

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

PROGRESS

The research magazine of Parkinson's UK
Issue 13: summer 2013

Why do 1 in 500
get Parkinson's?

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WELCOME

This issue our welcome comes from research supporter and active blogger Dr Jonny. As a scientist and a person living with Parkinson's, Jonny has a really interesting perspective on Parkinson's research.

Why do research? It may be a strange question to ask in a magazine devoted to research and it has an obvious answer (a cure!), but it is important to understand the nature of research.

Research is like an unpredictable, slowly erupting volcano. Within the volcano everything is fluid and constantly shifting. Sometimes a trickle of lava emerges which gradually builds and solidifies into knowledge. New treatment is built upon this solidified rock.

The analogy highlights the fact that research is slow and uncertain and deals with uncovering unknowns.

When lava does emerge and add to the scientific landscape it changes the context of previous knowledge, leading to new questions.

Science never stops. Research is hard, shifting, precarious work and can fail to find anything. Nonetheless, the build up of successful research has huge practical potential – modern life is built upon it, and it needs to be supported.

As someone with Parkinson's, I want treatments and solid answers now. But as a scientist I know today's research will take time to solidify into practical knowledge that leads to new treatment.

Research is important to me. When I was diagnosed with Parkinson's it felt like I was given a blank page. I didn't know how to fill that page and understand what was happening to me.



Above: Research supporter and blogger, Dr Jonny

Thankfully researchers had begun to unravel the causes of Parkinson's and the more I read, the more space I could fill on my page. I find understanding a great comfort.

Not only does research give hope for future treatments, it also provides the means to understand the strange Parkinson's landscape sufferers and their families are taken to when diagnosis comes. That's why magazines like *Progress* and public lectures are so important.

You can follow Dr Jonny's personal blog at:
<http://dialoguewithdisability.blogspot.co.uk>

INTERNATIONAL NEWS ROUNDUP

It's been an intriguing few months in the world of Parkinson's research. Here we share some of the most important stories from the year so far...

Cogane fails in Phase 2 trials

In February British Biotech Phytopharm announced that their new Parkinson's drug Cogane failed in Phase 2 clinical trials. This is disappointing news but it's crucial that negative results like these are shared.

In the 28-week trial which involved more than 400 people with Parkinson's, participants taking Cogane showed no benefit compared to those taking placebo (or dummy) treatment. parkinsons.org.uk/researchnews21feb2013

Parkinson's UK Twitter news

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

- *BBC News*: Using ballet to tackle Parkinson's <http://bbc.in/12OmWXe>
- Good mood boosts brain power in older adults <http://bit.ly/Vv7vwe>
- *BBC News*: Bad sleep 'dramatically' alters body <http://bbc.in/NM9xYM>

Follow us at www.twitter.com/parkinsonsuk

New brain research database launched

Researchers will be able to access samples from more than 7,000 donated human brains to help study conditions like Parkinson's, thanks to the UK Brain Banks Network database, launched by the Medical Research Council in March.

Five leading charities helped to supply data for the database: Parkinson's UK, the MS Society, Alzheimer's Society, Alzheimer's Research UK and Autistica. The new database will speed up access to samples held at 10 brain banks across the UK and help researchers track down the human brain tissue they need for their work.

parkinsons.org.uk/researchnews22mar2013

Siblings needed for research in the Thames Valley

Our researchers need brothers and sisters of people with Parkinson's to take part in a groundbreaking study in the Thames Valley area. The study will help us uncover more about the genetic origins of Parkinson's and develop better diagnostic tests.

If you have a brother or sister with Parkinson's and live in the Thames Valley area, please consider taking part in this groundbreaking research.

11 hospitals across the region are involved and volunteers can go to their nearest centre.

parkinsons.org.uk/researchnews5mar2013

Diabetes drug shows promise

Results published in May from a small clinical trial show that exenatide, a drug commonly used to treat diabetes, may have real promise in helping to slow down Parkinson's in some people, helping them to remain more mobile for longer.

This new research is an important step forward in the on-going fight to find a drug which can slow down, or even halt, the progression of Parkinson's.

45 people with mild to moderate Parkinson's took part. Half received exenatide and the other half remained on Parkinson's medication alone.

After 12 months, participants receiving exenatide symptoms had improved slightly, while those on standard Parkinson's medication had experienced a deterioration in their symptoms.

These results are encouraging but the study was conducted in a very small number of people and, crucially, without a placebo group – making it impossible to draw firm conclusions at this stage.

Now much larger and longer follow-up studies are needed to fully examine the usefulness of exenatide for people with Parkinson's.

<http://bit.ly/17VWWKT>

Obama backs brain mapping project

Barack Obama has announced that the US Government is investing \$100million in a new project to create a virtual map of the human brain.

The project will use powerful computer-based models and simulations to reconstruct a virtual human brain. Obama hopes the new brain map could have a similar impact to the Human Genome Project in studying conditions like Parkinson's and developing new treatments. bbc.in/YSxzE5

Could steroids have hidden benefits?

Scientists at Swansea University and Karolinska Institutet in Stockholm have identified two steroid-type molecules that play an important role in the survival and production of nerve cells in the brain.

Although steroids themselves are unlikely to become a treatment for Parkinson's, this discovery could lead to the development of new treatments. The findings were published in the journal Nature Chemical Biology and you can read more about them here <http://bit.ly/TIDzNH>

Get involved

Browse our list of research studies around the UK that are looking for people affected by Parkinson's to take part: parkinsons.org.uk/researchstudies

Learn more about Parkinson's by coming along to one of our upcoming research events: parkinsons.org.uk/researchevents

Sign the 'Science is Vital' petition to increase government contribution to research and development: <http://bit.ly/15udzYy>

Sign the 'All Trials' petition, campaigning for the publication of all clinical trial results: www.alltrials.net



WHAT CAUSES PARKINSON'S?

This is one of the most common questions we get asked by people living with Parkinson's. It's also one of the most difficult to answer, as frustratingly, the real answer is we don't know.

Most people have their hunches about why they developed Parkinson's. Often they put it down to a past experience in their life – such as a job or an accident. But the truth is it's impossible to know for sure. And research looking for the causes of illness (known as 'epidemiology') is notoriously difficult to do for complex conditions like Parkinson's.

In this article we explore this interesting and often confusing area of research and answer some of your most frequently asked questions.

Epidemiology explained

Epidemiology is the study of patterns of illnesses or health risks. It helps us unravel the causes of conditions like Parkinson's and identify people who are at greatest risk, which will hopefully one day help us to prevent these conditions altogether.

Epidemiologists look at health patterns across whole populations and try to see how different factors – such as smoking or weight – affect peoples' chances of developing a particular condition.

The father of epidemiology, Dr John Snow, would have celebrated his 200th birthday this year. Snow was a 19th century English doctor who proved that cholera, one of the most widespread and deadly diseases at the time, is spread through contaminated water – and not by 'bad air' as was generally believed at the time.

During the 1854 cholera outbreak in London, Snow created a map which showed that everyone who had become ill had drunk from the same water pump. He rightly guessed that water from this pump was the source of the outbreak and famously asked for the handle of the pump to be removed.

Although this kind of research may seem to be pretty straightforward – and in the case of cholera it was – most of the time the links between environmental factors and illness are much less clear cut.

A good example of this is the discovery in the 1950s of the link between smoking and lung cancer.

Although we all take this connection for granted now, and it seems obvious, in fact the discovery came as a complete surprise.



Even the researcher who discovered the link, Sir Richard Doll, had assumed lung cancer was increasing due to rising pollution.

How scientists study causes

The two tools you need for this kind of research are large numbers of people, and statistics. Types of studies include:

Case series

Small studies that look in depth at the experience of a small number of people who either have the same condition, or have all been put at risk of illness – such as by exposure to a toxic chemical.

These studies can help researchers come up with new ideas about what might be causing an illness or condition, but they're too small to provide concrete proof.

Case control studies

These are studies which compare a group of people with a particular condition to a similar group of people without. Participants are asked about their past experiences to spot things that may have a part to play in the condition. These studies can sometimes help identify causes, but are often unreliable as they depend on people's memories being accurate.

Cohort studies

Usually involve very large numbers of people (sometimes tens of thousands!) who are 'disease free' at the start of the study.

The group are then followed closely for long periods of time to see which individuals develop the condition being investigated. Cohort studies are the most reliable way to find links between environmental factors and disease but take a very long time and are very expensive.

It all comes down to statistics

Researchers use statistics to work out how much particular lifestyle or environmental factors may be related to risk of illness.

Results are only considered to be 'significant' (and therefore reliable) if they pass certain statistical



The case of the Frozen Addicts

In 1982, a student in California synthesised a new and very dangerous form of heroin called MPTP. This form of the drug selectively attacks the nerve cells in the brain that are lost in Parkinson's. Anyone who took heroin contaminated with the MPTP developed very severe Parkinson's-like symptoms almost immediately. These unlucky people became known as the 'Frozen Addicts', but their misfortune has led to significant scientific advances. MPTP has since been widely used in research and helped scientists learn much more about how and why nerve cells die in the condition.

tests which help researchers judge how likely it is the findings could be a coincidence rather than a real relationship. To pass these statistical tests you usually need to do very large studies, involving hundreds, if not thousands, of people. This makes epidemiology an expensive, time consuming and often very long process.

From statistics to the individual

Even when scientists do find something in the environment that increases risk of a condition like Parkinson's it's often very difficult to use this knowledge to predict risk in individual people.

So, just as it's impossible to predict exactly which reckless drivers will crash (although we know they are all more likely to), it's not yet possible to identify which people will develop Parkinson's based on the factors we think may increase risk. This is because Parkinson's is a very complex condition. For most people it's not caused by just one thing – but probably by their own unique mix of factors including genetics, lifestyle, environment and, most of all, ageing. The most important part of all this epidemiological research is that if we can identify important factors that increase risk of Parkinson's – such as particular chemicals or genes – we can then study how they cause the nerve cells affected to die. This will help us tackle the root causes of the condition, and one day produce a cure.

Find out more

- Watch TED video 'The Ghost Map': <http://bit.ly/G1jxb>
- Watch the *Horizon* documentary 'The Frozen Addicts': <http://bit.ly/18ynzkT>
- Unreliable neuroscience? Why power matters: <http://bit.ly/16MsWxK>
- What would John Snow make of epidemiology today? <http://bit.ly/156AP3W>

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4. Savica R et al (2013) 'High school football and risk of neurodegeneration: a community-based study' *Mayo Clin Proc*; 87:335.
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Putting the puzzle together...

"I have been wondering to what extent (if any) environmental factors are involved in the onset of Parkinson's? Does it tend to be more prevalent in people working in certain occupations (eg steel making or petrochemicals) or in certain parts of the country or indeed different countries? Does it tend to target certain ethnic groups or favour city dwellers over those in rural areas?"

A post by 'Christo' (forum member)

Viral infections?

There is some evidence that viral infections may increase a person's risk of developing Parkinson's.

In the 1920s there was an epidemic of encephalitis ('sleeping sickness') that may have been a viral infection. Many of the survivors went on to develop Parkinson's-like symptoms.

Researchers think this may be due to inflammation in the brain. Inflammation is now a hot topic in Parkinson's research and we're funding several projects to see how inflammation may be involved and whether reducing inflammation in the brain could be a fruitful avenue for developing new treatments.

Exposure to chemicals?

Some evidence also links exposure to certain types of chemicals to an increased risk of developing Parkinson's.

A study of men who'd been exposed to the chemical solvent TCE regularly in their work found they were more than six times more likely to develop Parkinson's compared to their twins without such exposures.

But this was a small study and still needs to be confirmed in larger population.

The most compelling evidence though is for the use pesticides. Lots of studies have been carried out and the majority (although not all) have found an increased risk of Parkinson's in people exposed to pesticides.

However, different studies have come up with different estimates of the increase in risk.

It's also important to highlight that the way we use potentially hazardous chemicals has changed quite a lot in the past 30 years. The use of many harmful chemicals has been banned.

In addition, the safety and protection in work places where strong chemicals are used has greatly improved in recent years.

Geography?

Research studies have been carried out all over the world to estimate how common Parkinson's is in different countries.

The results in different countries, regions and communities do vary widely. However, because the studies have all been carried out very differently and the populations are so diverse, it's very difficult to say where Parkinson's is most and least common.

We've carried out research in rural Tanzania, where the numbers of people with Parkinson's does seem to be significantly lower. But this may be largely explained by lower life expectancy in this population combined with a lack of awareness of the condition.

There have been reports of 'Parkinson's hotspots' in certain groups, such as Amish communities, but these are currently not backed up by research evidence.

Head injuries?

The evidence for whether head injuries increase risk of Parkinson's is conflicting.

Muhammad Ali, perhaps the world's most famous boxer, developed Parkinson's symptoms at a very young age and some people believe this resulted from the repeated blows to the head in the ring.

A couple of other boxers have also been diagnosed, including the famous boxing coach Freddie Roach, but the majority of ex-boxers do not develop Parkinson's.

A study published this year found that high school students who played American football in the 40s and 50s (when safety equipment was worse and concussion went untreated) did not have an increased risk of later developing neurodegenerative conditions compared to their non-football playing peers.

A 2009 study published in the British Medical Journal found that head injuries were much more common in the months leading up to diagnosis of Parkinson's.

But the researchers concluded that these injuries were actually an early symptom of Parkinson's as loss of balance was causing the falls.

Mercury fillings?

We are sometimes asked whether people with mercury fillings are more likely to get Parkinson's. Some people with Parkinson's have even told us they've had their mercury fillings replaced.

There have been a few small studies which have investigated this. But so far there is no firm evidence that mercury fillings play any part in the development of neurodegenerative conditions.



Fabio

We're asking people affected by Parkinson's and healthcare professionals to help us identify the top 10 unanswered questions in Parkinson's research. This will help to guide Parkinson's research and make sure that researchers are addressing the most urgent needs of people living with the condition.

How are we going to do it?

We're working with the James Lind Alliance, a not-for-profit organisation that brings patients, carers and healthcare professionals together to identify and prioritise the most pressing research questions for their condition.

The James Lind Alliance are experts in carrying out this type of research. They have already worked with a number of other medical research charities to identify the 'top 10' for conditions including asthma, prostate cancer and schizophrenia.

This massive project is being guided by members of our Research Support Network, who are helping us put together a survey to gather the thoughts of as many people affected by Parkinson's as possible.

Research Support Network member Richard Windle is helping us to plan the project and is passionate about what it could achieve:

"I believe that patient involvement in the research process will help in the search for better treatments and a cure. And because my career was spent working in market and social research, involving large data collection projects there are a lot of parallels with what we are doing here.

"I think many people with Parkinson's feel that they are not listened to. There is a lot of good research going on but it is driven by drug companies and researchers. This study is important because it gives people with Parkinson's a voice in the process – a 'bottom up' rather than a 'top-down' approach.

"It's important that we go into this process with open minds. But I'm personally interested to see if we find any links between Parkinson's and other conditions that haven't been spotted before.

"We need to come at the search for better treatments and a cure from as many different angles as possible. The results of this study may lead to new areas of research being investigated adding another piece to the Parkinson's puzzle that we all want to see solved."

How will we use the results?

For other charities that have already been through this process, the results have had a significant impact on their work.

Katherine Cowan will be chairing the Parkinson's Priority Setting Partnership on behalf of the James Lind Alliance (JLA):

"We've worked with organisations to identify the research priorities for sight loss, schizophrenia, eczema, and dementia.

"One of top priorities which emerged from our work on the asthma partnership was the need to investigate the effectiveness of breathing

exercises – which was something people living with asthma felt very strongly about. This has now led to a clinical trial of breathing exercises for asthma funded by the National Institute of Health Research which is part of the Department of Health."

Our Director of Research and Innovation, Dr Kieran Breen, explains how the results of this project could affect Parkinson's research:

"Without the input of people who have direct and personal experience of Parkinson's, it's impossible to be sure that we're addressing the right research questions.

"We will use the results of this massive survey to guide future research and inform our wider work as a charity. By sharing the results with the international Parkinson's research community, we hope to shape research into the condition all over the world. And crucially, the results could also lead to increased funding to address these questions from other sources, like the government.

"But all this will only be possible if thousands of people get involved and fill in our survey – so please look out for it later on in the year."

We need your help!

We need as many people as possible to complete the survey to help us get our 'top 10' right. That includes people living with Parkinson's, carers and healthcare professionals, too. We'll be launching our survey in October. It will be available to complete on our website and we'll be sending out paper copies to all our members with the autumn issue of *The Parkinson* magazine.

The survey will run for three months, then the task of analysing all the responses will begin. We plan to have results to share in 2014.

If you think you could help us to reach more people with Parkinson's, or healthcare professionals with our survey, please get in touch with us by email on research@parkinsons.org.uk or call us **0207 963 9352/9313**.

LOOKING FORWARD TO MONTREAL

Many of you probably remember the last World Parkinson Congress, which was held in Glasgow in 2010. We had a massive presence at the event and it was a truly inspirational experience for everyone who attended.

This year we're a partner in the third World Parkinson Congress, which takes place 1-4 October 2013 in Montreal, Canada.

And while it's much further away we're still keen to play an active part and share as much of what goes on there as possible with everyone affected by Parkinson's living in the UK.

The World Parkinson Congress gives researchers, people living with Parkinson's, healthcare professionals and Parkinson's organisations the chance to meet, share and inspire each other.

Meet the Parkinson's UK team

A small team from Parkinson's UK including volunteers with first-hand experience of life with Parkinson's and the charity, will travel to Montreal to showcase our work and learn from others around the world.

We had 40 fantastic applications for the four volunteer roles. A team of staff and volunteers had the hugely difficult task of interviewing applicants and selecting the final team of four from some very strong candidates.

We'll all work together to host the Parkinson's UK stand, show the world what we do as a charity and share what happens in Montreal with people who are unable to travel to the congress.

Alan Cameron (volunteer)



"I was diagnosed with Parkinson's a little over eight years ago at the age of 39. I volunteered to be part of the Parkinson's UK team in Montreal for three reasons:

"I want to help spread the word about Parkinson's UK among the wider Parkinson's community. I have a personal interest in the effect that Parkinson's has on people in work so I'm keen to learn about the experiences of working people with Parkinson's in other countries.

"And, while there will be fewer Parkinson's UK members in Canada than in Glasgow in 2010, I'm looking forward to working with the rest of the team to bring the learning and enthusiasm from Montreal back to the UK."

Janice Russell-Taylor (volunteer)



"I was fortunate enough to attend the last World Parkinson Congress in Glasgow with my late husband Brian three years ago.

"There was so much to learn and absorb. We attended plenary sessions, lectures, workshops and sessions in the 'renewal rooms'. We mingled and networked around the stands in the main hall

and met some fantastic people. It was the most uplifting and positive experience.

"Having been involved in many aspects of the work of the charity over the years I'm delighted to be part of the Parkinson's UK team and I'm looking forward to sharing what we do with the rest of the world in Montreal."

Martin Sewell (volunteer)



"Since being diagnosed with Parkinson's four years ago, I've done things I never dreamed of. I've become a volunteer educator for Parkinson's UK, cycled around Stratford on Avon to raise funds, taken part in research and even strutted

my stuff with 'Dr Dance' at the charity's research conference last year.

"I truly believe that a cure will be found in my lifetime and now I'm going to the World Parkinson Congress in Montreal.

"As a policeman, I hope to share the work I'm doing with Parkinson's UK within the police to raise awareness of the condition and target disability hate crime. I've already contacted the Mounties, Cavalry and local bobbies to tell them about our good work, and who knows, I might even meet Michael J Fox!"



Jenny Pearce (volunteer)

"Parkinson's catapulted itself into my life when I was 17 years old and my dad was diagnosed with the condition. Over the years I have seen first hand how Parkinson's can affect the lives of so many people in so many different ways.

"Throughout the tough times I have always believed that one day Parkinson's won't be the often challenging condition it currently is.

"By attending the World Parkinson Congress I am proud to be working alongside people who believe the same."

Parkinson's UK-funded researchers will also be attending the conference to share their work. One of them is Dr Rob Skelly, a geriatrician and Parkinson's UK-funded researcher at Derby Hospital, who tells us why he's going to Montreal:

Dr Rob Skelly (researcher)



"This will be my third World Parkinson Congress as I also attended the previous two in Washington and Glasgow.

"The Congress is unique because it's open to scientists, neurologists and other medical

doctors, nurses, therapists and, of course, people with Parkinson's and carers. This diversity means there really is something for everyone.

"I am personally very interested in how multidisciplinary teams of healthcare professionals can work together to deliver the most effective care to people living with Parkinson's. It goes without saying that I want to hear about the latest improvements in drug therapy, but I'm really keen to learn of developments in the non-drug aspects of care.

"I'm also looking forward to presenting the results of our Parkinson's UK-funded research project. We've been exploring the effects of a specialist Parkinson's hospital unit on medication management, length of stay and patient satisfaction."

Are you planning to go to Montreal?

If you're already going to the World Parkinson Congress we'd love to hear from you. Email us at rsn@parkinsons.org.uk. To find out more about attending the congress visit the World Parkinson Congress website: www.worldparkinsoncongress.org

Keep in touch with the Congress

We'll be reporting from the World Parkinson Congress through our website, blogs and social media. So if you're not able to be there you can still keep up-to-date and help us spread the word about the latest Parkinson's developments.



OUR NEW RESEARCH PROJECTS

Let's get creative!

Our innovation grants offer researchers a chance to test new, and sometimes controversial, ideas with a small grant for up to a year.

Unlike with our larger grants, we're willing to take a few risks and try out bold ideas. We only introduced innovation grants in 2009, but they've quickly become one of our most popular schemes, and have already led to some exciting breakthroughs. Here are some of the newest ones:

Spotting the earliest signs of Parkinson's Dr Anette Schrag

Where? University College London
What? £34,444 over 12 months

Anette's project will use one of the largest patient databases in the world to study the earliest stages of Parkinson's. This could potentially help doctors spot people at higher risk before the movement symptoms appear.

How is the tau gene involved in Parkinson's? Dr Rohan de Silva

Where? University College London
What? £34,957 over eight months

Since the last issue of *Progress* magazine we've awarded a wide range of new research grants, which aim to tackle everything from diagnosis to dyskinesia. We'll tell you about some of them over the next few pages, but for further details and to keep abreast of all the latest projects visit our website: parkinsons.org.uk/currentresearch

The tau gene is mainly linked to Alzheimer's but recent studies have found that people who carry a certain form of the tau gene are at increased risk of Parkinson's. Rohan's project will tell us more about this crucial gene.

Investigating 'traffic jams' inside brain cells in Parkinson's Dr Chris Wilkinson

Where? University of London
What? £34,786 over 12 months

Chris's project could provide fresh ideas to develop new treatments – such as drugs that help keep traffic moving inside nerve cells. And this may lead to treatments that could slow or stop the progression of Parkinson's.

Taking research from the lab to life

In 2012 we introduced translational research grants to turn exciting basic discoveries into real benefits for people with Parkinson's.

Research produces vitally important discoveries that have the potential to improve health, but turning them into treatments can be a stumbling block. We received a wide range of applications, and our team of scientific experts and lay reviewers chose three which aim to deliver real outcomes to people living with Parkinson's.

Testing new drugs for dyskinesia

Professor Riccardo Brambilla

Where? University of Cardiff

What? £150,000 over 18 months

We don't fully understand the causes of dyskinesia, and at the moment there are no effective treatments. In a previous Parkinson's UK-funded study, Riccardo and his team identified a pathway inside nerve cells, which they believe may be key to the development of dyskinesia.

In this project they will plan to test the effects of eight drugs that target different points in the pathway to see if they reduce dyskinesia in a mouse model of Parkinson's.

If the project is successful it could ultimately lead to clinical trials of drugs that have the potential to stop or even reverse this distressing side-effect of Parkinson's medication.

Developing a simple test for Parkinson's

Dr Jason Davis

Where? University of Oxford

What? £150,000 over 18 months

Developing simple tests to diagnose and monitor Parkinson's is a key part of our research strategy and researchers around the world are using many different approaches – from smell tests to ultrasound scans.

Jason and his team hope to show that measuring the levels of proteins called 'antibodies' in the blood could be developed into a simple test for Parkinson's.

This could lead to the first blood test for Parkinson's, which would revolutionise diagnosis and monitoring of the condition. Being able to accurately measure the progression would also speed up the hunt for new treatments by improving the way we carry out clinical trials.

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

Dr James Duce

Where? University of Leeds

What? £149,551 over 18 months

Iron is essential for the normal function of the body and the brain and is a vital ingredient for cells to survive and work properly.

To stay healthy, cells need to have the right balance of iron – too little or too much causes serious problems. Higher levels of iron are found inside the brain areas affected in Parkinson's and may play an important part in the death of nerve cells.

James and his colleagues will investigate whether a drug that can help the brain to handle iron better has potential as a future treatment for Parkinson's. And if successful this could open up a whole new avenue for treatments.



Training the next generation of Parkinson's researchers

It's crucial that we support a vibrant Parkinson's research community here in the UK – and that we enable it to grow. Providing research grants that attract the best and brightest new graduates into Parkinson's is vital if we are to build for the future.

Later this year we'll have two new students embarking on their scientific careers funded by Parkinson's UK funded PhD studentships. Both projects build upon previous Parkinson's UK-funded grants and will hopefully produce the research stars of the future.

Studying LRRK2 in the fruit fly eye

Dr Chris Elliot

Where? University of York

What? £88,213 over three years

In a previous innovation grant funded by Parkinson's UK, Chris's team created fruit flies with a gene called LRRK2 which is linked to Parkinson's. They found that flies with the faulty form of LRRK2 lost dopamine-producing nerve cells in their eyes. Now Chris is bringing a PhD student into his lab to use this new animal model to tease out how the LRRK2 gene is involved in nerve cell death. It may also help explain why some people with Parkinson's experience problems with their eyes.

Investigating the role of calcium in Parkinson's

Professor Sandip Patel

Where? University College London

What? £92,276 over three years

Calcium is very important for healthy bones and teeth. But you may be surprised to hear that calcium is also essential for keeping the nerve cells inside our brains working properly. And that calcium may play a part in the death of the nerve cells lost in Parkinson's. Sandip's new PhD student will use cell and animal models to further explore how

calcium may be involved in nerve cell death in Parkinson's. This could produce exciting new insights into why nerve cells die, and important ideas for new treatments.

Tracking Parkinson's gets a boost

Our Tracking Parkinson's study is the world's largest ever in-depth study of people with Parkinson's. When we launched the project last year we knew we had an opportunity to do something really special for Parkinson's research.

Tracking Parkinson's is helping us to build a huge database of information and blood samples from people with Parkinson's for researchers all over the world to study. And recently we've awarded two new grants to add value to this already groundbreaking study. The first will add the extra dimension of brain scanning to the project, the second will build in the largest ever study of pain in Parkinson's carried out anywhere in the world.

Developing better brain scans for Parkinson's

Professor Dorothee Auer

Where? University of Nottingham

What? £657,105 over three years

Dorothee's project aims to use the Tracking Parkinson's study to develop highly accurate new brain imaging techniques for Parkinson's.





300 people with Parkinson's who are already participating in Tracking Parkinson's and 100 people without the condition (as a comparison group) will be invited to have advanced MRI scans.

The scans and data collected will be combined with the data from Tracking Parkinson's and made freely (but anonymously) available to the global research community as a 'virtual brain bank'.

This unique resource has the potential to revolutionise diagnosis and accelerate research to find better treatments and a cure.

The largest ever study of pain in Parkinson's

Dr Monty Silverdale

Where? Salford Royal Foundation Trust

What? £16,060 over four years

More than half of all people with Parkinson's also experience chronic pain. Despite this, there has not been much research on pain in Parkinson's.

By building upon the Tracking Parkinson's study, Monty and his colleagues will be able to perform the largest and most detailed assessment of pain in Parkinson's that there has ever been, with relatively little extra funding. Monty and his colleagues aim to recruit more than 1,000 participants from the Tracking Parkinson's study to complete a short pain questionnaire and a painless eye exam.

The information they collect alongside data being collected in the Tracking Parkinson's study will help us understand a great deal more about why pain occurs in Parkinson's and how to spot people who are at risk of developing pain. This will help researchers identify new treatments that will ultimately improve the lives of many people living with the condition.

The Tracking Parkinson's team are still looking for people diagnosed in the last three years to get involved in the project. Visit parkinsons.org.uk/tracking or call **020 7963 9313** to find out more.

Over to you...

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

STEM CELL TREATMENTS ABROAD

I'm concerned about a company offering treatment with embryonic stem cells for people with Parkinson's.

I contacted the company after seeing an advertisement. All their communications have been by phone, with nothing in writing apart from promotional books on the internet. Nothing is published because 'it's too controversial' and no clinical trials have been carried out.

The treatment is illegal in the USA so they take you to Mexico for a day where you are injected with stem cells at a cost of \$30,000.

I am very concerned that vulnerable people will be persuaded to pay a lot of money and be disappointed.

I think stem cells may well be the cure of the future and good work should not be sabotaged by charlatans.

Jane Clarke

Thank you so much for your letter. We receive many enquiries about these overseas clinics and absolutely share your concerns.

As you say, no clinical trials have been carried out to test the techniques they're using, so we have no way of knowing if the treatments they provide are safe, let alone effective.

"I find the magazine very interesting and it is reassuring that progress is being made in the fight against this horrible condition." **Anonymous**

WHAT A CURE MEANS TO SHAZIA

A cure for Parkinson's would mean the world to me and my incredible mother.

From the age of nine, this illness has changed my life and my mum's and it deeply saddens me when, every time I mention that my mother suffers from the condition, people ask what Parkinson's is.

My mum has suffered with this condition for almost a decade but there are people out there who have had the condition for several decades. This is why the work that which Parkinson's UK does is so vital. Raising awareness is key to finding a cure.

The more people that are involved, the higher the likelihood that the lives of thousands will be improved.

Neurological disorders such as Parkinson's are on the increase and now is the time to act before many more lives are ruined. We can't let Parkinson's win.

Shazia

Shazia shared her story on our website. Read more stories or tell us what a cure for Parkinson's would mean to you by visiting findacure.parkinsons.org.uk

OPEN YOUR MIND

At a monthly meeting of the Sheffield branch I met Sally Blyth, who was studying for her Diploma in Sound Therapy.

Having completed the academic part of the course, she was embarking on a research project to assess the effects of sound therapy on the symptoms of Parkinson's and needed some volunteers.

Being sceptical, I agreed to take part with no expectation of beneficial results. But my scepticism has been replaced by a puzzled acceptance that sound therapy does work, at least for me.

That first session had the most dramatic results. I lay still, was unusually relaxed, emotions forgotten, drifting towards sleep as the different vibrating notes seemed to go deep into my body. I felt as though I was being gently massaged. My aching back seemed to sink into a feather bed and my legs felt as light as those feathers!

No two people with Parkinson's are the same and we all have different results from different therapies, but everyone who tried it seemed to find the sessions relaxing and calming. I don't claim to understand how or why this therapy works, but I accept that, inexplicably, it does for me!

Jennie

Thank you for sharing your experiences. We know many people with Parkinson's find complementary therapies beneficial. For more information please see our information booklet *Complementary therapies and Parkinson's*.

BAD PHARMA?

I have just started reading a book by Ben Goldacre called 'Bad Pharma' and wondered what Parkinson's UK made of it.

Also (obviously) I now have questions like 'is Parkinson's UK sponsored by pharmaceutical companies?' and 'is all your research independent?' and 'do you publish all your trials?' I am hoping for reassurance here.

A post by 'parkwife' (forum member)

Approximately 0.5% of our income originates from pharmaceutical companies but they do not have any influence on the research we fund. All our grants are reviewed through the same independent and transparent process by scientific experts and people affected by Parkinson's.

Our researchers share their findings through scientific journals, meetings and conferences, and our website and magazines.

Air your opinions and debate the latest hot topics. Join the discussion at parkinsons.org.uk/forum

"Progress is such an interesting magazine. It gives hope to people with Parkinson's that so much research is going on and that one day we may have a cure."

Anonymous



Keep your comments coming!

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

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

research@parkinsons.org.uk
0207 963 9326

AS EASY AS RIDING A BICYCLE?

Catherine Hess's essay was recently "Highly commended" by the judges of the Wellcome Trust science writing prize and highlights some fascinating research into cycling and Parkinson's. Catherine is a postgraduate researcher in anthropology at Bournemouth University. Here is her prize-winning entry.



Most of us remember our first two-wheeled bicycle. It's a rite of passage really, symbolizing our transition from little kid to big kid. Even more exhilarating is the day we take our first ride, sans stabilisers.

What most of us don't realise is just how complex the art of riding a bicycle actually is. So complex, in fact, that researchers are just beginning to investigate how on earth we manage to propel ourselves, constantly rocking back and forth with the movement of our legs, on two skinny wheels – simultaneously navigating movement in multiple planes, while trying to avoid countless obstacles.

Most extraordinary is what the act of riding a bicycle can tell us about the human brain. In 2010 researchers from the Netherlands published a dramatic medical case study in the *New England Journal of Medicine*.

The researchers had examined people affected by Parkinson's. One such patient, a 58-year-old man, experienced what researchers call 'freezing'.

He struggled so much with walking that he needed visual guides to help him move one foot in front of the other and after a few steps would lose his balance completely.

Astonishingly, however, this gentleman could still ride his bicycle ... flawlessly. Video evidence, submitted with the published case study (and now available on YouTube), shows him shuffling slowly and unsurely down a hallway, while being guided by another individual. After several steps, he begins to stumble forward until he falls to the ground.

In the second video, he is seen riding a bicycle at a consistent pace and with perfect balance and coordination. He cycles away from the camera, turns around and cycles back, slowing stopping and dismounting perfectly. Once dismounted however, he is again unable to walk.

This phenomenon is called 'kinesia paradoxia'. Whilst the mechanisms involved are still not understood, the knowledge is invaluable and may lead to new forms of physical therapy for people with Parkinson's.

The 'bicycle sign' (whether someone can still cycle or not) may also be an effective and inexpensive way to differentiate between Parkinson's and other forms of Parkinsonism – such as multiple system atrophy

and progressive supranuclear palsy. People with Parkinson's who were able to ride a bicycle before the onset of symptoms retain their ability to cycle. People with other forms of Parkinsonism do not.

"I cycle a short distance about twice a week and find it easier than walking. When my pills have stopped working and walking is an effort, especially lifting the affected leg, the cycling movement is strangely enough not a problem." Kate – forum

But how is it possible for a man to ride a bicycle, when he is essentially wheelchair bound? More importantly, how does anyone adapt to the sensory whirlwind that is bicycle riding? Research teams at the University of California, Davis in America and The University of Delft, Netherlands, are trying to find out. What they have discovered is surprising.

While we take it for granted that riding a bicycle is as easy as ... well, riding a bicycle, it turns out that it is anything but. Led by Professors Mont Hubbard and Ron Hess, American researchers are attempting to understand the physical and neurological processes involved.

"Riding a bicycle involves continuous use of all the human's primary sensory capabilities, visual, vestibular (balance) and proprioceptive (the awareness of one's body and limb positioning)," says Hess.

The goal of this research is to develop bicycles that maximize performance, whether the rider is a Tour de France cyclist or a disabled cyclist needing greater stability or control. What is clear from research is that despite the bicycle's simplicity, we have yet to fully understand how it is that we manage to control it, and what is happening in the brain when we do. Our first wobbly bicycle ride then, is a more remarkable event than we ever imagined.

References

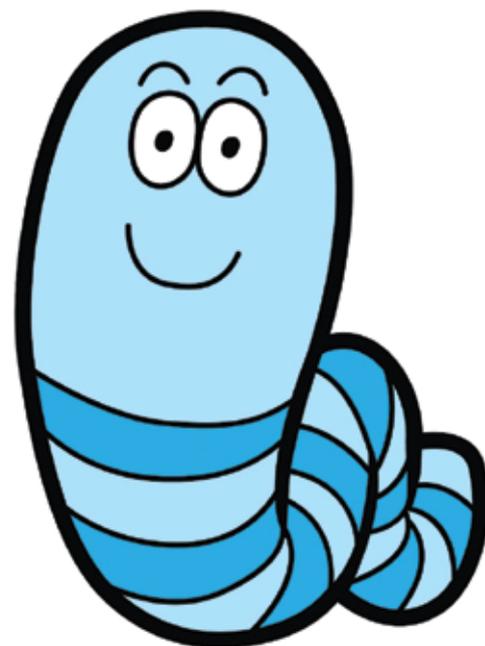
Snijders A and Bloem B (2010) 'Cycling for freezing of gait' *N Engl J Med*; 362:e46 <http://bit.ly/IU3ly2>

Find out more

Watch the video <http://bit.ly/dx6t01>

MEET DAVE THE WORM

The newest member of the Parkinson's UK Research team is helping to find a cure for Parkinson's.



Hi Dave! Could you tell me a little bit about who you are?

I'm Dave the Worm. I'm a C. Elegans worm (but I prefer to be called a V. Elegant worm!). My family of C. Elegans worms have been working in the field of research for quite some time. We've even been part of Nobel Prize winning discoveries. We're now encouraging people to sponsor Parkinson's UK research.

Facts about C. Elegans worms

- C. Elegans worms are about 1mm long and transparent, so need to be studied under a microscope.
- They are among the smallest and simplest organisms that have a nervous system.
- C. Elegans worms have 302 nerve cells.
- They have approximately 20,000 genes and were one of the first living organisms to have their genomes fully sequenced.

How did you get involved with Parkinson's UK?

C. Elegans worms have eight nerve cells that are like the ones affected in the brains of people living with Parkinson's.

About two years ago, some of my cousins started working with Parkinson's UK researcher Dr Anton Gartner at the University of Dundee. They've been looking at the mutations in the LRRK2 gene that cause the nerve cells to die, leading to Parkinson's.

What results have you achieved so far?

Dr Anton Gartner and his team at the University of Dundee have identified a gene that helps protect the nerve cells lost in Parkinson's. This discovery is really exciting.

It means that the researchers can focus on fully understanding how the gene works. Most importantly, they want to find out how it protects the nerve cells. The next step will be to look for other genes that protect nerve cells in a similar way.

What is your main goal while working with Parkinson's UK?

I want to help support more amazing researchers like Dr Gartner to find a cure for Parkinson's. So I'm asking everyone to sponsor me – Dave the Worm – for £5 a month.

Make a difference – sponsor Dave

- Donate by visiting davetheworm.org
- Tell your friends and family about Dave the Worm
- Like Dave on Facebook: facebook.com/davetheworm
- Follow Dave on Twitter: twitter.com/ParkinsonsWorm

RESEARCH RESULTS

Every project we fund aims to make important steps forward in our work to find a cure and improve life for people affected by Parkinson's. Over the next few pages (p23-29) you can read about six of the latest results from projects covering everything from genetics and why nerve cells die, to swallowing problems and posture. Keep up with results from all the projects we fund on the website at parkinsons.org.uk/researchresults

Genetic database will benefit global Parkinson's research

A team at University College London has developed a new genetic database, which will allow researchers around the world to see how individual genes affect a person's risk of developing Parkinson's.

The project, led by Professor John Hardy, was made possible by a three year grant of £163,668, awarded in 2009.

From genes to proteins

Our genes contain the instructions needed to make proteins, the building blocks of our cells. Whether a gene is 'switched on' and the amount of a protein made by that gene can vary in different parts of the body – this is known as 'expression'. And several different forms of a protein can be made from a single gene – this is known as 'splicing'.

John explains:

"Several years ago, we showed that certain changes in the genes which make proteins called alpha-synuclein and tau can affect their expression and splicing the brain. And this influences how likely a person is to develop Parkinson's.

"We realised that this may be the case for other genes. So we wanted to build a database of genetic information to study this systematically."



Above: Multiple DNA samples loaded onto a gel for analysis. Image from iStockphoto.

A valuable research tool

The database will be publicly accessible, making it a hugely important resource for the Parkinson's research community.

Reference

1. Charlesworth G et al (2012) 'Tau acts as an independent genetic risk factor in pathologically proven PD' *Neurobiology of Aging*; 33:838.e7–838.e11
2. Devine MJ et al (2011) 'Parkinson's disease and α -synuclein expression' *Movement Disorders*; 26:2160–2168



New insight into depression in Parkinson's

Many people with Parkinson's may be affected by depression during the course of their condition. The world's largest and most detailed study of depression in Parkinson's has revealed important insights that will shape future research into its causes, diagnosis and treatment.

More than 500 people with Parkinson's took part in the study, led by Professor Richard Brown from King's College London. The six year themed research grant of £972,430 was awarded in 2006 to help us understand the complex relationship between Parkinson's and mental health.

What the study found

The research team, based at centres across the UK, followed participants over time at up to four annual assessments.

Richard describes the key findings:

"It looks as if focusing solely on depression may have led previous research to miss other mood-related symptoms of Parkinson's. 10% of the people we interviewed had strong feelings of sadness. But anxiety was the most common emotion, reported by 20% of people, followed by

irritability and anger. On a positive note, almost two-thirds of our participants reported few problems and remained 'psychologically healthy' throughout.

More than one condition

The team saw important differences between people who had depression with anxiety, and people who had depression without anxiety. Depression with anxiety was more common in people who had developed Parkinson's at a younger age, and who experienced an inconsistent response to their Parkinson's medication. And depression without anxiety was more common in people with cognitive (thinking and memory) and balance problems. This suggests that there are at least two types of depression in Parkinson's that may have different causes and could potentially respond to different treatments.

"I have Parkinson's, I'm 47 and always lived my life as a 'glass half full' sort of guy. I was diagnosed four years ago and took the news well. However for the last two years I've been depressed."

David, on the forum

Richard comments:

"Depression in Parkinson's isn't necessarily the same as depression in people without the condition. We now have a much clearer understanding of what depression in Parkinson's looks like, which we hope will mean problems are recognised earlier.

"We are continuing to study depression and anxiety in Parkinson's. And next we plan to examine how best to treat these problems in practical ways."

Reference

Brown RG et al (2011) Depression and anxiety-related subtypes in Parkinson's disease. *Journal of Neurology Neurosurgery and Psychiatry*, 82:803-809

Find out more

See our information sheets *Anxiety and Parkinson's* and *Depression and Parkinson's*. Order publications for free or download at parkinsons.org.uk/publications

A movement-based computer game for people with Parkinson's

Researchers at Newcastle University have developed a new movement-based computer game specifically for people with Parkinson's.

The design and preliminary testing of the Xbox Kinect game, which targets posture and balance, was supported by an innovation grant of £31,836 awarded to Professor Lynn Rochester in 2012.

About the game

In the last issue of *Progress*, we shared the results of our funded research into the benefits of the Nintendo Wii for people with Parkinson's.

The Xbox Kinect also allows players to control games with their body movements, but uses a camera-based controller instead of a remote control and balance board.

"It is not like any other physical exercise. It made me use my mind and body."

Participant

The game, called 'Scrup', is the first ever Kinect game to be made with people with Parkinson's in mind.

Players take the role of a farmer standing on a moving tractor. The aim is to reach out to collect fruit and step to avoid obstacles like farm animals and birds.

Safe and fun

Nine people with Parkinson's tested the game. Everyone said they felt safe when playing. Importantly, there were no trips or falls during testing.

Most of the participants enjoyed playing the game and thought it would be a useful way to exercise. Eight said they would buy the game if it was available in the shops, especially if they felt it would improve their balance.

Lynn comments on the social aspects of the game: "An advantage of movement-based computer games is that they can engage carers and family,

leading to increased participation. This could ultimately have a positive impact on independence and quality of life."

"Slow movements can be off-putting but the movements in the game were right for me and didn't trigger my tremor."

Participant

Potential as a monitoring tool

Because the Kinect tracks the players' body movements, it also has huge potential as a tool to monitor changes in Parkinson's symptoms.

The researchers found that the Kinect can measure the timing and pattern of movements used in standard clinical tests – like standing up from a chair and walking on the spot. The measurements weren't quite as accurate as those taken by the 'gold standard' 3D motion analysis equipment in their lab.

What next?

Lynn hopes to carry out a trial to find out how effective the game is in improving and maintaining mobility in people with Parkinson's. She also hopes the system can be further developed to allow reliable home-based monitoring of symptoms in future.

Find out more

Visit parkinsons.org.uk/exercise for information about exercising when you have Parkinson's.

Below: Scrup, the first Kinect game for Parkinson's



Postural changes in Parkinson's may benefit from non-surgical treatment

Pioneering research at University College London has shown that the postural changes experienced by some people with Parkinson's do not usually involve permanent changes in the spine.

Neurologist Dr Karen Doherty led the small but detailed study which involved 26 people with Parkinson's.

Her findings suggest that camptocormia (stooping forward) and Pisa syndrome (leaning to one side) could potentially be improved with non-surgical interventions like physiotherapy.

The project was funded by an innovation grant of £28,175 awarded in 2010. And Karen is now planning a small pilot study to test whether treating people with early postural problems is helpful.



Above: Non-surgical interventions like physiotherapy might help people with postural problems.

We had an overwhelming response when we first wrote about the study in the summer 2011 issue of *Progress*, with several people expressing an interest in taking part. So we're pleased to be able to share Karen's final report.

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

"I meet lots of people with Parkinson's in the clinic who have changes in their posture. These changes can cause discomfort, make walking difficult, and even cause difficulty looking up. All of which can have a huge impact on a person's quality of life.

"Although recognised for a long time, postural changes in Parkinson's are poorly understood.

"There is no consensus as to why they happen to some people and not others, what causes them or how to treat them. We wanted to change this, and decided to focus our research in this area.

What were your goals for the project?

"We wanted to describe how posture can change in Parkinson's, and improve understanding of the underlying causes. Using detailed medical history taking, physical examinations and radiological imaging (X-rays and CT scans), we aimed to identify factors that may explain why some people are more susceptible than others.

"I find that my stooped posture is an embarrassment to me and to the company I keep. It is also quite a hindrance when I go about my daily chores. Fortunately all becomes right again in bed. I attend a very good nurse specialist every six months and she passes on my lack of progress to my doctors. I have reached the maximum dosage of levodopa so I don't know what the next step will be. My diagnosis with Parkinson's goes back 13 years but it is only in this last year that camptocormia has become a problem."

Robert, by email



Above: Posture problems in people with Parkinson's can be severe when they are standing (images on left), but often disappear completely when people lie down flat (images on right)

What have you found?

"While most of the people who took part in our study had difficulty correcting their posture by themselves, very few actually had permanent changes in their spine.

"The changes we saw tended to involve muscles and joints becoming stuck in the wrong position – like bent knees or a tilted pelvis. This suggests that people may benefit from non-surgical interventions like physiotherapy.

What are the next steps?

"We plan to share our findings with health professionals who work with people with Parkinson's by publishing in peer-reviewed journals and presenting at conferences.

"We also hope to carry out a small pilot study of a potential new treatment. If successful, this could lead to a larger clinical trial.

How will your research help people with Parkinson's?

"We hope our work will help health professionals to recognise postural changes in Parkinson's, so they can intervene earlier and potentially prevent future deterioration and disability.

What advice would you give to people with Parkinson's who are experiencing changes in their posture?

"It's important that you talk to your specialist or Parkinson's nurse. At the moment there are no established guidelines for treating postural changes in Parkinson's. So it's vital that people are assessed as individuals and treatment options are chosen accordingly.

"Keeping active and working on strengthening core postural muscles might be helpful. A physiotherapist should be able to guide you as to which muscles you should be aiming to work on. This will differ depending on your posture – no two people are the same!"

Reference

Doherty KM et al (2013) 'Pisa syndrome in Parkinson's disease: a mobile or fixed deformity?' *Journal of Neurology, Neurosurgery and Psychiatry*, Epub ahead of print.

Find out more

See our information sheet *Physiotherapy and Parkinson's*. Our publications can be ordered for free or downloaded at [parkinsons.org.uk/publications](https://www.parkinsons.org.uk/publications)

Swallowing problems in Parkinson's linked to changes in the brain

Preliminary findings from the University of Manchester show there may be differences in brain activity between those people with Parkinson's who have problems with swallowing and those who don't.

The project, funded by a two-year innovation grant of £15,576 awarded to Professor Shaheen Hamdy in 2010, will provide a vital foundation for future research into the management and rehabilitation of this troublesome symptom.

What the team did

Many people with Parkinson's experience problems with swallowing. But relatively little research has been carried out to understand why.

27 people with Parkinson's took part in this initial pilot study, which combined questionnaires



and physical tests with a technique called transcranial magnetic stimulation (TMS), to measure brain activity, when they were on and off Parkinson's medication.

The next steps

The team are building on this work by carrying out functional magnetic resonance imaging (fMRI) brain scans to get a better understanding of how different parts of the brain work together to control swallowing.

They also plan to investigate whether stimulation methods and voice training can be used to improve swallowing.

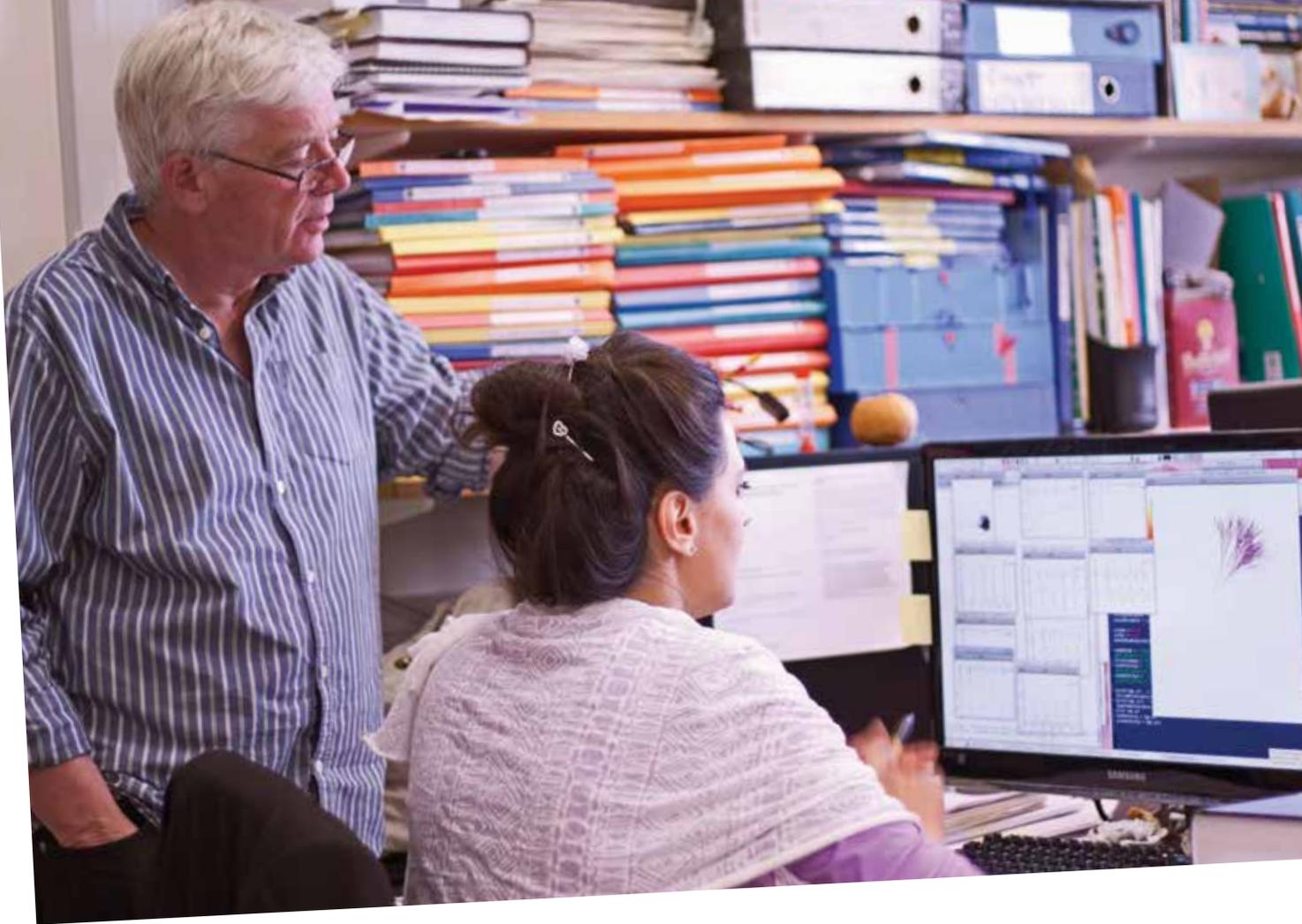
The project generated a great deal of interest among people affected by Parkinson's in the north west. This led to the formation of a new public and patient involvement (PPI) group, who will play an important role as the research moves forward.

Shaheen said:

"We were amazed by the level of interest in our study, and would like to thank everyone for their help and participation."

Reference

Michou E and Hamdy S (2010) 'Dysphagia in Parkinson's disease: a therapeutic challenge?' *Expert Review of Neurotherapeutics*; 10:875–878



Above: Paul and Eleftheria using their computer model

Why do nerve cells die? Clues from a computer model

Researchers at the University of Oxford have successfully generated the world's first computer model of the dopamine-producing nerve cells affected in Parkinson's.

The model shows that these cells need more energy to do their job than other types of nerve cells, which may explain why they are especially vulnerable in Parkinson's.

The project was funded by an innovation grant of £34,866 awarded to Professor Paul Bolam in 2011, which enabled him to take on computational neuroscientist Dr Eleftheria Pissadaki. The team now plan to make the model freely available to the scientific community.

Well connected

The researchers previously showed that the relevant group of dopamine-producing nerve cells in the rat brain make many more connections than other types of nerve cells.

In this project, they made a computer model to calculate how much energy these cells need to communicate with such a large network.

Living on the edge

Paul believes that the energy demand on dopamine-producing nerve cells is a key factor in the development of Parkinson's:

"The dopamine-producing nerve cells lost in Parkinson's are bigger, more complex, and make more connections than other types of nerve cells in the brain. This means they are under huge pressure as they need a massive energy supply just to function normally. Any extra strain may tip them over the edge and lead to Parkinson's."

Reference

1. Bolam JP and Pissadaki EK (2012) 'Living on the edge with too many mouths to feed: why dopamine neurons die' *Movement Disorders* 27:1478-83.
2. Pissadaki EK and Bolam JP (2013) 'The energy cost of action potential propagation in dopamine neurons: clues to susceptibility in Parkinson's disease' *Frontiers in Computational Neuroscience*; 7:13

DIARY OF A DRUG TRIAL

Caroline Maxwell has Parkinson's and in 2012 signed up to take part in a Parkinson's UK-funded study that is testing whether a dementia drug may help improve balance and prevent falls. Here Caroline shares her experiences of participating in a drug trial:

August 2012

Earlier this month I received an email from Parkinson's UK highlighting the opportunity to take part in a new trial of a drug to help reduce falls. I spent a week in hospital in January following a bad fall, and have had several minor falls since then so contacted the team for further information straight away.

I received an information booklet explaining more about the study, which will investigate whether Rivastigmine, a drug already used by people with memory problems, can help prevent people with Parkinson's falling.

Taking part involves two appointments, 32 weeks apart, taking the tablets, keeping a diary of any falls and monthly phone calls with the research team.

None of this put me off so following a chat to my GP who encouraged me to join, I applied.



"I am delighted that Caroline has found taking part in the study valuable and that she feels that her walking and balance may have improved. Without people who are willing to take part in research trials it would be impossible to find new treatments that may help people with Parkinson's. I hope that reading Caroline's diary gives other people the confidence and encouragement to take part in research trials that may improve the care of people with Parkinson's in the future."

Dr Emily Henderson, leading this Parkinson's UK-funded study

September 2012

Today I received a phone call from lead researcher, Dr Emily Henderson, to check my eligibility for the study. After a brief chat I was accepted onto the trial and invited down to Bristol for my first assessment.

October 2012

Today I travelled down to Frenchay Hospital in Bristol to a warm welcome by Emily and her research nurse assistant. After signing the consent forms, I answered lots of questions about my general health, the diagnosis and progress of my Parkinson's, my education background and my home life. Next came a series of mental tests. I was asked to remember short lists of words, to answer questions like 'What is the name of the Prime Minister?' and do 'dot-to-dot' style puzzles.

There were also physical tests of my balance and coordination, including walking up and down a 20-yard track while trying to say as many words as possible beginning with the letter 'M'. Once all the tests had been done I was presented with the medication, instructions on how to take it and diary sheets to complete in the event of a fall. The research staff will also phone me every month to discuss any falls and how I'm getting on with the medication.

March 2013

I'm now just over half way through the 32-week study and have been taking the top dose for about two weeks now. I may be on the placebo, but I'm beginning to believe I am on the drug itself. One morning I felt particularly unsteady on my feet and when I looked at my pill dispenser I could see I had forgotten to take my evening tablet. I haven't fallen in around four weeks now and I feel more confident of my balance. It's strange, but I find it very difficult to remember how I felt before I started taking the drugs, and because the dose has increased so slowly the improvement has been inch by inch. But I am beginning to wonder what will happen at the end of the trial as I think it will be difficult to stop taking the medication, which I feel is doing me good.

November 2012 – the trial begins

I arrived home with tablets labelled 1.5mg, 3mg, 4.5mg and 6mg. They may be the real drug being tested, or they may be placebos (dummy pills). This is a 'double blind' study, so neither I nor the researchers know, and we'll only find out once the study has finished.

I started with the lowest dose, taking one tablet in the morning and one in the evening, and have to move on to the next dose every four weeks. To begin with I didn't notice any change, but after a couple of weeks I found my skin becoming very itchy and dry. Apparently this isn't a common side effect but I choose to think it's caused by the drug because that would mean I'm taking 'the real thing'.

I also think my walking has improved. Lately, there have been times when I've walked easily and confidently across a room, and only realised when I reached the other side, that I have not teetered, staggered or halted. I have, admittedly, fallen a couple of times when I was concentrating on something else – like getting dressed or making the bed – and ignoring my feet. I live alone and take some pride in 'managing' so I'd rather not admit to these falls, especially as I have not been hurt. But this is not an option. I am part of a scientific experiment and must record what happens. So I've filled in the falls on the monthly record sheet and hope to have less to record next month.

Find out more

Join our Research Support Network to find out about how you could get involved in research
parkinsons.org.uk/researchsupportnetwork

THE PARKINSON'S UK BRAIN BANK

We're the UK's largest brain bank dedicated to Parkinson's. We collect the brain, spinal cord and a sample of cerebrospinal fluid from people with and without the condition. These tissues are supplied free of charge to researchers studying Parkinson's all over the world.

The Parkinson's UK Brain Bank is one of the oldest and largest dedicated to Parkinson's anywhere in the world. The Brain Bank started back in 1984, and is still going strong with brain tissue research as important as ever to Parkinson's research.

Why study human brain tissue?

Parkinson's is a uniquely human condition. Animals don't naturally develop the condition, and the animal, cell and computer models that scientists use to study Parkinson's are far from perfect.

We cannot yet accurately recreate what happens inside the Parkinson's brain. So it's essential that researchers have access to high quality tissue from people with and without the condition to unlock the secrets of Parkinson's.

Did you know?

The Brain Bank team have recently sent tissue to researchers in Germany, Italy, France, Spain, Norway, Sweden and the USA, as well as the UK.

Still so much to learn

Although our Brain Bank team have been supplying Parkinson's researchers around the world with tissue for decades, there is still a lot to learn from the brains they collect. Science has advanced at incredible pace and the things we're able to

Did you know?

The team collected 173 brains last year, including 105 from people with Parkinson's.

do today would have been unimaginable when the Brain Bank started. The techniques used to preserve brain tissue have improved so scientists today have better quality tissue to work with. Alongside this, scientists now have access to better tools and techniques for studying tissue, so they're able to explore changes in the brain tissue in much greater detail than ever before.

How donated tissue is helping people with Parkinson's

Tissue from the Parkinson's UK Brain Bank is being used by researchers around the world to better understand the condition and work towards a cure.

Better diagnosis

Examining the brain after death is still the only way to diagnose Parkinson's with 100% certainty. But our Brain Bank is helping researchers pave the way towards better diagnostic tests. Researchers at Lancaster University have used samples of

Did you know?

Around 500 people joined the Parkinson's UK brain donor scheme in 2012.



Did you know?

Last year 54 research teams requested tissue from our brain bank.

Above: Parkinson's UK researcher Ilaria Bravi explains about her work to visitors to the Brain Bank

cerebrospinal fluid – the clear, colourless liquid that surrounds the brain and spinal cord – to look for subtle changes in proteins that could be used to develop simple tests for the condition. Their work may pave the way towards simple tests that can not only be used to diagnose Parkinson's accurately, but also to reliably monitor the condition.

Did you know?

Our Brain Bank moved to a new home at Imperial College in 2003 and has just celebrated its 10th birthday there.

Understanding the causes

We still don't understand why people develop Parkinson's, but tissue from our Brain Bank has led to major breakthroughs in this area. In 1989, researchers using our brain tissue discovered problems with mitochondria in the nerve cells affected in Parkinson's. Mitochondria are the tiny energy-producing batteries that power all our cells and are essential for keeping them healthy. Brain Bank tissue has also played a key role in the recent genetic revolution in Parkinson's. Our tissue has been used in massive, international genetic analysis studies. And in 2011 it helped

researchers identify five new genes involved in Parkinson's, revealing that genetic factors play a greater role in Parkinson's than previously believed. Groundbreaking studies like this one are helping us to piece together the complex jigsaw puzzle of factors that are involved in Parkinson's.

Clues for new drugs

Understanding what goes wrong inside the brain is the key to developing better treatments and a cure. Researchers using human brain tissue from the Parkinson's UK Brain Bank found that increased levels of iron in the brain may play a part in nerve cell death. And this led directly to a trial of 'deferiprone' – a drug that helps remove excess iron from the body and is already used to treat the blood disorder thalassemia. Results are expected in 2014 and if positive, deferiprone may prove to be a vital drug for slowing the progression of Parkinson's.

Find out more

Find out more about the Brain Bank. Visit parkinsons.org.uk/brainbank, email brainbank@imperial.ac.uk or call 020 7594 9732.

JOIN US IN BIRMINGHAM

On Saturday 23 November, we're hosting a special day for people affected by Parkinson's to come and hear talks from some of the UK's top researchers.

Our speakers will cover a wide range of topics during the day.

- **Professor Anthony Schapira** (University College London) will reflect on what we have learnt so far about the causes of Parkinson's.
- **Dr Rosemary Fricker** (Keele University) will talk about how stem cell research holds such potential for Parkinson's.
- **Dr Oliver Bandmann** (University of Sheffield) will discuss his thoughts on the future treatments and how we get new drugs from the lab into the clinic.
- **Professor K Ray Chaudhuri** (King's College London) will discuss how research looking at the non-motor symptoms of Parkinson's is helping to improve day to day life.

The event will be free and is open to anyone affected by Parkinson's.

Places are limited and must be booked in advance by contacting **researchevents@parkinsons.org.uk** or calling **020 7963 9313**.

Can't make it to Birmingham?

Visit parkinsons.org.uk/researchevents for further information about all our upcoming research events.

Or join the Research Support Network and we'll keep you up to date with opportunities to get involved in Parkinson's research.

Find out more

Visit parkinsons.org.uk/researchsupportnetwork
Email rsn@parkinsons.org.uk
Call **020 7963 9398**

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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 or by calling

020 7963 9326.

Publications

Available online at parkinsons.org.uk/publications

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

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Don't forget you can also

find *Progress* online at

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

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Front cover illustration
Illustration depicting one in 500 diagnosed with Parkinson's.

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