this project will guide our future research using bone marrow stem cells in an animal model of Parkinson's. We hope our work will ultimately lead to a clinical trial.”

Publication:

Whone AL et al (2012) 'Human bone marrow mesenchymal stem cells protect catecholaminergic and serotonergic neuronal perikarya and transporter function from oxidative stress by the secretion of glial-derived neurotrophic factor' *Brain Research*; 1431;86-96

Fruit fly research reveals protective protein

Research led by Dr Frank Hirth at King's College London has shown that the protein 'alternative oxidase' can protect nerve cells in a fruit fly model of Parkinson's. This results offer hope for future treatments that could slow or halt the progression of Parkinson's.

The team published their findings, supported by a project grant of £184,696 awarded in 2008, in the journal *Human Molecular Genetics*.

What the team did

First, the researchers made genetically modified fruit flies with faulty mitochondria, the tiny energy-producing batteries that are damaged in the nerve cells affected in Parkinson's.

As a result these fruit flies showed some of the key features of Parkinson's, including movement problems and gradual loss of dopamine-producing nerve cells.

Next, they caused these flies to make extra proteins, to see if they could protect the nerve cells. They found that alternative oxidase, a protein that helps mitochondria work in animals, like worms and sea squirts, prevented the flies' nerve cells from dying.

Why fruit flies?

Frank explains why fruit flies are so useful for Parkinson's research:

"Discoveries in fruit flies have made a huge contribution to our understanding of Parkinson's. Despite their tiny size, these flies have dopamine-producing nerve cells in their brains which are very similar to those affected in people with the condition.

"They're easy to keep, reproduce rapidly, and it's relatively simple to manipulate their genes – making them an ideal animal model."

Publication:

Humphrey D et al (2012) 'Alternative oxidase rescues mitochondria-mediated dopaminergic cell loss in *Drosophila*' *Human Molecular Genetics*; in press



Above: Adult fruit fly on pencil

Can electrical stimulation be given through the scalp?

In one of the first studies of its kind, researchers at Southampton University have shown that transcranial direct current stimulation, or tDCS, is safe for people with Parkinson's.

This cutting-edge research was funded by an innovation grant of £33,608, awarded to Professor Ann Ashburn in 2010. tDCS is a technique for stimulating nerve cells in the brain. It's done using electrodes placed on the surface of the scalp, so it's painless and non-invasive.

What the team did

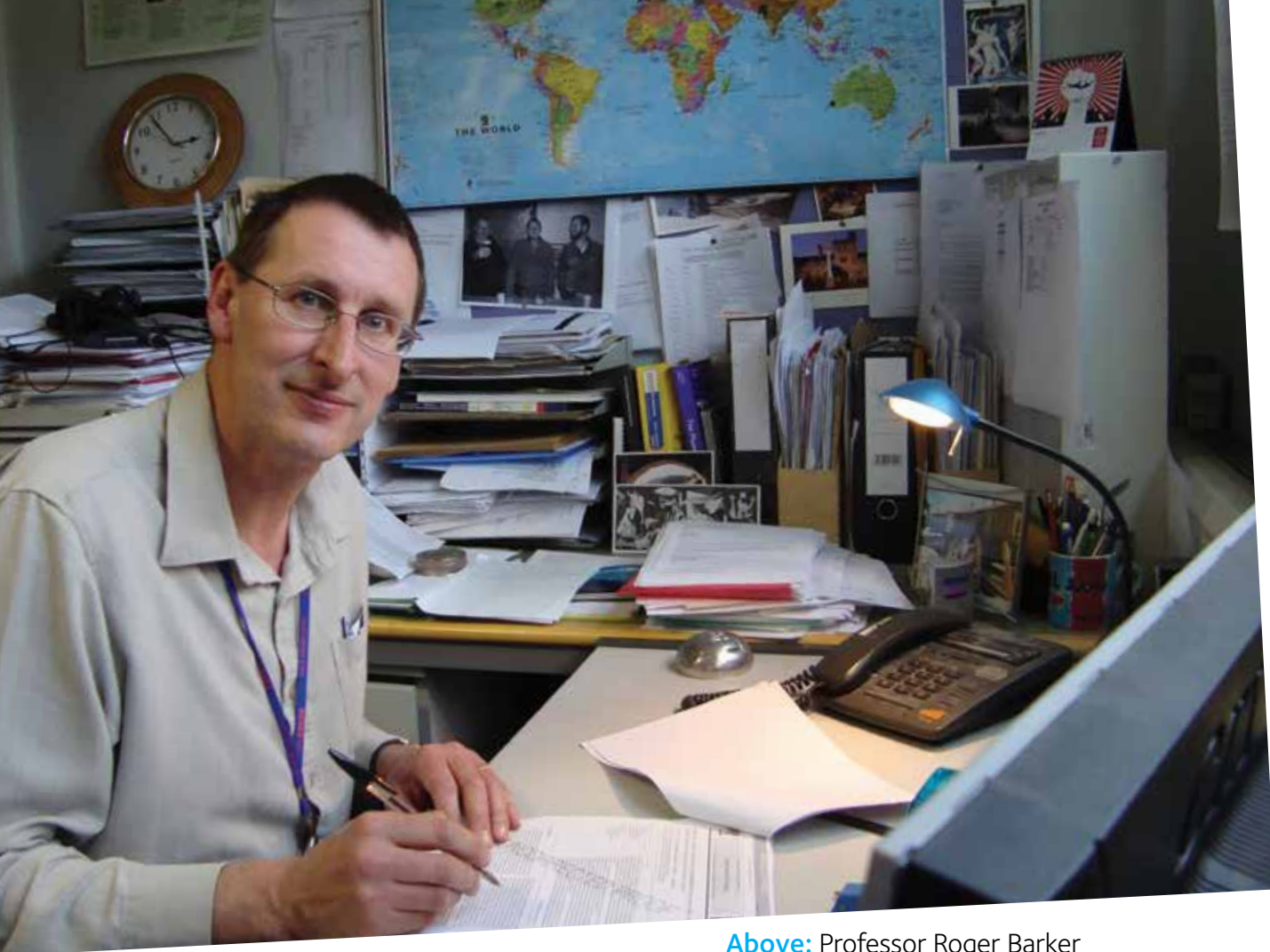
A few small studies had already shown that tDCS helps improve movement in people with neurological conditions. In this study, the team wanted to look specifically at the effects of tDCS on everyday movements like standing up from a chair, starting to walk or turning while walking, which many people with Parkinson's have trouble with.

What they found

Ann comments:

"We have shown that this kind of electrical stimulation is safe for people with Parkinson's, and that the side-effects are very minor.

"Unfortunately we didn't see any improvements in movement. But this was a small pilot study, so we're hopeful that further research can develop the technique and its potential as a therapy."



Above: Professor Roger Barker

A new clue to thinking problems in Parkinson's

Researchers at the University of Cambridge and Imperial College London have made an important step towards understanding the cause of some of the thinking problems in Parkinson's.

Their pioneering research could help us develop strategies to manage these problems better in the future.

The team, led by Professors Roger Barker and Paola Piccini, recently completed a project supported by a three-year grant of £96,323, investigating a gene called COMT.

The COMT protein (which is made from the gene) breaks down the chemical messenger dopamine – particularly in a part of the brain called the frontal cortex, which is involved in thinking.

All of us have one of three common variations in the COMT gene that affect how the protein works.

But this variation could have a particular impact on people with Parkinson's who take drugs which increase the amount of dopamine in the brain.

It's thought that too much or too little dopamine in the frontal cortex could explain some of the thinking problems in some people with Parkinson's.

We talked to Roger about his research.

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

"The movement symptoms of Parkinson's are well known, and have been the focus of a great deal of research. But so-called 'non-motor' symptoms, like thinking problems, can also have a major effect on quality of life. My team has been working to understand these problems for over a decade.

"Our aim is to show that thinking problems in Parkinson's can vary from person to person, and that not all thinking problems are linked to dementia.

What were your goals for the project?

"We wanted to compare people with early stage Parkinson's with and without a particular change in the COMT gene.

"We used brain scans to investigate what happens to dopamine in the frontal cortex in people with different versions of the gene.

What have you found?

"We found that people with Parkinson's with a particular version of the COMT gene had more dopamine in their frontal cortex compared to people with the other versions.

What are the next steps?

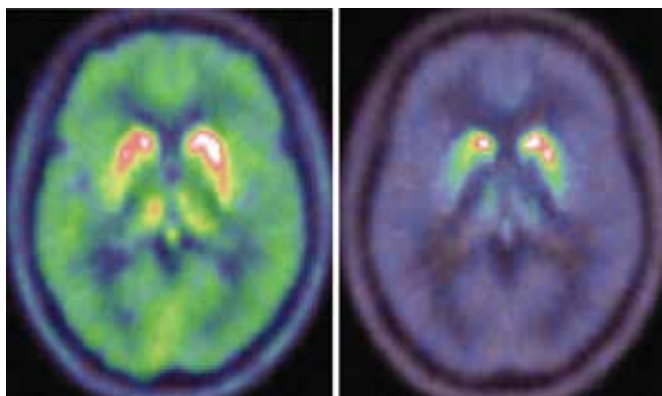
"We're hoping to use this information to see how Parkinson's drugs may affect thinking in people at different stages of the condition, and with different versions of the COMT gene.

"We also want to investigate the range of thinking problems in Parkinson's affected by this particular genetic change.

How will your research help people with Parkinson's?

"We now have a clearer picture of what may be causing some of the thinking problems in some people with Parkinson's, and how this relates to current drugs.

"In the future this could help doctors to tailor people's treatment to reduce certain types of



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

thinking problems. Our research may also shed more light on the relationship between thinking problems and the risk of developing dementia.

What advice would you give to people with Parkinson's who are worried about thinking problems?

"If you're having thinking or memory problems it's important to talk to your specialist or Parkinson's nurse. They'll tell you what can be done to help. This could involve altering your medication, or they may refer you to a specialist if needed."

Find out more

See our information sheets *Mild memory problems* and *Parkinson's dementia* to find out more. Our publications can be ordered for free (see p35) or downloaded from parkinsons.org.uk/publications

Below: People who took part in the study had PET brain scans



A new target for less invasive brain stimulation?

Our researchers at Aston University in Birmingham have made an important step towards developing an alternative to deep brain stimulation.

Using rats, the team showed that an area at the surface of the brain, called the motor cortex, could become a future target for less invasive brain stimulation. Their work was made possible by a project grant of £203,059 awarded to Dr Ian Stanford in 2008.

Stimulating the brain to treat Parkinson's

The loss of dopamine-producing nerve cells in Parkinson's causes an area deep within the brain – called the subthalamic nucleus (STN) – to become overactive. The STN has an important role in controlling movement, and this change in activity seems to be linked to the development of mobility problems.

The STN is a common target for deep brain stimulation which involves surgery to implant wires in the brain. A small electrical current sent through these wires can help relieve Parkinson's symptoms including slowness, tremor and stiffness.

The same result from a different target?

Deep brain stimulation is effective but very expensive and requires a significant operation

to implant the wires in precisely the right place in the brain. So, Ian wanted to investigate whether there might be another way to achieve the same results.

The motor cortex and the STN are connected and work together to control movement. The team used recordings from the rat brain to show that stimulating the motor cortex can change the activity in the STN.

Ian comments:

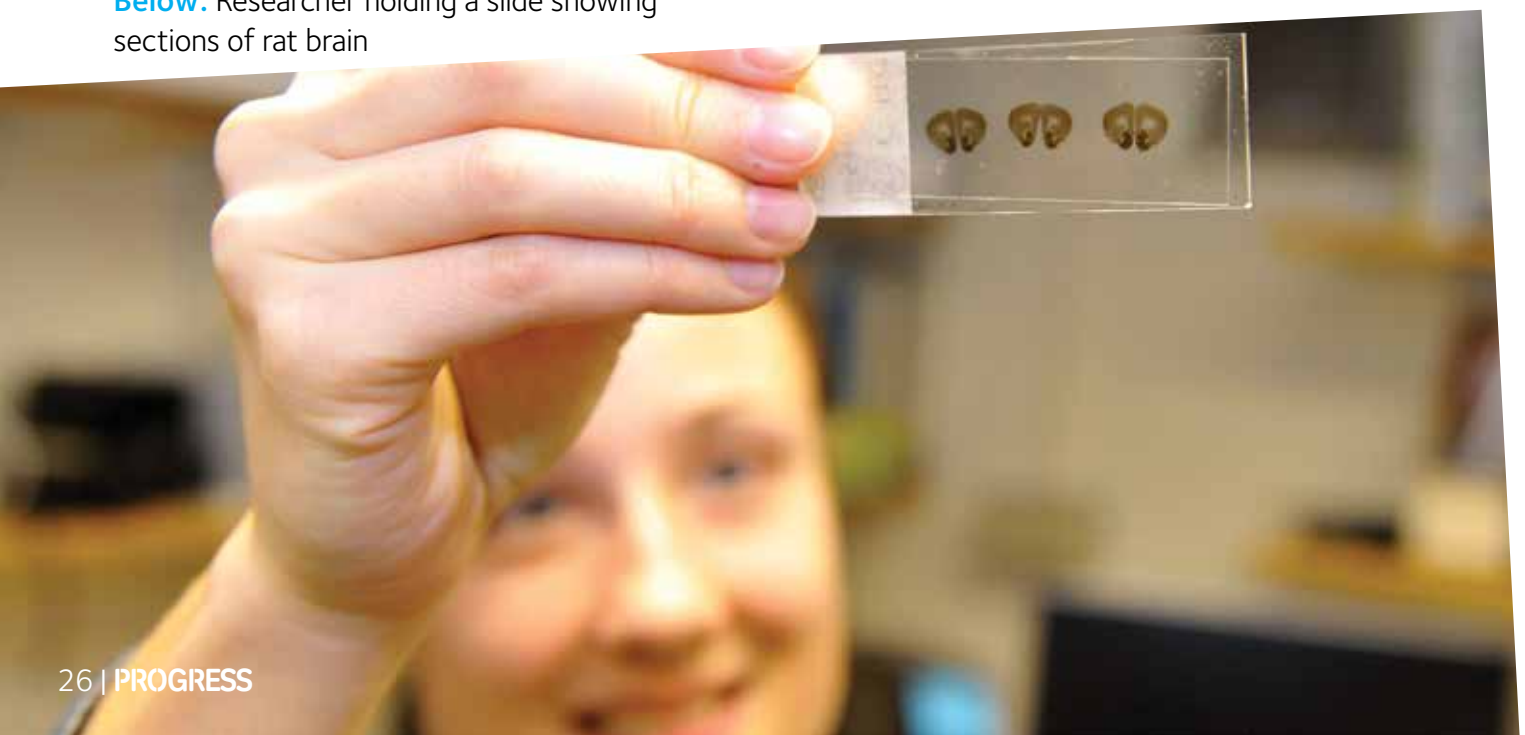
“The invasive nature and cost of deep brain stimulation means that not everyone who could benefit from this treatment will be able to have it. We hope our findings will inform the development of motor cortex stimulation as a treatment for Parkinson's.”

We're continuing to fund Ian's vital research. In September last year we awarded Ian another three-year project grant to find out whether the sleep drug zolpidem can improve the symptoms of Parkinson's.

Find out more

Deep brain stimulation is not suitable for everyone and is not a cure for Parkinson's. See parkinsons.org.uk/dbs or our booklet *Surgery and Parkinson's* to find out more. Our publications can be ordered for free (see p35).

Below: Researcher holding a slide showing sections of rat brain



Below: Olivia, a Tanzanian Parkinson's nurse and a person with Parkinson's



Below: Researcher Dr Catherine Dotchin with a patient in Tanzania



Treating people with Parkinson's in Tanzania

Back in 2006, Professor Richard Walker and his colleague Dr Catherine Dotchin carried out a Parkinson's UK-funded study to find out more about Parkinson's in rural Tanzania.

Richard comments:

"We found that Parkinson's is actually more common than we thought in sub-Saharan Africa. But very few people are diagnosed, due to low awareness of the condition. Even fewer have access to treatment, so their quality of life is very poor.

"We found 33 people with Parkinson's living in rural Tanzania, but most of them were totally unaware they had Parkinson's, which meant they had never received any treatment."

Now the people they found are cared for by Tanzanian Parkinson's nurses trained by Richard and his team in the UK. And the participants in the study have been receiving medication (levodopa) for the past five years.

In 2011, Richard and his team were awarded a grant of £37,874 by Parkinson's UK to continue following the people from the original Tanzanian study for a further three years.

"So far, the combination of drug treatments and Parkinson's nurses is working really well. And thankfully, by keeping levodopa doses relatively low and careful monitoring, side effects like dyskinesia have not been a major problem.

"If our approach works, it could provide a blueprint for delivering care for people with Parkinson's in other developing countries. We are already working to set up similar schemes in other African countries.

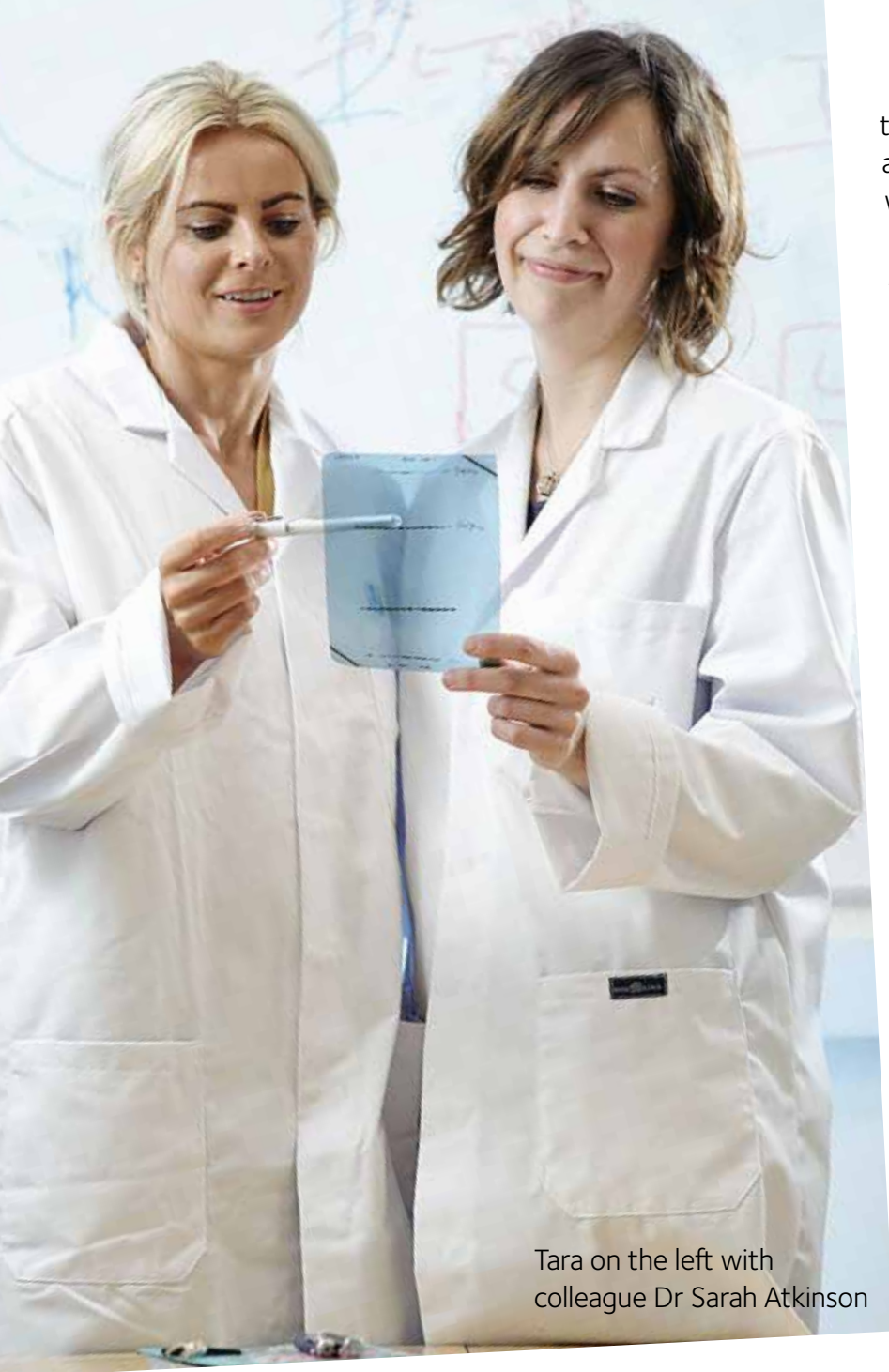
"We also hope to learn more about what causes the side effects of drugs, such as dyskinesia – which could provide valuable insights for treating all people with Parkinson's."

Richard and the team are training more nurses in 2012. And UK nurses are also supporting the scheme by acting as email mentors for nurses in Tanzania. Ultimately this project could bring widespread and affordable care for people with Parkinson's in sub-Saharan Africa closer.

It will also hopefully benefit all people with Parkinson's by teaching us more about how and why the side effects of medications like levodopa develop and how to prevent them.

Publication:

Dotchin C et al (2011) 'Three year follow up of levodopa treatment in a prevalent cohort of patients with Parkinson's disease in Hai, Tanzania' *Journal of Neurology* 258:1649



Tara on the left with colleague Dr Sarah Atkinson

Eye problems more common in people with Parkinson's

Eye problems are more common in people with Parkinson's and can appear long before Parkinson's diagnosis, according to new research led by Dr Tara Moore at the University of Ulster.

This research, funded by a £32,962 innovation grant awarded in 2009, is the first to investigate a possible link between Parkinson's and eye conditions. The team interviewed 150 people with and without Parkinson's and found that dry eyes and chronic inflammation of the eyelid (blepharitis) are more common in people with the condition. In

the majority of cases eye conditions were a long term problem before Parkinson's was diagnosed.

Many people with Parkinson's reported troublesome eyes from a young age, remembering dry eyes and eye infections throughout their lives.

Tara explains:

"My husband, Professor Johnny Moore, is a consultant ophthalmologist. He noticed that many patients with Parkinson's had eye conditions.

"It's possible that people with Parkinson's develop eye conditions because they blink less often. But we suspected there was a more significant link between a history of eye trouble and Parkinson's."

Now Tara plans to find out if people with Parkinson's have different bacteria on the surface of their eyes compared to people without the condition.

Johnny adds:

"The optic nerve is a direct link from the eye to the brain. So as well as being important for understanding eye health in Parkinson's, our research could uncover a connection between Parkinson's and eye conditions. Eye conditions can be treated. If you're having trouble with your eyes, the best person to speak to first is your GP. They will refer you to a specialist if needed."

Find out more

See our information sheet *Parkinson's and eyes for more information*. Our publications can be ordered for free (see p35) or downloaded from parkinsons.org.uk/publications

GET INVOLVED IN RESEARCH

People affected by Parkinson's have a vital role to play at every stage of the research process – not just as participants in clinical trials – and there are lots of ways to get involved.

Help shape Parkinson's research

Through our Research Support Network, people with Parkinson's are helping researchers to plan, design, and deliver Parkinson's research studies.

Guiding researchers

People affected by Parkinson's play an important part in studies that we fund. Dennis Fricker has Parkinson's and lives in the north west of England. He is part of the steering group for Professor Sheila Kitchen's Parkinson's UK-funded project at King's College London investigating assistive technologies. Assistive technologies are devices or aids that help make everyday life easier for people with Parkinson's – such as walking aids or pill boxes.

Dennis explains:

“The group supports and guides the work done by the researchers. For example, we helped them with their plans to widen the project to involve people affected by Parkinson's in different parts of the country. Our views helped the researchers to consider the wide range of needs that people with Parkinson's have, and to recruit participants effectively.

“I was keen to join the group because I'm very interested in research that can help people like me now or in the immediate future. Research that's looking for an ultimate cure is very valuable, but I'm nearly 80 now and am keen to support projects that will have more immediate results.

“I enjoy being part of the group – everyone is friendly and it's interesting to hear other perspectives from people like Parkinson's nurses in London who face different challenges than we do in the north west.”

Dr Nadine Geddes is the post-doctoral researcher carrying out this project:

“Involving people who are directly affected by the condition means our research is focused upon the things that really matter. Parkinson's UK helped us find three people with Parkinson's and a carer to sit on a steering group to guide our project. The steering group also means our project will run more smoothly – helping us to ask the right questions, spot potential problems early and recruit participants.”



Above: Pill boxes can be a useful aid to help people remember to take their medications on time

Developing research ideas

Dr Catherine Hurt of City University, London, is currently working on a proposal for a new research project in partnership with King's College, London:

"We want to investigate why many people with Parkinson's don't mention the non-motor symptoms they experience to their clinicians. We hope to make it easier for people to talk about non-motor issues and make sure they get the help they need.

"To help develop our project proposal, I organised a focus group with Parkinson's UK to talk to people affected by Parkinson's about my ideas.

"Some really useful feedback came out of the meeting. For example, the lack of GP knowledge about Parkinson's was clearly very important to people, so we've added that into our research plan.

"It helped us decide to use a questionnaire that can be completed either online or by post in our study. We're also looking into using a 'buddying system', to help people complete the questionnaires, a new idea that came out of the focus group."

Jack Spencer, who was diagnosed with Parkinson's in 2007, took part in the focus group:

"Doctors are great at prescribing pills, but they don't always know about other opportunities in the community for activities that can help people control their symptoms.

"In my branch we find Pilates and other types of physical exercise really helpful. When you've got Parkinson's you look at the world through Parkinson's eyes.

"Researchers can only imagine, so it was good to be asked for our feedback. I found the discussion interesting, especially hearing suggestions from other participants."

Research events so far in 2012

We work with researchers, research supporters and our local groups to arrange visits to labs, events, open days and talks around the UK. There have already been events up and down the country in 2012, with many local groups and research supporters arranging their own brilliant lectures and talks.

Cambridge

Almost 200 supporters joined us in April for the third Gretschen Amphlet lecture.

Steph Camp is one of our research supporters and attended this memorial lecture:

"Generously funded by the Amphlet family, this very positive research lecture, which marked Parkinson's Awareness Week, focused on 'finding a cure'. This year's speakers were Dr Peter Magill from the MRC Anatomical Neuropharmacology Unit, and his 'support act' (as he described himself), Professor Peter Brown from the Division of Clinical Neurology.

"Together they hope to work out how and why the brain rhythms become disrupted in Parkinson's – and ultimately develop better treatments to correct these such as deep brain stimulation. The lecture had some very interesting feedback and was quite motivating for all those who attended and positivity flowed across the room during the questions and answers."

Oxford

Forty research supporters joined us at the Oxford Parkinson's Disease Centre (OPDC) in May to hear talks covering everything from stem cells to brain scanning.

North East

Members of the Redcar and District Branch organised a research talk for local groups across the region during Parkinson's Awareness Week.

London

In March, our supporters visited Professor Richard Brown, King's College London, to hear about his Parkinson's UK funded research exploring mood changes and depression.

Basingstoke

In May, more than 130 supporters learnt about our research into stem cells, assistive technologies and preventing falls at a conference funded by the Freemasons' Grand Charity donation to Berkshire and Hampshire local groups.

Edinburgh

In May, the Edinburgh Branch organised their own research lecture for almost 300 people, with guest speaker Professor Roger Barker from the University of Cambridge.

Dundee

Our supporters visited the University of Dundee in May to find out how worms are helping us to understand how nerve cells die.

Belfast

During Parkinson's Awareness Week, our Northern Ireland team held a massively successful research day in Belfast – attended by around 100 people.

Arrange your own event

If you feel inspired and would like to host your own research event, we can help you organise and promote it – however big or small.

Ken Bowler chairs the Research Interest Group of the Edinburgh Branch, which organised the Edinburgh lecture:

“Staff in the Scotland team and the Research team in London supported us by helping to spread the word about our lecture. By promoting it through their website, we reached a lot more people than we could have done alone, and this meant more people had the opportunity to hear a really inspiring and interesting talk.”

Find out more

Contact rsn@parkinsons.org.uk, call **0207 963 9376** or visit parkinsons.org.uk/researchsupportnetwork

Join us in York, 4 November 2012

On the eve of the biannual Parkinson's UK research conference, we'll be hosting a day of talks for our research supporters. Places are limited and must be booked in advance. Contact rsn@parkinsons.org.uk. Visit parkinsons.org.uk/researchevents for further details of all our upcoming research events or join the Research Support Network.



BRAIN DONATION: YOUR QUESTIONS ANSWERED

Following our Brain Bank article in the last issue of *Progress* we received a lot of questions from people interested in donating their brains to Parkinson's research. So we invited Dr David Dexter, Scientific Director at the Parkinson's UK Brain Bank, to answer these questions for you.

How do I get a Brain Bank donor card?

"If you'd like to register as a brain donor all you need to do is fill in an application pack which you can request by contacting the Brain Bank (see adjacent for details).

"Once we receive your completed forms we'll add you to our database and send you the Brain Bank donor card.

I already have an organ donor card. Can I still leave my brain for Parkinson's research?

"Yes, many of our donors are also members of the NHS Organ Donor Register or other donation schemes. Just let us know which other donor scheme you are registered with.

"The only one we cannot work with is whole body donation for medical research as this requires the whole body including the brain.

How quickly does brain tissue need to be collected?

"Brain and spinal cord tissue deteriorate very rapidly. So we aim to collect tissue within 24 hours of death when it will be most useful to researchers.

"We can accept brains up to 48 hours after death but after that tissue is no longer useable for research and therefore cannot be collected.

"The Parkinson's UK Brain Bank team is on call 24 hours a day and we aim to organise and carry out the donation as quickly and smoothly as possible. But it's vital that your next of kin and the healthcare professionals looking after you know of your wish to donate so we can act quickly when the time comes.

I don't have Parkinson's. Can I still donate my brain?

"Yes, researchers urgently need brains without Parkinson's – also called 'control' brains. Control brains are essential for experiments. Scientists can only work out what is wrong in Parkinson's by comparing control brains with the brains of people with Parkinson's.

I'm a donor. What should my family or next-of-kin do when I die?

"The first thing to do is call our emergency number, **07659 104537** as soon as possible. The number is on your Brain Bank card.

"The call can be made even before a donor dies if they are not expected to live much longer. The sooner they can tell us, the more time we have to arrange the donation.

"We'll arrange for the body to be transported to the nearest hospital where the tissue will be removed by a pathologist or post-mortem technician.

“One of the Brain Bank team will come to collect your tissue and take it back to the Brain Bank for processing and storage. Then we’ll arrange for the body to be returned to undertakers for the funeral.

Will donating my brain affect my funeral arrangements or having an open casket?

“No, brain donation will not delay or interfere with your plans for a funeral, cremation or burial. The brain and spinal cord are removed in a respectful and careful manner that will not affect the appearance of the body.

What if I sign up to become a donor and then change my mind?

“We know that brain donation isn’t right for everyone. You are free to change your mind at any time. All you have to do is contact the Brain Bank to let us know and we will return your signed consent forms and remove your details from our database.

I live in the far north of Scotland and worry about my brain not getting to the bank because of my distance from it. Can my local hospital help?

“Unfortunately not all local hospitals are equipped to help with the tissue removal so sometimes we will have to transport the body to the closest main hospital with facilities for carrying out post mortems.

“Although this does cause an extra delay in the donation process, this has worked well in the past and has even allowed the Brain Bank to collect brains from remote islands with no road access. If we have advanced warning of your death, it gives us time to get the necessary transport in place so the donation can take place.”

Find out more

Do you still have questions? Contact the Brain Bank. Visit parkinsons.org.uk/brainbank, email brainbank@imperial.ac.uk or call **020 7594 9732**.

“

I really felt for Celia Chappell when I read about her unsuccessful attempt to have her father’s brain tissue collected by the Brain Bank.

My own experience was so different. My husband died suddenly in hospital. I gave the nurse his donor card, she made a phone call, and that was it.

Everything went like clockwork. My husband was a keen supporter of Parkinson’s UK and was really anxious that his brain should be used to benefit others. At a time of distress I found it comforting to know that his last wish had been fulfilled.

”

Joan

BRAIN DONOR CARD
in the event of my death,
immediately call
07659 104537 (24hr)

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

Imperial College
London
Version 1/2011

I wish to donate my tissue
to Parkinson's research

Name: _____
Signature: _____
Date: _____ Donor number: _____

For all other general enquiries contact 020 7594 9732
Parkinson's UK Brain Bank, Centre for Neuroscience, Imperial
College London, Hammersmith Hospital Campus
160 Du Cane Road, London W12 0NN

Above: The Brain Bank card gives permission for the brain to be used for vital Parkinson’s research

MY LIFE IN RESEARCH

Dr Laura Silveira-Moriyama is a Senior Clinical Research Fellow at University College London Institute of Neurology and is currently involved in two Parkinson's UK-funded projects.



I was born and raised in south-east Brazil in a large and warm hearted family.

My dad's parents were immigrants from Japan (hence the Moriyama) and were delighted when I chose to follow my father's steps and become a doctor. My mother's family is a typical Brazilian family with a strong Portuguese ancestry. Their business is helping others, so medicine ticked the box on that side too.

I finished my neurology training in 2003 and was eager to work with people with Parkinson's as my great-aunt developed Parkinson's at a very young age and I helped look after her in the final years of her life. She was bed-bound and experienced terrible dyskinesia. But she never lost the sparkle in her eyes and her passion for life.

I was very lucky when a famous Parkinson's specialist in Brazil took me in as a young addition to his dedicated team of clinicians and researchers. And in 2004, Professor Andrew Lees invited me to come to London and work with him in Queen's Square, the short name for the National Hospital for Neurology and Neurosurgery and its affiliated research institution: the UCL Institute of Neurology – it's a world-leading centre for Parkinson's research.

Working with so many big names was scary at first, but the responsibility of dealing with such a serious condition helped me focus and I got to work pretty quickly.

So what do I do? As well as treating patients, like all members of Professor Lees' team, I also carry out research into Parkinson's or related conditions.

I'm involved in two quite different Parkinson's UK-funded research projects. One with Dr Alastair Noyce called 'Predict PD' which is trying to find new ways to identify people at risk of developing Parkinson's, or in the very early stages of the condition.

The other, with another colleague Dr Karen Doherty, explores the posture problems that can affect people with Parkinson's and how best to treat them.

Once a week we have team coffee on Tuesdays. Those coffee times keep the large team together and remind us again and again that life is about people. We are not scientists, or doctors. We are people. We don't treat patients or conditions. We treat people. It may seem plain, but the boss says sometimes you can forget that. I like to think we don't.



Above: Laura and the rest of the National Hospital for Neurology and Neurosurgery team at Tuesday coffee

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

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*calls are free from UK landlines and most mobile networks

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

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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 or by calling 020 7963 9326.

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

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