

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

PROGRESS

The research magazine of Parkinson's UK
Issue 15 Summer 2014

Stem cells – the
story so far...

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WELCOME

This issue our welcome comes from research supporter Meg Kierek-Bell whose husband Robin was diagnosed with Parkinson's in 2003 at the age of 52.

It happened in October 2011, my husband Robin and I attended an event for younger people affected by Parkinson's in Stratford-Upon-Avon. The day focused on Parkinson's research and by the time we were heading home we'd joined the Research Support Network (RSN). I had no idea how we could help but there was lots of energy and enthusiasm from the Parkinson's UK staff and it was catching.

In October 2012, I became a Volunteer Lay Grant Reviewer through the RSN, helping review requests from researchers for Parkinson's UK funding and I have been swept along with the charity's work ever since.

This role really appealed to me as I wanted mental stimulation and although crosswords are excellent, we are not compatible. I felt my nursing skills and experience of supporting my husband Robin met the criteria. I wanted to make a contribution.

We receive regular emails from the Research team offering grant applications for review, allowing me to remain in control of the workload, and in many instances choose applications I find most interesting.

Last summer an opportunity arose for me to sit on a panel alongside experts in the field to interview young researchers applying for a Career Development Awards from Parkinson's UK. It was great to be involved in such an important area of the charity's work.

I now happily forward the monthly 'Research Roundup' emails and any opportunities for volunteers to take part in research studies to our local group members. I find the bite-sized information user friendly, interesting and really helpful in making research accessible to anyone interested. Other opportunities filter through linked to research projects with questionnaires or patient information sheets that need fine tuning. Robin will gladly give his measured opinion along with mine.

Being part of the Research Support Network has also given us the chance to meet the clinicians, researchers and Parkinson's UK staff through visits to research projects and conferences across the country. I genuinely feel this personal contact is vital for both parties and I wish I could attend more. There are many threads to research support and there will be something to suit you, it's just finding the right one and it can be fun! Robin and I are always glad to oblige!



INTERNATIONAL NEWS ROUNDUP

Over the past few months there have been some important developments in the world of Parkinson's research. Here we round up the most interesting, promising and unusual...

Diabetes drug shows further promise for Parkinson's

Further results from a small, early stage clinical trial show that the diabetes drug exenatide may have long-term benefits for people with Parkinson's.

In a recent trial 20 people with Parkinson's received exenatide over a 12-month period while 24 others served as a control group.

After 12 months, those taking exenatide had improved motor symptoms, thinking and memory compared to the control group. And even 12 months after stopping exenatide, those who had taken it were still better off compared to those who hadn't, indicating that the drug may have lasting benefits.

New trials are just getting underway at University College London and recruitment of the 60 people with Parkinson's needed has already begun.

parkinsons.org.uk/researchnews23apr2014

Rescue therapy takes important steps towards the market

Many people with Parkinson's experience 'off periods' when their Parkinson's drugs suddenly stop working which can leave them frozen to the spot for long periods.

Now, results from a phase 1 trial in healthy participants showed that a thin film strip applied under the tongue could help to combat these debilitating 'off periods'.

The film strip releases apomorphine—a drug that is only currently available by injection or pump. This completely new way of delivering apomorphine could provide an easier way to manage the often distressing 'off periods'.

The company, Cynapsus Therapeutics, has secured a further \$25million to further develop this therapy and is currently planning a trial to test the strips in people with Parkinson's.

parkinsons.org.uk/researchnews23apr2014



A sticky solution to drug delivery?

Researchers in South Korea and the USA have developed a futuristic 'plaster' fitted with the latest nanotechnology that could be used to deliver Parkinson's drugs in the future.

The hi-tech plaster can detect muscle activity, such as tremor or cramps, and release drugs directly through the skin.

This means the plasters could one day be used to deliver Parkinson's drugs speedily as and when they're needed, and may help reduce the number of pills that people have to take.

<http://dailym.ai/1mjnbNQ>

Smart glasses

Google Glass—a voice-operated computer that is worn like a pair of glasses—is being tested for the first time to find out if it could help people living with Parkinson's.

Google Glass is not currently available in the UK but Google donated five pairs to researchers at Newcastle University.

Now, the team is working with people with Parkinson's to see whether the technology could help tackle some of the challenges people with Parkinson's face.

The new technology could help remind people to take their medication, speak more loudly or swallow to prevent drooling. The motion sensors in Glass could also be used to help people with Parkinson's overcome mobility problems like freezing.

parkinsons.org.uk/researchnews9apr2014

Parkinson's UK Twitter news

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

- **Is Parkinson's an autoimmune condition?**
We still don't know why people develop Parkinson's, but new research suggests brain cells may be mistaken for foreign invaders and attacked by the person's own immune system.
<http://bit.ly/1pxhnre>
- **New funding for regenerative medicine research.**
We're working with the British Council in Israel to fund exciting research that will bring regenerative therapies, like stem cells, closer for Parkinson's.
<http://bit.ly/1eeeTDN>
- **Vitamin D may improve some non-motor symptoms.**
New research suggests vitamin D supplements could help improve thinking, memory and mood for people with Parkinson's.
<http://bit.ly/1jmXNtM>
- **Sharing data for the greater good.**
In this article for the BBC, Prof Peter Johnson from Cancer Research UK explains why sharing our personal data is crucial for understanding and tackling all conditions
<http://bbc.in/1e8QUEi>
- **How online gamers are solving science's biggest problems.**
This article from *The Guardian* explains how online games are helping scientists solve puzzles involving genes, conservation and the universe.
<http://bit.ly/1d4IHko>

Find the full stories using the links or keep your finger on the pulse by following us at www.twitter.com/parkinsonsuk



STEM CELLS – THE STORY SO FAR...

Stem cells can develop into almost any cell in the body. They are the original cells from which we are made and are responsible for repairing our tissues and organs when they get damaged. Since their discovery researchers have been trying to find ways to use them to treat conditions like Parkinson's where cells have been lost or damaged beyond repair.

When we think of stem cells we think of the very latest, cutting-edge research. However people have known that our tissues and organs have the capacity to regrow for thousands of years. The regenerative ability of the liver even features in Greek mythology. The myth goes that when Prometheus defied the gods they sentenced him to eternal torment, each day a vulture would eat his liver only for it to regrow as fast as it was damaged.

We now know that the ability of our tissues to regrow is due to the presence of stem cells. We also know that some animals – like the salamander, which can regrow a whole new tail should the original be lost or damaged – have even more regenerative ability than humans.

If researchers can harness the power of these cells we may be able to grow new healthy cells to replace the precious dopamine-producing cells that are lost in Parkinson's.

You're younger than you think...

Whatever your age, your body is many years younger. In fact, even if you're middle aged, most of you may be just 10 years old or less. The cells lining your stomach last only five days. Your red blood cells, after traveling nearly 1,000 miles around your circulatory system, last around four months. And even your skeleton is thought to be replaced every 10 years or so.

This is because almost all of our organs and tissues contain 'adult stem cells' that can turn into many different types of cells and help our body to replace old or damaged tissue. Adult stem cells were first discovered in the 1960s, and we now know they can be found all over the body including, in our brains.

Adult stem cells are already used to treat some conditions. Bone marrow contains adult stem cells that make all our different blood cells. And bone marrow transplants are therefore used to treat blood disorders like leukaemia.

But adult stem cells can only develop into a limited number of cell types. For example instance, bone marrow stem cells naturally develop into blood cells but not brain cells.

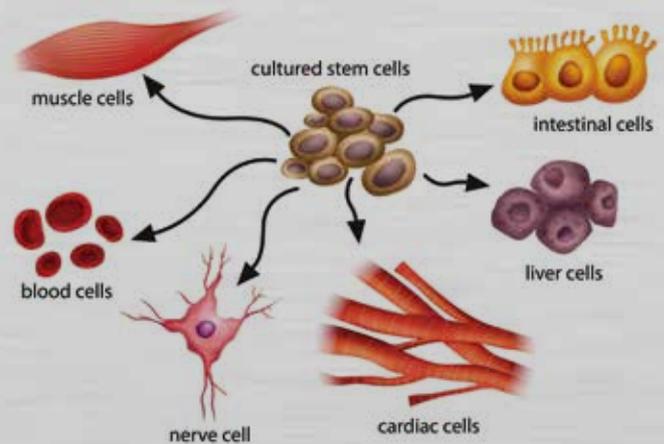
The power to become any cell type

The next major discovery came in the early 1980s when researchers found stem cells inside developing embryos.

When a sperm fertilises an egg, a one-cell embryo is formed. Pretty soon, this cell starts to divide and a few days later it will have grown into a tiny ball of around one hundred cells, this is about the same size as a grain of sand. This tiny clump of cells can be used to grow embryonic stem cells in the laboratory.

Unlike adult stem cells, which are limited in the types of cells that they can develop into, embryonic stem cells can be converted into any type of cell in the whole body.

This ability, known as 'pluripotency', makes embryonic stem cells extremely powerful as they are much easier for researchers to manipulate into the cells they need. However, there is a risk that stem cells may grow uncontrollably in the body, which could lead to the formation of tumours.



There are also ethical issues surrounding the use of embryonic cells that means their use needs to be very carefully controlled. In the UK, human embryonic stem cells can be collected from left-over embryos produced as part of in vitro fertilisation (IVF). This can only be done legally under strict UK guidelines from the Human Fertilisation and Embryology Authority (HFEA) and only very early-stage embryos can be used in research – up to a maximum of 14 days of development.

STEM CELLS – THE STORY SO FAR...

Reprogramming skin cells

The latest breakthrough came in 2006 when scientists in Japan worked out how to turn normal adult cells into stem cells. These cells are called 'induced pluripotent stem cells' or iPS cells.

In the future iPS cells may provide a way of using each patient's own skin cells to treat conditions like Parkinson's. This would have a huge advantage, as new tissues made from our own cells would not come with the same risk of 'rejection' as cells from someone else.

In 2010, scientists in the USA treated rats with nerve cells made from human skin cells using iPS techniques. The transplanted cells improved symptoms of Parkinson's in the rats. But it's not yet clear whether this approach would work in people.

Transplantation is not the only way stem cells can help people with Parkinson's. Our scientists are using these techniques to grow nerve cells to study Parkinson's in the lab. These cells are like a 'window into the brain', which is helping us understand why nerve cells die in Parkinson's and providing a new way to test potential treatments.

Although these are gripping discoveries, iPS cells are not identical to embryonic stem cells and the differences need to be fully investigated.

Scientists are still exploring the best and safest ways to generate iPS cells. Early techniques involved changing the DNA in a cell to turn it into an iPS cell, which had the potential to cause long-term harmful effects. The initial experiments also used viruses to import the new genes into cells - a technique that

1961

Researchers find first evidence of adult stem cells.

1981

Embryonic stem cells found in mice.

1989

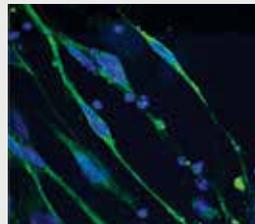
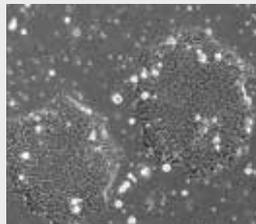
First transplant trials using foetal cells carried out for Parkinson's.

1994

Stem cells found in human embryos.

1997

Dolly the sheep is born.



risks changing the cells into cancer cells. However, more recent research indicates that it may be possible to generate iPS cells without the use of viruses, which would be a much safer approach.

How can we bring stem cell therapies closer?

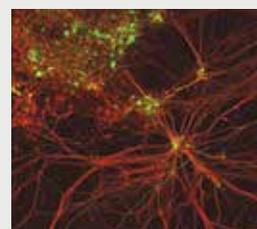
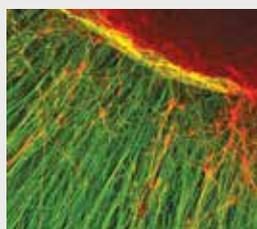
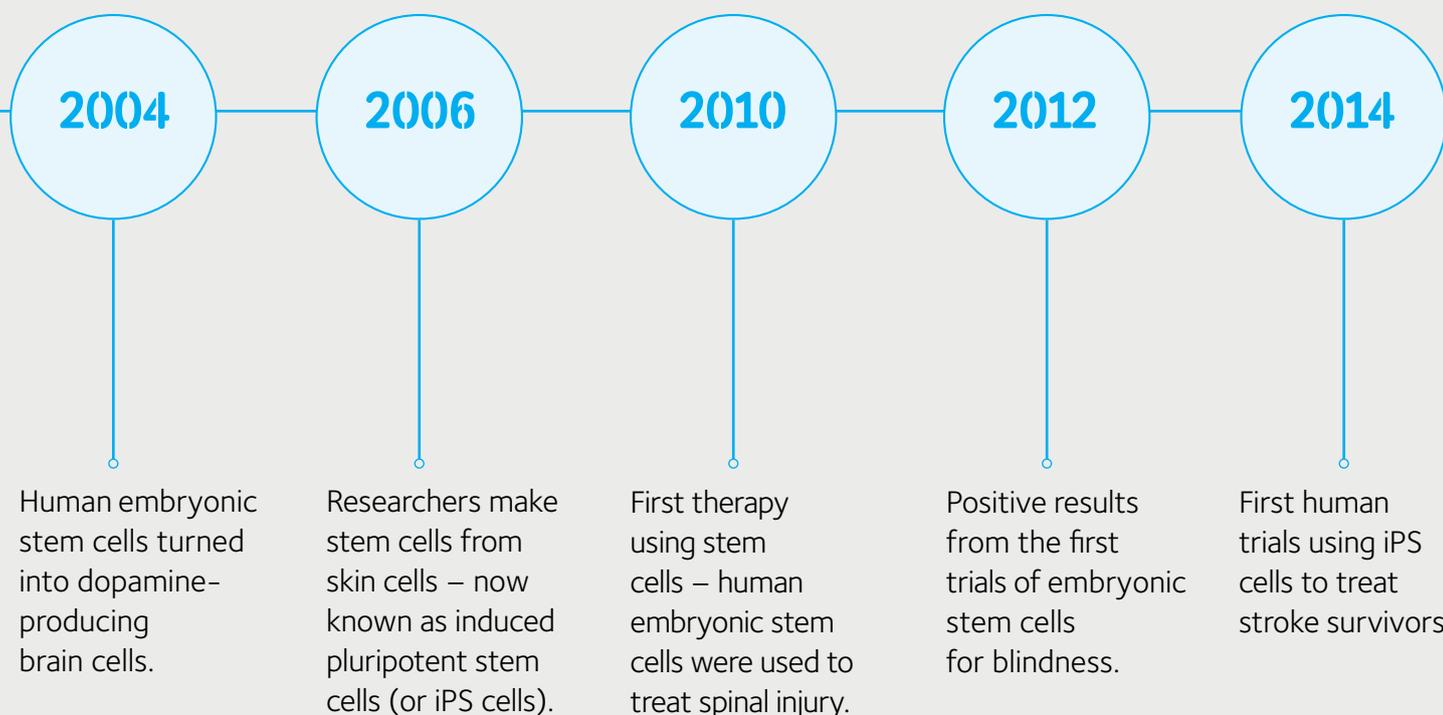
As Europe's largest charitable funder of Parkinson's research, we're currently supporting vital research projects that aim to make stem cell treatments a reality for people with Parkinson's.

But we cannot do it alone. It's essential that the whole research community works together to tackle these challenges. This means charities, the pharmaceutical industry, regulators and government bodies all pulling together towards a common goal.

The UK government has recently established a new centre, the 'Cell Therapy Catapult', which aims to help the UK become a global leader in the development and commercialisation of cell therapies.

The Catapult aims to speed up the translation of promising discoveries and advances being made by stem cell scientists in the lab, into real treatments in the clinic that are available to people with conditions like Parkinson's.

This is a really promising step in the right direction, and we're excited by the opportunities ahead for developing the next generation of cell therapies that are so urgently needed for Parkinson's.



Stem cells: your questions answered

Will stem cell treatments be available in my lifetime?

Stem cells definitely hold huge potential for developing therapies for Parkinson's, but we still have a number of questions to answer and challenges to address before we can begin testing them in people with the condition.

How long this will take is, unfortunately, impossible to say. We may solve the problems straight away but, then again, we may uncover new challenges too. And the more we and other funders can invest in the research, the faster we'll get there.

It's difficult to put a date on when clinical trials of stem cell therapies for Parkinson's may start but we're optimistic that it could be in the next few years.

What are the barriers we need to overcome to make stem cell treatments a reality?

There are three major challenges:

Are they safe? Because stem cells are so powerful and have the ability to become many cell types, they could lead to tumours forming in the brain or the cells could even escape into other areas. We need to be confident that the cells we transplant stay in the right place and do the right thing.

Will they work? The brain is unimaginably complex, it contains billions of nerve cells which are all connected in complex circuits. How can we be sure that the new, healthy cells we grow will be able to integrate into the brain and do the job of the ones that have been lost? And will new cells be able to survive in the Parkinson's brain when other cells have already died?

Are they practical? Using living cells to treat illnesses is much more complicated than using drugs. Each patient may need 100 million cells! How will we grow enough cells of the right type

to treat thousands of patients? And how will we regulate these new treatments to make sure the cells being produced are the right ones and are of high enough quality? Will stem cell treatments be cost-effective enough to be provided on the NHS?

Are stem cell treatments for Parkinson's available in other countries?

You may come across treatments in the media or on the internet in other countries that are marketed as 'stem cell therapies'. However none of these therapies have been proven to work in clinical trials, so we don't if they are safe or if they work. They also charge thousands of pounds, which we believe to be highly unethical.

Could I use umbilical cord blood banking as a source of stem cells?

Cord blood banking can be useful for the treatment of blood diseases. However, there is not enough evidence to support the use of umbilical cord blood as a source of stem cells to repair the brains of people with Parkinson's. We would not recommend that people pay for this in case they get Parkinson's in the future, given the current advances in the development of stem cell technology.

Are volunteers needed for trials of stem cell treatments for Parkinson's?

Not at the moment but we hope that there will be opportunities to take part in stem cell therapy trials in future.

We monitor research happening in the UK and around the world to keep abreast of all the latest developments and share any new advances through our website and magazines.

The best way to keep up to date with opportunities to participate in research is to join our Research Support Network – see p16-17 for more on how to get involved.

Find out more: see our stem cell research and Parkinson's information sheet. Our publications can be ordered for free or downloaded at parkinsons.org.uk/publications

The stepping stone to stem cell therapies?

Funded by a €12million grant from the European Commission, TRANSEURO is one of the largest and most ambitious transplantation trials ever to be attempted for Parkinson's.



The team conducting this transplant trial aren't using stem cells, they're using cells collected from donated human fetal tissue.

Transplantation using fetal tissue is not new. During the late 1980s and early 1990s, several studies attempted to transplant human foetal dopamine nerve cells into the brains of people with Parkinson's.

But the results were inconsistent.

Some people did remarkably well and a few were even able to come off their Parkinson's medication. But some experienced little or no improvement. And a few unfortunately developed distressing uncontrollable movements.

The TRANSEURO trial which began in 2010 aims to prove that cell transplants can work consistently for people with Parkinson's.

Here Professor Roger Barker, who is co-ordinating this international study, explains their progress so far.

"The early trials showed us that fetal dopamine cell transplants can work for people with Parkinson's but it wasn't clear why it worked for some people but not for others.

"Unlike previous studies, which mainly involved people with quite advanced Parkinson's, we're looking at younger patients in the earlier stages of the condition who we hope will respond better to the treatment.

"We've already successfully recruited 150 patients from across Europe – including Cambridge, Cardiff and London in the UK, as well as in France, Germany and Sweden.

"From this group, 40 randomly selected patients will be offered the chance to have a cell transplant. 20 patients will receive a transplant and sophisticated PET brain scans, and the other 20 will be a non-transplant comparison group who will also have brain scans.

"We are just at the stage of doing this now and hope to be able to start transplantations in the UK this summer.

"The scale and complexity of this study has meant it's taken us much longer to get to this point than we hoped. Co-ordinating the collection and preparation of fetal tissue has been much harder than we expected, and because each country has its own regulatory processes for clinical trials – getting everything set up has been very complicated.

"But if all goes according to plan, we hope to have results to share in 2017/2018.

"Alongside the TRANSEURO trial we are continuing to work on developing the next generation of stem cell therapies for Parkinson's. If we can prove that transplants can work consistently for people with Parkinson's, we'll be able to move into trials with stem cell-derived nerve cells as quickly as possible."

NEW RESEARCH PROJECTS

We've awarded Dr Amy Reeve at Newcastle University a Parkinson's UK Career Development Award to explore how energy-production is affected inside the brain cells that are lost in Parkinson's, and look for new treatments that could help.

We caught up with Amy to find out more about her research and ask her a few questions.

Protecting brain cells when energy levels run low



Who?

Dr Amy Reeve

Where?

Newcastle University

What?

£249,958 over three years

What do we already know about energy levels inside the brain cells lost in Parkinson's?

As we age, the cells of our body show a decline in a number of important processes, including their ability to produce energy. And research has shown that the cells that are lost in the brains of people with Parkinson's are particularly vulnerable to these changes.

Mitochondria are the tiny batteries inside our cells that provide the energy they need to live and function properly. Brain cells need lots of energy because of the huge number of tasks they perform, and if their mitochondria don't work properly the cells stop working properly and eventually die.

Sticky bundles of proteins called 'Lewy bodies' also appear inside the brain cells affected in Parkinson's. We do not yet fully understand why Lewy bodies form or what effect they have on cells, but the main protein found inside them alpha-synuclein may be the key. Researchers have already found clues that alpha-synuclein may affect how mitochondria work and produce energy inside brain cells.

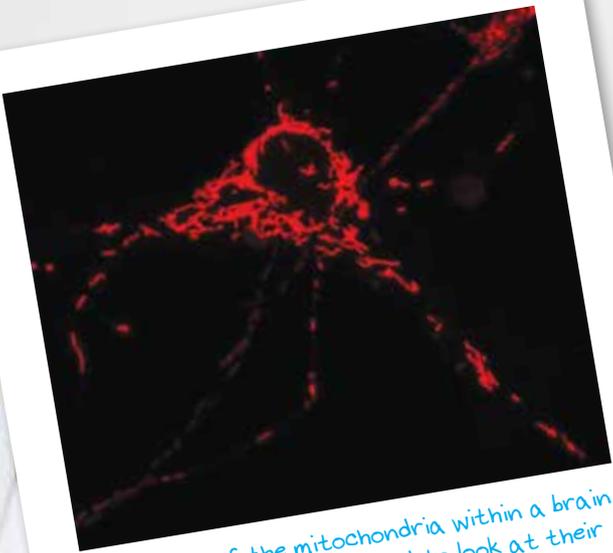
So how will your new project get to the bottom of all this?

In this project I want to learn more about how changes in mitochondria affect energy production and contribute to brain cell death in Parkinson's.

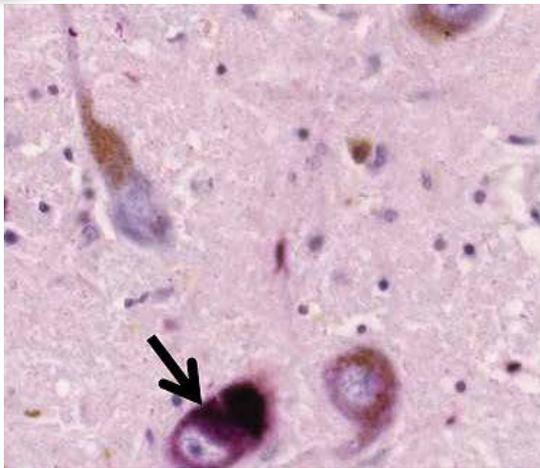
I hope to answer two key questions:

1. What happens to brain cells when their mitochondria stop working properly?
2. How do brain cells with faulty mitochondria respond to the presence of alpha-synuclein?

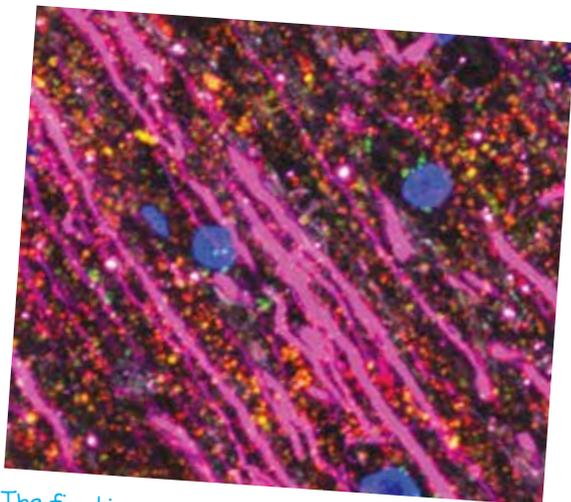
And I will use this new knowledge to test a range of drugs that are known to interact with mitochondria to see if they can protect brain cells against the problems caused by faulty mitochondria and alpha-synuclein.



This one is of the mitochondria within a brain cell. I have stained them red to look at their 'membrane potential', which is an important part of their ability to generate energy.



The second is of two brain cells within a brain section, the purple colour is the mitochondria and the deep red is alpha-synuclein. The cell with the arrow pointing to it contains the most alpha-synuclein and has more purple colour suggesting more mitochondria.



The final image shows brain cells in pink and the mitochondria in red and green within the brain. I am using this to look at the effect of mitochondrial function on other parts of the cell.

To do this I will study donated post-mortem brain tissue from people with Parkinson's and those with inherited mitochondrial defects, as well as using human brain cells grown in the lab and mice that produce too much of the alpha-synuclein protein.

How will your research help people with Parkinson's?

I believe that understanding how changes in mitochondria are involved in brain cell death could be the key to treatments that protect against energy loss and help cells survive into old age.

I hope my research will uncover new and promising targets for treatments that could help save the precious nerve cells lost in the condition and offers hope for a future cure.

I'm passionate about communicating all aspects of my research to people affected by Parkinson's and hope to take part in events to raise awareness of the research that I'm undertaking. Since my research could lead to new therapies, it is particularly important to involve patients and members of the public in open discussions about the techniques I use and the impact of my research.

Find out more: browse all our archive projects on our website parkinsons.org.uk/currentresearch

What is life like for people with Parkinson's in care homes?

Who?

Professor Richard Walker

Where?

North Tyneside General Hospital

What?

£34,990 over two years

We hear many stories, both good and bad, about life for people with Parkinson's in care homes. But we need systematic research to give us solid evidence about the standards of care currently being provided by care homes. This will help us give clear and evidence-based guidance to care homes for how they can best meet people with Parkinson's often complex needs.

"My dad is 70 years old and has recently moved to the nursing home. This has been a long, challenging process and it takes time for the care staff to fully understand the wants, needs and capabilities of a person with Parkinson's.

"I have a white board in his room where I leave messages and notes for the staff. Parkinson's is a hard condition to explain because each person is different. I keep in constant contact with the staff and a member of the family goes every day.

"Handing care of a loved one to others is not easy to do, but when you can no longer meet the person's needs at home, you have no choice. It takes time to build trust with the care staff and you will always feel guilty. Finding good quality care is the key."

Sue, whose father has Parkinson's



To address this, we've commissioned some new research to gather evidence about what life in care homes is really like for people with Parkinson's.

Richard and his team will complete in-depth interviews with people with Parkinson's and carers to explore who they are, their needs, quality of life, and how and why they came to be in care.

The researchers will also be interviewing staff from the Parkinson's UK Helpline and Parkinson's nurses to investigate how care differs across the UK.

Understanding the issues and concerns for people with Parkinson's living in care homes will give us the evidence we need to help care homes to better meet the needs of people with the condition.

The findings will be used to define what a quality Parkinson's service looks like in a care home setting and will ultimately help to improve quality of life for thousands of people with Parkinson's and their families.

Is imitation an underused tool for treating Parkinson's?

Dr Ellen Poliakoff, a senior lecturer in psychology at the University of Manchester, explains why she's exploring the potential of imitation for helping with movement problems caused by Parkinson's.



People with Parkinson's find it difficult to start movements and often make movements that are smaller than they should be, such as taking shorter steps or having smaller handwriting.

Finding simple ways to help people improve their movements can make a real difference to their quality of life. Currently, this is done by using cues, such as visual markers on the floor to help people increase their stride length, or sound cues to help time their steps.

This project will investigate another possible way for improving movement in Parkinson's – imitation.

When we imitate someone, we watch how they carry out a movement and then copy their actions. It's much easier to copy a movement, like a tennis serve or a dance step, than it is to follow written instructions. So imitation could be an important route towards improving movements for people with Parkinson's.

However, despite the obvious potential for imitation to be used therapeutically, there have been very few studies into imitation in Parkinson's.

I have recently been awarded £300,000 by the Economic and Social Research Council to carry out an in-depth study of imitation in people with Parkinson's.

We will examine how effective imitation is at improving movement in people with Parkinson's, compared to a group of healthy volunteers of a similar age. We will ask them to copy a simple sequence of hand movements from a video clip, and compare this to when they follow verbal instructions to make the same movements.

I hope our study will provide vital new insights into how people with Parkinson's imitate movements, which could lead to the development of new therapeutic techniques that people with the condition could use in their day-to-day lives.

Ellen is also currently supported by Parkinson's UK for her project: [Non-verbal communication in Parkinson's](#).

BE PART OF THE SEARCH FOR A CURE...

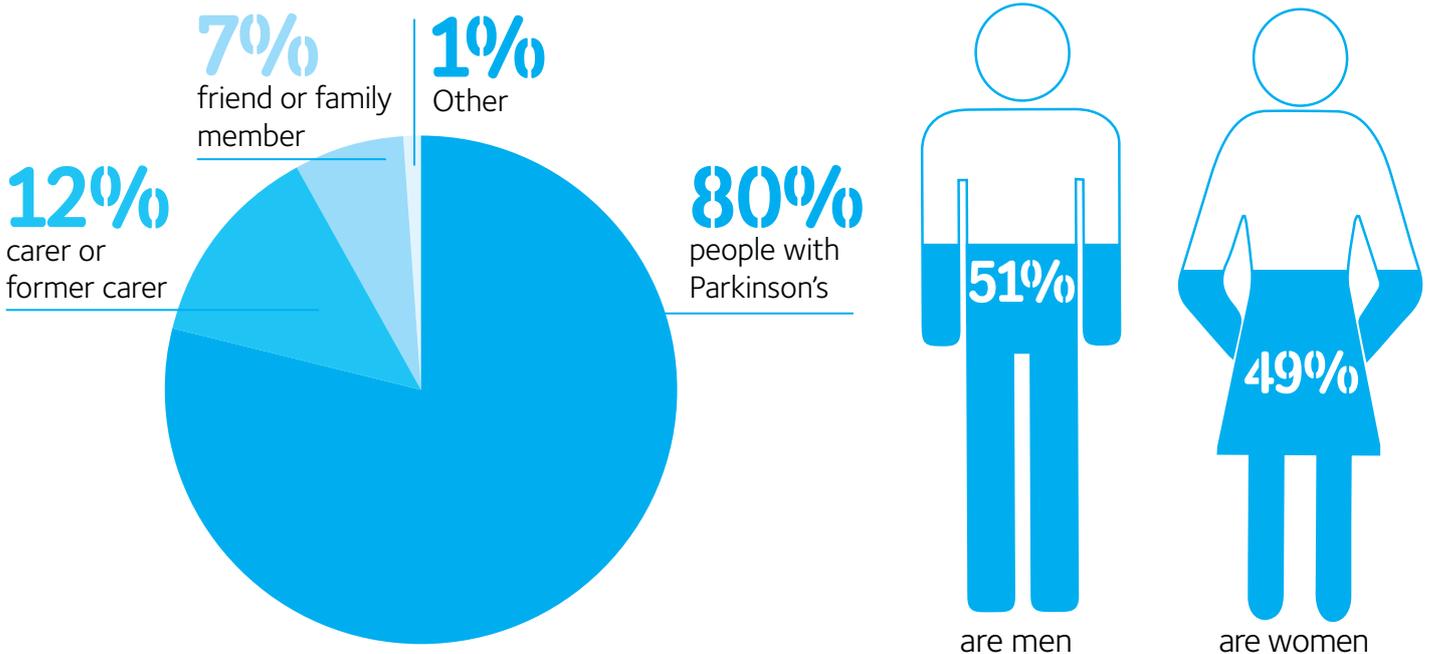
Our Research Support Network brings together people with Parkinson's, carers, family, friends and researchers who are all passionate to play a part in our search for a cure and better treatments for Parkinson's.

The network was set up in 2012 and aims to provide an easy way for people to keep up to date with research news and events as well as play an active part in research at every stage.

Two years and more than 1,000 members later, it's time to find out who our research supporters are, and what the network means to them.

Our research supporters – who are they?

Here's a breakdown of the people who are part of the network today



Why are you a research supporter?

Our research supporters all have their own motivation and specific interest in Parkinson's research with different expectations of the network.

"At a UK and regional level the Research Support Network enables me to engage with like minded people and make a personal contribution, thus maintaining my hopes and motivation.



"Actively participating in research provides me with a greater understanding of this strange condition about which so much and yet so little is really understood and helps sustain my hope for the future."

Roger

Why did you join the network?

88%

to keep up to date with Parkinson's research

60%

to take part in research studies or clinical trials

58%

to find out about research events

43%

to help shape research

34%

to connect with other research supporters

The network has grown hugely over the last two years and we are working hard to provide supporters with interesting opportunities and events that allow them to play an active part in Parkinson's research.

"The network has enabled me to feedback to other interested people about what is going on in regards to Parkinson's research. I feel as if my brain is working again!"

"The network is a mutual interest network: it is not only about how people with Parkinson's best support research but very much about how research can best support people with Parkinson's"

78%

say joining the network has met their expectations

All the comments collected through the survey are helping to shape the future of the network. One area raised by a number of research supporters was the need to ensure we provide feedback to show exactly how their efforts have made a difference. This is something we will aim to improve over the coming months.

Supporting the search for a cure

57%

research supporters have taken part in an activity through the Research Support Network

"The network has given me the opportunity to feel that the knowledge I gained about Parkinson's through caring for my mother is being put to good use."

"As research becomes more technically advanced and focused on small but vital parts of the big picture, there is a danger that some

researchers may lose the patients' perspectives on Parkinson's. I think an important role of the network should be to increase the flows of information in both directions. After all, knowing and explaining some of the symptoms may give new perspectives on brain biochemistry."

Become a research supporter

Joining the network ensures you will receive emails with the latest opportunities to support Parkinson's research.

All you have to do is choose an opportunity that interests you!

Find out more about the research support network at parkinsons.org.uk/researchsupportnetwork or by calling us on **0207 963 9398**.

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.

MUSIC

Congratulations on the last issue of *Progress* magazine, it kept me concentrating for two hours – which is a first as my usual attention span is about 20 minutes!

I felt compelled to write to you in response to Alastair's letter "As easy as riding a bike". I've never been able to ride a bike but have discovered a pleasant way which enables me to walk at a steady pace, instead of weaving my way along the pavement, or so slowly that I realise I've almost stopped.

Three years ago my late husband bought me an MP3 player for Christmas, since then I never go out without it in my ears. I walk to the beat of the music, favourites are Queen or Prince (do you see the connection?). Then when I tire, I switch to something slower until I get my breath back.

Yes, I'm on many drugs but personal choice is friends, family and the ability to laugh, especially at yourself.

Thank you,

Anne

"I'm really impressed with the effort that goes into producing *Progress* magazine. The layout is engaging and colourful and good thought given to the style and language, with good the bite sized information and links for further information – very visual."

A GOOD DAY'S WORK...

Just before Christmas, my neighbour who lives opposite and works for a biotechnology company came over to ask me whether I knew anybody who could give a talk about Parkinson's to his colleagues.

"Yes!" I said "me".

I got in touch with Parkinson's UK to see if someone from the research team would be able to come along with me to speak to the staff.

And Dr Katie Le Blond, Research Development Manager at Parkinson's UK, volunteered to be the second speaker on the day.

Several months and much organising later, Katie and I arrived at 'BioFocus'.

We expected to be speaking to a handful of people but more than 100 scientists from across the company came to listen to our presentations.

Afterwards, Katie and I were given a guided tour of their facilities, and we learned about how they take ideas and attempt to develop them into treatments.

It was an honour to be given such a rare insight into the complex world of drug development. And, who knows, our day out could lead to Parkinson's UK and BioFocus working together on research in future.

So, find out about your neighbours – you never know what it could lead to!

Phil

BRAIN WORKOUT

Everyone must be aware of the importance of keeping physically active when you have Parkinson's but, in my opinion, it is equally vital to give your brain a regular workout.

Being mentally idle will only result in you starting to focus more on your Parkinson's with the result that you will be more likely to start suffering from depression. Achieving mental tasks will also promote a general feeling of well-being.

Suitable exercises for those little, grey cells can include Sudoku, crosswords, codewords and solving mathematical puzzles. I personally include writing poetry, reading the novels of Charles Dickens, studying foreign languages, reading Shakespeare's sonnets, listening to classical music, memorising the whole of Grey's *Elegy*, watercolour painting, wood carving and general knowledge quizzes.

Believe you me, Parkies doesn't get a look in.

A post by 'Christo', a member of our online discussion forum

[Join the discussion at parkinsons.org.uk/forum](https://www.parkinsons.org.uk/forum)

GLIMMERS OF HOPE

My dad is 56 and has had Parkinson's for six years. Every day is a struggle and every day we wish he had a better quality of life but just think what they could find if they keep looking for the 'cure'.

I live in hope that someday there will be treatment to help stop Parkinson's in its tracks, to prevent it's onset in those susceptible, a greater understanding in society of its complexity, and more and more treatments that can help improve the lives of people with Parkinson's at different stages.

Quality of life means different things to different people but we all know for people with Parkinson's that medication is crucial, as is getting it on time. The more research that is done, the more and more wee glimmers of hope they find.

A post from Susan on our Facebook page

www.facebook.com/parkinsonsuk

"Progress is the best magazine out, very informative and written with empathy."



Have your say

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

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

research@parkinsons.org.uk
0207 963 9326

DONATING YOUR DATA – ARE YOU UP TO SPEED?

Patient records have the power to save lives and the information they hold is vital for medical research. They help researchers spot patterns in health, such as the discovery that smoking causes lung cancer, and to compare responses to different treatments and services. But until now, our patient records have been difficult to access and underused. All that is about to change...

Every time you visit an NHS hospital or your GP, information about your health is recorded and stored in your own personal record.

Your record helps doctors and other health professionals understand your medical history and provide you with the best possible care – but soon NHS records will be used to do even more.

The NHS in England has created a new system called [care.data](#) to share anonymised information from patient records with health care providers, the NHS and researchers, to improve care and research.

In a consultation of Parkinson's UK members, 90% agreed that they would be happy for their NHS data to be used for research purposes.

But because your patient record contains such personal information about your health, it must be handled very carefully and accessed safely and securely to protect your confidentiality and prevent data being misused.



Is care.data safe?

The widespread media coverage of care.data stimulated some interesting comments on the Parkinson's UK online discussion forum, including this post from one member:

It seems that the only thing you will be able to trust on the internet will be your own medical records ... once the government's sold them on.

The new care.data database brings together everyone's medical records. Mega datasets like this are extremely useful. It's the only way the non-link between MMR vaccine and autism was proved for example. Parkinson's researchers will find the data invaluable, and so Parkinson's UK has joined with other medical research charities to champion the new scheme.

But there are increasing worries about the privacy of our data, according to doctors and others writing to *The Guardian* newspaper. Far from being anonymised and aggregated, "the government makes no secret of its intentions to sell whatever data the commercial market wants to buy."

There is plenty in my medical record of 'sensitive data', my Parkinson's status being only one of them. Do I allow anyone who wants to, to buy my personal records for whatever reason they like and damage my chances of employment, of my standing where I live, of my credit rating? Or do I deny researchers the chance to cure Parkinson's more quickly?

Or should I not have to make the choice?

Semele

parkinsons.org.uk/forum

Improvements are being made

As a result of concerns like Semele's the launch of care.data was pushed back from February until autumn 2014 to give people more time to find out about the plans and the opportunity to opt out.

We're calling on the NHS to use this pause as an opportunity to communicate with the public and tighten the rules to ensure the data is only used for legitimate medical research.

MPs have recently voted in favour of an amendment to the Care Bill that clarifies who can access NHS patient data through the care.data scheme.

Health Minister Dr Dan Poulter explained in the debate that data could be shared for research relating to health and care services but insurance companies would not be given access.

Even more encouragingly, the Health Research Authority (HRA) – which promotes and protects the interests of patients in health research – has also been given greater powers to advise on how data is shared.

Your data, your decision

This autumn, information from GP practices will be transferred in to the new data sharing system, so now is the time to make sure you understand how your own personal information will be shared and to decide whether you want to opt out.

Please use this time to find out more about the scheme and make your own decision on the benefits and risks. Speak with your GP if you have any concerns.

For more information about how your medical records can be used for research and the new scheme please visit www.nhs.uk/caredata or speak to your GP.

JOIN US AT A RESEARCH EVENT

We work with researchers and supporters to arrange a wide range of research events up and down the country to give people directly affected by Parkinson's the chance to find out more about Parkinson's research.

These include visits to researcher's labs, university open days, conferences, talks and lectures. We also provide research speakers for local groups and regional events.

Bringing people together

Crucially, research events not only give people affected by Parkinson's a chance to learn about the latest research, they also give researchers a valuable opportunity to learn from people living with the condition.

Stem cell scientist Dr Emma Lane, who spoke at our conference for supporters last year, comments:

"I found the Parkinson's supporters conference to be a fantastic medium through which to share the exciting progress in the field with those who will hopefully benefit. It was also great for me as a scientist to be able to talk informally to people affected by the condition.

"Their insightful questions can help to direct your science, and to realise the true potential impact of your work to their future."

Helping us to get it right

Input from volunteers and supporters help us to shape our events to make sure we're focusing on the topics that people want to hear about and choosing the most appropriate speakers. We also work closely with our speakers to help them explain their research in plain and clear English ... although this is sometimes a challenge!

Finally, we collect feedback from everyone who comes to our events which helps us keep improving on every aspect, including the registration process, catering and venue, as well as the content.

"What a magnificent day ... we have learnt so much! Thank you so much for managing to find us two places. Also a big thank you to you and your team for your faultless organisation of the day!"

"Thanks very much for being part of the team which put this conference together. Annie and I, both recently diagnosed, were buzzing when we left."

"Please thank all of your team for such an interesting and varied day. Your speakers were all easy to understand and it is encouraging to see at last there seems to be light in the near future? Excellent!"



UPCOMING EVENTS

University open day

Dundee, 2 September 2014

Our second open day at the University of Dundee will showcase research into genetics and Parkinson's. We will also be joined by a neurologist who will talk about current and new treatments that may become available to people living with Parkinson's in the future.

Open day: Tracking Parkinson's update

St Helens, 11 September 2014

Join us to hear Dr Donald Grosset from Southern General Hospital in Glasgow and Dr Monty Silverdale from Salford NHS Trust talk about the world's largest in-depth study of Parkinson's, and how it's speeding the search for better treatments and a cure.

Conference for research supporters

York, 2 November 2014

We're delighted to announce we will be holding our third research conference for people affected by Parkinson's. Highlights will include Professor Roger Barker discussing the latest developments in cell and gene therapies, and Dr Alastair Noyce sharing how his innovative research is taking us closer to predicting Parkinson's before symptoms appear.

Royal Institution lecture

London, 6 November 2014

Join us at the world famous Royal Institution to hear about our research that aims to identify the early warning signs of Parkinson's and how understanding the differences between people with the condition could lead to personalised treatment.

Keep up to date with research events

Visit our website for a full list of upcoming events and to book your place: parkinsons.org.uk/researchevents
Or contact us directly at researchevents@parkinsons.org.uk
or call **020 7963 9356**.



RESEARCH RESULTS

We keep a close eye on all our research and over the next few pages (p26-31) we share important results from six projects. To keep up with all the latest findings visit parkinsons.org.uk/researchresults

New clues to sleep problems in Parkinson's

Our researchers at University of Cambridge have found vital new evidence that the sleep problems experienced by people with Parkinson's may be caused by key changes in their internal body clock.

Sleep problems are very common in Parkinson's and have a massive impact on people's quality of life. But at the moment we don't have a good understanding of the root causes of these problems, which makes them extremely difficult to treat.

What the research team did

The research team began by assessing sleep problems in 239 people recently diagnosed with Parkinson's using a range of questionnaires and assessments.

They then carried out more comprehensive tests – including measuring changes in the levels of different chemicals in their blood and brain activity during sleep – in 30 men and women with Parkinson's and 15 healthy men and women of a similar age.

What they found

The team found that:

- Sleep problems are common even for people in the early stages of Parkinson's.
- People with Parkinson's often take longer to get to sleep and have poorer quality of sleep than people without the condition.
- People with Parkinson's who experience sleep problems also report poorer quality of life.

Crucially, the team discovered important changes in the levels of two hormones, melatonin and cortisol, and in the activity of a key gene called Bmal1 – which are all involved in regulating our sleep patterns.

What next?

This study provides the first compelling evidence that the sleep problems experienced by people with Parkinson's are caused by changes in the biological mechanisms that regulate their internal body clock.

This knowledge is going to be absolutely vital to developing treatments and therapies that can help the thousands of people with Parkinson's who experience problems with sleep.

“Sleep is the biggest issue at the moment – I am still a working person. Despite having sleeping pills, I still don't sleep. I have tried lavender spray/ hop pillow but still no luck”

'lakenhamneil' from
parkinsons.org.uk/forum

References

Breen D et al (2014) 'Sleep and Circadian Rhythm Regulation in Early Parkinson Disease' *JAMA Neurol*, 71 (5):589 – 595.



Using yeast to help us understand the complex genetics of Parkinson's

Researchers at the University of Leicester have been using tiny yeast cells to understand genes involved in Parkinson's.

A small number of people – probably less than 5% – have a rare inherited form of Parkinson's. One of several genes that has been linked to early-onset inherited Parkinson's is called DJ-1. But at the moment it's unclear what role the DJ-1 gene plays inside nerve cells and how changes (called mutations) in the gene may upset how it works.

We awarded Dr Flaviano Giorgini and his team a project grant of £242,759 to investigate what DJ-1 does and how changes in this gene may affect the brain cells of people with Parkinson's.

Why use yeast?

Yeast, a tiny organism well known as a key ingredient for making bread and beer, is also an important research tool. Yeast is a simple organism, it's really easy to grow and study in the lab and we actually share many similar genes – which makes it the ideal 'living test tube' for studying how genes work inside our own cells.

What they found

Using their yeast model, the team discovered that DJ-1 is involved in autophagy – an essential process for recycling old and damaged parts of the cell. They also found that DJ-1 may have a role to play when yeast cells get stressed by helping to protect important genetic information from damage.

Flaviano comments:

"We are tremendously excited by our results. The family of proteins under investigation have always been a bit of a 'black box', and a true understanding of what these proteins do at a cellular level and why they are important has remained elusive. This work provides a step into this darkness.

"There are currently no treatments that can prevent or slow the progress of Parkinson's.

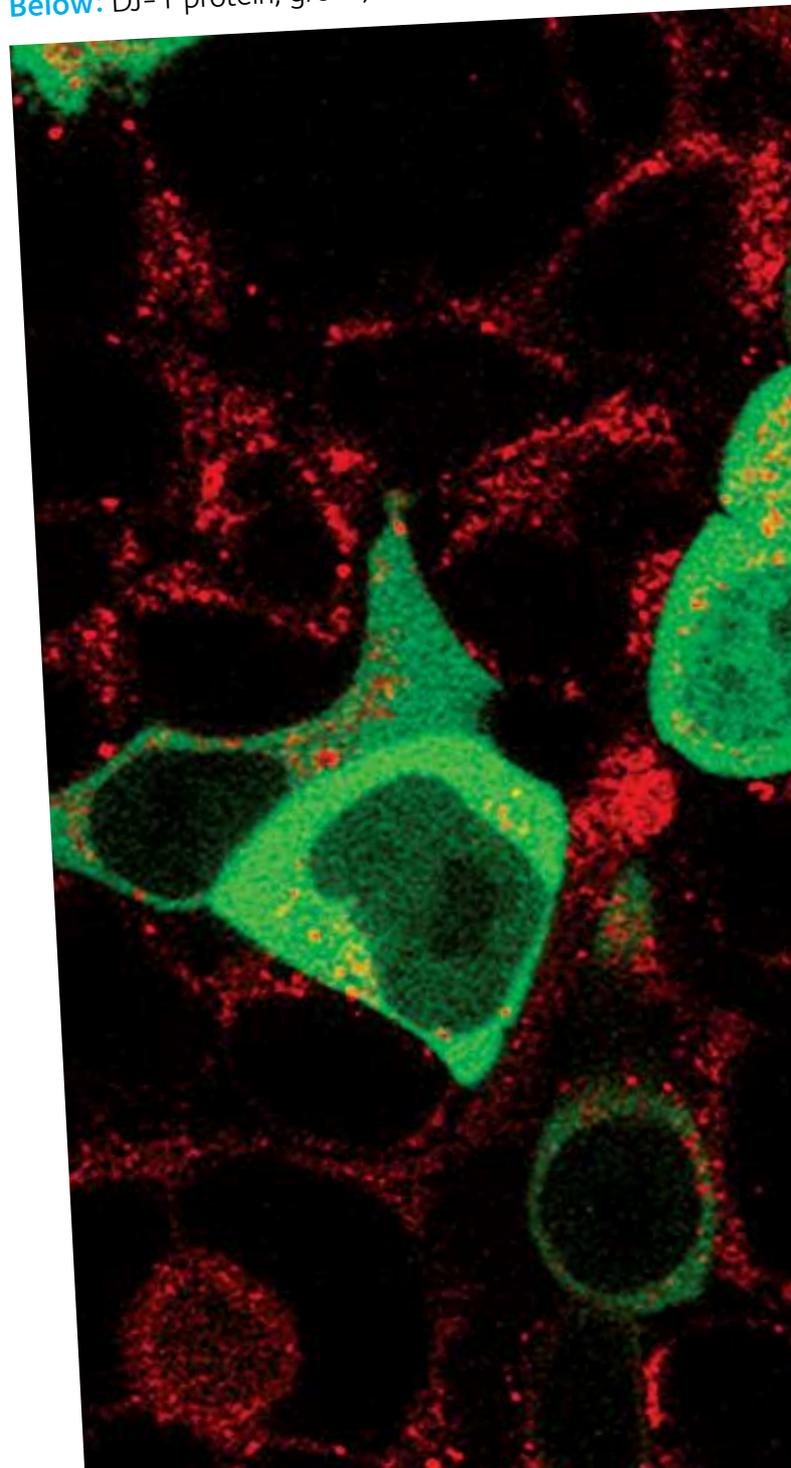
Understanding more about the biology of Parkinson's may allow us to intervene and prevent or correct the problems that happen in the cells affected in the condition.

"We hope that the knowledge and tools developed during project will bring us a step closer to identifying better treatments for Parkinson's."

References

Miller-Fleming L et al (2014) 'Yeast DJ-1 superfamily members are required for diauxic-shift reprogramming and cell survival in stationary phase' *PNAS* (in press)

Below: DJ-1 protein, green, in human cells.



Our researchers make important strides towards tackling dyskinesia

Uncontrollable movements called dyskinesia are one of the most common side effects of Parkinson's medication.

Levodopa is the main drug used to treat the symptoms of Parkinson's. It helps nerve cells in the brain make more of a chemical called dopamine that's important for co-ordinating movement.

Levodopa works well at first but can produce complications later. More than one in three people who take it for more than five years develop dyskinesia – uncontrolled movements that seriously affect their quality of life.

"I used to suffer from really bad involuntary movements (dyskinesia). Sometimes it was so bad that I couldn't keep still at all, and when I went out I could feel people staring at me. The only way to control it was to reduce or delay my medication, but the impact of this was that all my movements slowed right down, so it was debatable which was worse. I was just about managing at work, but it was a struggle!"

'Kathy C' from
parkinsons.org.uk/forum

These jerky movements or twitches don't affect everyone with Parkinson's. But they can make daily life even more challenging for those who do. Our researchers have been trying to identify who is at risk of developing dyskinesia and how to stop this side effect in these two research projects.

Predicting risk of dyskinesia

Our research at the University of Oxford may pave the way towards new techniques for predicting people's risk of developing dyskinesia.

One of the biggest challenges of dyskinesia is that we cannot predict who will develop it. The ability to do this is crucial if we are to develop treatments and strategies that can prevent these uncontrolled movements developing in the first place.

We awarded Dr Binith Cheeran an innovation grant worth £19,792 to develop new techniques to identify people at increased risk of developing dyskinesia.

What the team did

The study involved 42 people recently diagnosed with Parkinson's who had not yet developed dyskinesia.

The team used a test that involves placing a device called a 'coil' on participants' heads to produce very brief, painless and safe, electrical activity in the brain. This test is called Transcranial Magnetic Stimulation (TMS) and can be used to look at how nerve cells are connected in the brain.

What they found

They found that, in some people with Parkinson's that don't have dyskinesia, the drugs used to treat Parkinson's changed the way cells are connected inside their brains. These changes were similar to those seen in people with Parkinson's who do have dyskinesia.

Binith comments:

"This test may help identify individuals with an increased risk of developing dyskinesia but we still need to do more research to be sure.

"Our study will take another two to three years – this is because we have to wait to see which people develop dyskinesia. We will then be able to look back at their test results and identify the differences that might help us to predict people who are at risk."

Testing new drugs for dyskinesia

We awarded scientists at Cardiff University a £150,000 grant last year to test a range of drugs that may hold the key to reducing dyskinesia.

In a previous Parkinson's UK study the team, led by Dr Riccardo Brambilla, found that drugs which target a molecular pathway or chain of events that happens inside brain cells – called the Ras-ERK pathway – might tackle dyskinesia.

What the team are doing now

In their new project the team is exploring the effects of eight potential new drugs that target this pathway.

Riccardo explains:

“We don't fully understand the causes of dyskinesia and at the moment there are no effective treatments for people living with this.

“We believe our project may identify future treatments that could stop or even reverse this distressing side effect of Parkinson's medication.

“Having an effective treatment would mean that people could control their symptoms with medication for longer which would greatly improve their quality of life.”

Progress so far

The team have now tested a number of the drugs in a mouse model of Parkinson's and have already identified one drug that seems to show promise in controlling dyskinesia.

Importantly this drug is able to cross from the bloodstream into the brain, which many drugs cannot.

Once in the brain the drug successfully blocked the Ras-ERK pathway and reduced dyskinesia in the mouse model by 40%.

This drug is particularly promising as it is already being tested in people as a cancer therapy. The team hope in the future it could also be tested in people with Parkinson's who experience dyskinesia.

The next steps

The team still have more drugs which target the Ras-ERK pathway to test in their mouse model. They also want to examine the drug they've already identified in more depth to see how and why it reduces dyskinesia.



Above: Taking Parkinson's medication

Using exercise to prevent breathing problems

Many people with Parkinson's experience breathing problems at some stage. A team at North Tyneside General Hospital investigated if exercise could help tackle these difficulties.

100 people with Parkinson's took part in the study led by Dr Richard Walker, a consultant physician with a special interest in Parkinson's. The one year innovation grant of £15,619 was awarded in 2012 to assess if a structured exercise programme could improve certain aspects of health.

The researchers wanted to know if three 45-minute exercise sessions a week could improve lung function, breathing muscle strength and the fitness of the cardiorespiratory system (the heart, lungs and blood vessels).

The exercise sessions were individually tailored and increased in intensity over 12 weeks. Participants moved around a circuit with 12 different activities doing 30 minutes of aerobic exercise – such as running on a treadmill and cycling – and 15 minutes of resistance training, such as lifting weights.

Both male and female participants particularly enjoyed one of the aerobic stations where they wore boxing gloves and hit hand pads worn by the instructors. This activity was designed to get the heart pumping faster to improve cardiovascular fitness and also built core and upper body strength.

The data collected from the study is still being analysed, however the team found that exercise improved the fitness of the cardiorespiratory system and increased the distance that individuals with Parkinson's were able to walk within a set time.

The team hope that the results will encourage other research studies into breathing problems in Parkinson's and lead to the provision of services – for example exercise programmes for those with the condition.

“I'd say that exercise is as important as the right combination of meds. I wouldn't want to be without either. Over my 17 years with Parkinson's now, there have been times when I've gotten lazy or have been ill and skipped my exercise routine. Believe me, I felt the difference!

“In my youth I spent very little time on sports or exercise, considering games a waste of time. Before my diagnosis, though, I discovered I enjoyed hiking. After the diagnosis I added workouts at a gym and stretching exercises at home. I still have to force myself to exercise, but I really feel the benefits in flexibility, stamina, and level of pain. For improvement in balance, I take T'ai Chi classes. They are so enjoyable that I go eagerly rather than reluctantly!”

'J of Grey Cottage' on
parkinsons.org.uk/forum



Developing a bone marrow stem cell therapy for Parkinson's

This study, led by Parkinson's UK funded researcher Alan Whone, explored the potential of bone marrow stem cells to treat Parkinson's.

Current treatments for Parkinson's help ease the symptoms but don't slow it down or stop it progressing. But stem cells offer tremendous potential because they are capable of becoming any of the 200 different types of cells that make up the human body. For people with Parkinson's, the hope is that we will be able to grow new dopamine-producing nerve cells that could one day be used to replace those lost in the Parkinson's brain.

Dr Whone's team, at Frenchay hospital in Bristol, investigated how bone marrow stem cells may help protect the damaged brain cells in Parkinson's. This study was made possible by a Parkinson's UK grant of £13,130 awarded in 2012.

"I am interested in the stem cell research ... I hope that this area of research will continue as it appears to be a very important possibility for the future."
Response from our unanswered research questions

What could bone marrow stem cells do?

The idea is that bone marrow stem cells could be taken from the pelvis and then fed into the bloodstream through a drip. From the blood these cells may be able to get into the brain and travel to areas affected in Parkinson's.

But before testing this as a treatment for Parkinson's, Alan wanted to investigate the properties of bone marrow stem cells and the 'growth factors' they produce.

Growth factors are special proteins that are naturally produced inside the brain and support the

survival of many types of brain cell. Alan and his team found that bone marrow stem cells produce growth factors that can protect nerve cells against the damage caused by toxic chemicals.

The team also tried to genetically modify the bone marrow stem cells to boost the production of these protective growth factors but were unsuccessful.

This project has helped shed new light on the potential of bone marrow stem cells, and the growth factors they produce, to protect the nerve cells affected in Parkinson's.

Alan comments:

"Bone marrow stem cells hold much potential to treat damaged brain cells. Anolmer group at Frenchay hospital are about to launch a clinical trial using these cells in people with multiple sclerosis – a condition that affects the nerves in the brain and spinal cord.

"I am also involved in a clinical trial investigating the potential benefit of infusing GDNF growth factor into the brains of people with Parkinson's. Armed with the evidence from these two trials we hope to explore bone marrow stem cell therapy as a possible future treatment for Parkinson's."

Reference

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.





RAISING FUNDS FOR RESEARCH

There are many different ways to raise the vital funds we need to support Parkinson's research. Here we look at a few different approaches to raising both awareness and funds to support the search for a cure.

Making a Racquet about Parkinson's

Tim Carroll explains how a network of younger people with Parkinson's, and their families and friends, are creating a stir in South London.

"A diagnosis of Parkinson's is a blow at the best of times. But being diagnosed at a younger age can be psychologically shattering. Think of Michael J Fox. His response, diagnosed at the age of 30, was to embark on a year-long, booze-fuelled state of denial.

"Around one in 20 people with Parkinson's are diagnosed before the age of 40. Many more are diagnosed in their 40s and 50s, as Kate Wellington, a young Australian living in South London, discovered when her father was diagnosed in his mid-50s.

"Kate's response was to set up what is now called the South London Younger Parkinson's Network or SLYPN.

"The group arranges regular social events and educational talks. Members learn about aspects of Parkinson's that apply to their age group. They can share their experiences and seek mutual support in a relaxed, informal environment among their contemporaries.

"The group is also becoming more focused on raising funds. Members, family and friends have taken part in dozens of 'fun runs', walks, cycle rides and marathons. There was a classical concert and upcoming events include a 'Making a Racquet about Parkinson's' tennis tournament, and a 310-mile cycle ride from London to Land's End.

"The focus is on research because Kate quickly found that better medication and diagnosis were common topics of conversation among the members. 'It lifts people's spirits to know that they could actually do something,' she says.

"Kate adds, 'I also saw an untapped opportunity in the members of the Network who are still working. They would be able to use their professional networks to raise awareness of the condition. I hoped that that, in turn, would trigger people to donate or choose Parkinson's research for their next fundraising activity.'

"That hope is being quickly realised. The group has already raised more than £20,000 for Parkinson's research and there's a lot more to come."

Find out more about the South London Younger Person's Network at www.slypn.org.uk

New charity of the year partnership with international science company LGC



Our corporate fundraising team is based at UK office in the business development department. The team manage any kind of national, company giving, such as sponsorship, payroll giving, gifts in kind and Charity of the Year opportunities like our 2014 partnership with one of the world's leading banks, Credit Suisse.

On World Parkinson's Day the corporate fundraising team were thrilled to announce that LGC Group had also chosen Parkinson's UK as their Charity of the Year for 2014.

LGC provide a wide range of scientific services to industries across the world and are the largest private provider of forensic science services to the criminal justice system. LGC operates out of 22 countries, so as well as employee fundraising this partnership is a fantastic opportunity to raise awareness of Parkinson's and the work of Parkinson's UK worldwide.

Lauren McGoldrick, Chair of the LGC Charity Fundraising Team, said:

"Many of our employees have a personal connection with Parkinson's and know the devastating effect it can have on lives, which is why Parkinson's UK was chosen.

"Our employees, both in the UK and overseas, will be fundraising specifically to support the Tracking Parkinson's research project, looking into the causes of Parkinson's and, ultimately, helping to find a cure."

Paul Jackson-Clark, our Director of Fundraising, said: "It seemed particularly apt, on World Parkinson's Day, to be announcing a partnership of this kind which will help to spread global awareness of Parkinson's research. We very much appreciate their support."

If you work for a company with a Charity of the Year opportunity, or perhaps know someone who does, please contact New Business and Sponsorship Manager, Ghalib Ullah on **020 7963 9333** or email gullah@parkinsons.org.uk



Raising funds doesn't have to be hard work. Why not hold a quiz and raise funds for Parkinson's research?

We've already done the hard work for you so all you need to do is request our quiz night pack:

On our website parkinsons.org.uk/quiznight

By email fundraising@parkinsons.org.uk

By phone **020 7963 9330** or **020 7963 9367**

Then follow our three easy steps:

- 1** Use the special posters from our pack to advertise your quiz. Get people's attention by decorating your venue with our balloons and beer mats. Then no one can forget why they're there!
- 2** Charge people either as a team or individually to take part. We'll give you all the questions you'll need—and the answers (which always helps!). Why not have a raffle too and help raise your fundraising total?
- 3** After the event, send your money to Parkinson's UK and give yourself a big pat on the back for making a difference.



THE PARKINSON'S UK BRAIN BANK

A CHECK LIST FOR DONORS

The Parkinson's UK Brain Bank's is the largest dedicated to Parkinson's based in the UK. The team supply to tissue free of charge to researchers studying Parkinson's all over the world.

There are currently 5,850 people on the brain donor register. When the time comes for those to make their donation, it can be a very overwhelming and difficult time for family and friends. This became clear to research supporter Meg one warm sunny day at a Parkinson's Carers' Support Group.

Julie, the wife of a retired minister with Parkinson's asked for help in sorting out her husband's brain donation request. Mixed feelings had resulted in her throwing away the paper work years ago but time had changed her feelings. However she was at a loss at how to deal with the whole process. 'Ask Meg, she'll know', a branch member chirpily announced—

I didn't know but I said I would find out as it was the least I could do for this carer.

Julie is a very able person but felt overwhelmed and unable to address the problem, as well as not having the time or energy, a position many carers may find themselves in. I agreed to contact the Brain Bank myself to find out exactly what needed to be done.

Using the information they provided I put together a simple check list with some simple steps to help donors and their families to be prepared when the time comes. This includes:

- informing your GP of the donor's wishes
- making sure you have the Brain Bank's emergency contact number to hand and that friends and family are aware of the need to ring them immediately when a donor passes away
- if the donor is admitted to hospital, making sure the hospital staff are aware of their wishes and that the emergency number and donor code are recorded in the hospital medical and nursing notes

Time is of the essence and it's vital to be organised and have the right paperwork in place so that the donor's wishes can be followed through.

Sadly, Julie put my check list to its final test earlier this year. Her comment was that it 'worked perfectly' and made everything so easy.

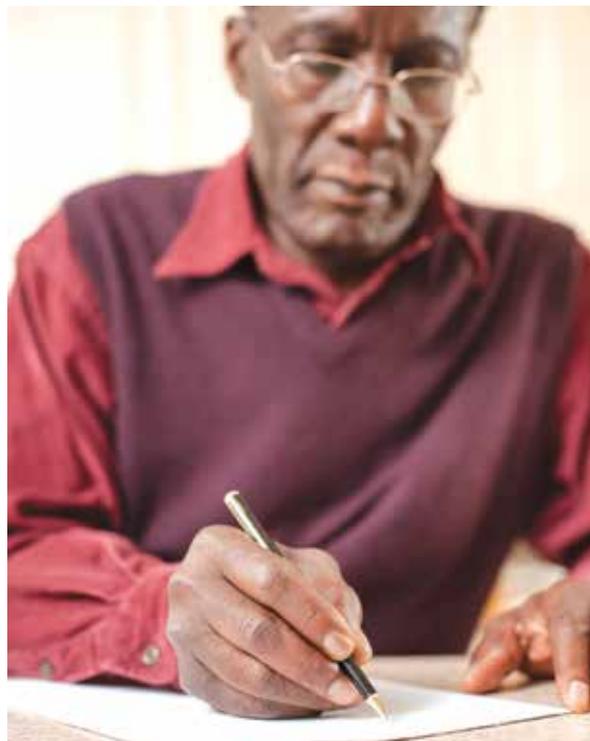
Professor David Dexter, Scientific Director of the Parkinson's UK Brain Bank comments:

"The Parkinson's UK Brain Bank team is on call 24 hours a day and we aim to organise and carry out donations as quickly and smoothly as possible.

"If you're a donor, the best way to help us is to make sure that your next of kin (or legal representative) and the healthcare professionals looking after you know of your wish to donate and understand what to do when the time comes.

"Remember to keep our 24 hour emergency contact number with you at all times – it should be on your donor card along with your personal donor number.

"And if you have any questions or concerns about the process you can always contact the team by phone or email."



Contact the Parkinson's UK Brain Bank

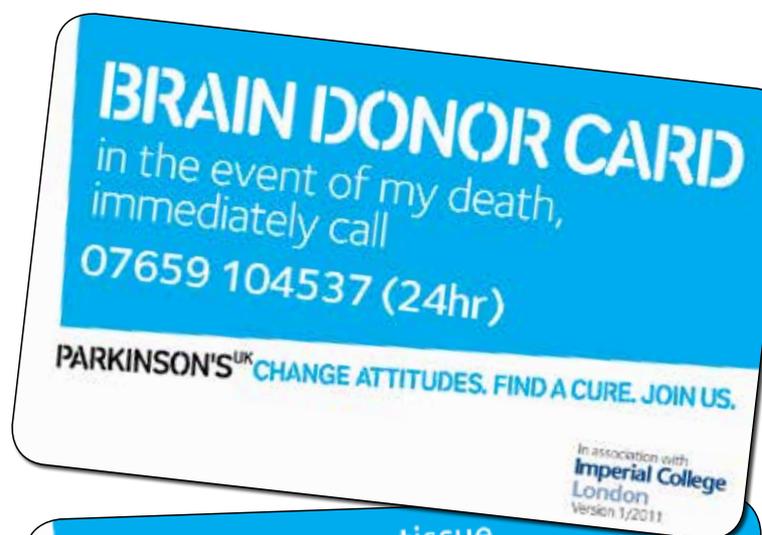
020 7594 9732

parkinsons.org.uk/brainbank

brainbank@imperial.ac.uk

Emergency number: **07659 104 537**

(please only use this number in the event of an emergency)



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
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CAN A GARBAGE STRIKE IN NERVE CELLS CAUSE PARKINSON'S?

Helle Bogetofte is a PhD student at the University of Southern Denmark. Her essay, describing research funded by Parkinson's UK was commended by the judges in the Europe PubMed Central "Access to Understanding" science writing competition.



Helle explains why she chose to write about Parkinson's UK funded research fellow Lynn Bedford's recent paper:

"Like the paper, the focus of my PhD project is to gain a better understanding of the

disease mechanisms leading to Parkinson's. This is of utmost importance for developing better treatments. I thought the paper and its surprising results were very fascinating and I hoped to share that feeling."

Here's an extract from Helle's entry:

Despite many years of research the exact cause of Parkinson's is still unknown.

One thing we know for certain is that clumps of protein and leftover material, called Lewy bodies, build-up inside the dopamine-producing nerve cells.

The major component of Lewy bodies is alpha-synuclein, a protein thought to be a primary cause of Parkinson's. The fact that mutations in the alpha-synuclein gene increase the risk of developing Parkinson's supports this theory.

The proteasome is part of the cells "garbage disposal" system and its job is to recycle damaged or broken proteins.

If unusable proteins are not disposed of, they clutter up the nerve cell and can form so-called 'pale bodies'. These are small precursors of Lewy bodies.

To further investigate the interaction between alpha-synuclein and proteasomes researchers from the University of Nottingham used genetically modified mice.

The DNA of the mice was changed so that certain genes were not produced.

The garbage disposal system in these mice therefore did not work properly and they quickly developed extensive nerve cell death and pale bodies comparable to the ones seen in people with Parkinson's.

You can read the full competition entry at: <http://a2ucomp.org/story/b>

Reference

Paine SML et al (2013) 'Pale body-like inclusion formation and neurodegeneration following depletion of 26S proteasomes in mouse brain neurones are independent of α -synuclein.' PLoS one 8.1: e54711.

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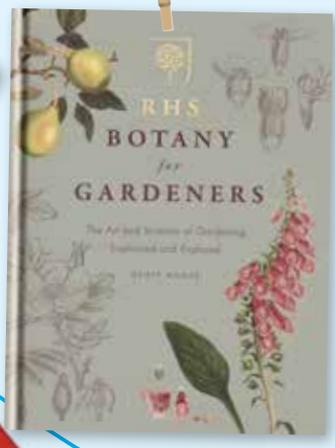


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