PROGRESS

The research magazine of Parkinson's UK | Autumn 2017

Getting to grips with genetics

Why our genes matter

DRUG HURDLES
What happens after the clinical trial?

GROWTH FACTORS
The key to new treatments?

DESIGNING NEW DRUGS FOR PARKINSON'S
The science of better drugs

WELCOME

Ameila Hursey
Senior Research Participation Officer
Parkinson's UK

It was during my Masters degree in Cognitive Neuropsychology that I discovered my interest in neurodegeneration.

After completing my degree I realised how little I knew and wanted time to learn more. I decided the best way to do this was to enter the practical research world.

Delivering cutting-edge research in the NHS was one of the most exciting and nerve-racking job starts I've ever had, and was a very steep learning curve – the truth is research happens in an entirely different language!

From the moment I met my first research participants I knew Parkinson's research was going to be my future. Not only were all the people I met incredibly keen to find out more about Parkinson's, but they also had the desire to try to help others in the future.

I was very fortunate to work with a brilliant consultant who taught me the complexities of Parkinson's as a condition, but also how varied his patients were.

Each person's journey with Parkinson's is unique, and sharing research opportunities to support these journeys was key. After five years, I was ready for a new challenge and, luckily, found my current role of Senior Research Participation Officer at Parkinson's UK.

This role was created to bring a focus to, and drive forward, how we can help people find opportunities to take part in Parkinson's research.

So, two years in, we've helped more people than ever find out about studies they can take part in, and we're being approached by more researchers year on year about sharing their research. And we have more exciting projects in the pipeline.

Many of you have been part of this success. And for those of you who have yet to do so, please join our Research Support Network at **parkinsons.org.uk/rsn** so we can share with you all the exciting moves we're making to improve opportunities to take part in Parkinson's research. ■

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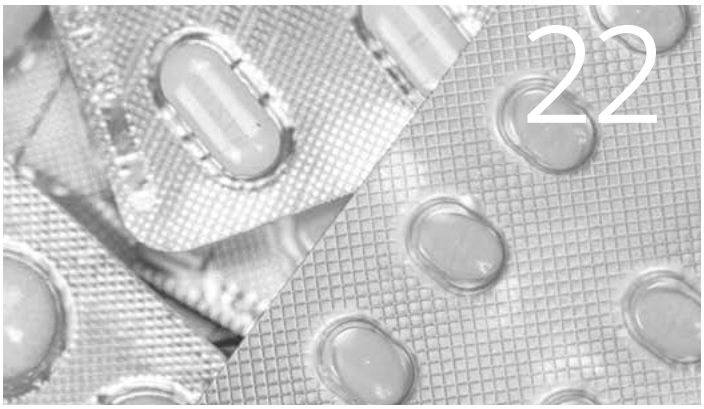
ON THE COVER

Image depicting genetic data. Scientists are becoming more aware of the importance of genetics in Parkinson's.

NEWS



FEATURES

ALSO IN THIS ISSUE...

Progress is our free, twice-yearly magazine on the latest research into Parkinson's. You can find previous issues and subscribe to *Progress* on our website at **parkinsons.org.uk/progress** or by contacting the Research team directly by email **reseach@parkinsons.org.uk** or phone on **020 7936 9313**.

Asthma drugs could decrease risk of Parkinson's

Researchers have discovered that a class of drug commonly used to treat asthma could lower the risk of Parkinson's.

Results from an international study, published in the journal *Science*, found drugs that activate proteins called beta-adrenoceptors protect brain cells in a mouse model of Parkinson's.

Building on this, the study also showed that prescription asthma drugs, which target these beta-adrenoceptors proteins, reduced the risk of Parkinson's by half.

Professor David Dexter, Deputy Director of Research at Parkinson's UK, explains: "These drugs appear to protect the cells destroyed in Parkinson's, and produce small but significant changes in risk, which can only be seen when studying many thousands of people."

NEWS ROUNDUP

The role of the immune system in Parkinson's

New research suggests that the immune system plays an important role in the progression of Parkinson's.

A team of researchers in the US compared immune cells from people with Parkinson's and healthy participants. The results show that the condition may cause an autoimmune response, which means that the immune system mistakenly attacks and damages healthy cells in the body.

The researchers suggest that changes in the alpha-synuclein protein, which is known to be involved in Parkinson's, could cause the immune system to start attacking dopamine-producing brain cells.

Professor David Dexter comments: "We still need to understand more about how the immune system may be involved in the complex chain of events that contribute to Parkinson's, but ultimately this presents an exciting new avenue to explore to help develop new treatments that may be able to slow or stop the condition in its tracks."

Diabetes drug may have potential

Scientists have shared promising results of a phase 2 clinical trial of the type 2 diabetes drug exenatide in people with Parkinson's.

The trial involved 60 people with moderate Parkinson's. Half received exenatide once a week for 48 weeks, while the other half (the placebo group) received a dummy injection.

At the end of the study, those who received exenatide had a slight but significant improvement in movement symptoms when measured off their regular Parkinson's medication.

In comparison, participants who received the placebo worsened slightly over the course of the study.

Professor David Dexter commented: "These interesting results build upon an earlier, smaller trial and offer further encouragement that diabetes treatments could provide new treatments for Parkinson's in the future.

"Although these results show promise they don't provide sufficient evidence for exenatide to become an approved treatment at this stage.

"Repurposing existing drugs in this way could allow treatments to be made available more quickly than starting from scratch to develop entirely new medication."

Replacing brain cells in Parkinson's

Recent studies have made significant strides towards cell transplant therapies for Parkinson's.

Results published by a Japanese team of researchers show that dopamine-producing brain cells made from skin and blood cells can be successfully transplanted into the brain of a primate model of Parkinson's.

Over the next 12 months, these cells integrated into the brain and gradually reduced movement symptoms.

The team was also able to use the same principles of matching for organ donation to match dopamine-producing brain cells to the primate immune system to avoid transplant rejection.

Commenting on the papers, Professor David Dexter says: "These studies represent an important development in the field of transplantation as a potential treatment for Parkinson's."

READ OUR BLOG
Find out the latest research news, and go behind the headlines, on our new research blog **medium.com/parkinsons-uk** ■

Getting to grips with GENETICS

We're still building a picture of why people get Parkinson's, but understanding the pieces of this complex puzzle will help us unlock better treatments and, one day, a cure.

Scientists are becoming more aware of the importance of genetics in Parkinson's. Here we find out the latest research.

It is 20 years since researchers uncovered the first genetic variant linked to Parkinson's. In 1997, the discovery of a family in Italy who had an inherited form of the condition, caused by a single genetic change, sent shockwaves through the research community.

Since that defining moment, a steady stream of new genetic discoveries has transformed our understanding of the condition. But does that mean people should worry about passing Parkinson's on to their children or consider genetic testing?

How our genes make us who we are

The human genome contains 23,000 genes – because we have two copies of each that's 46,000 in total. These genes act as the blueprint that makes us.

We all share the same basic blueprint but there are subtle variations that make each individual's genome unique. These differences in our genes are what make us all different.

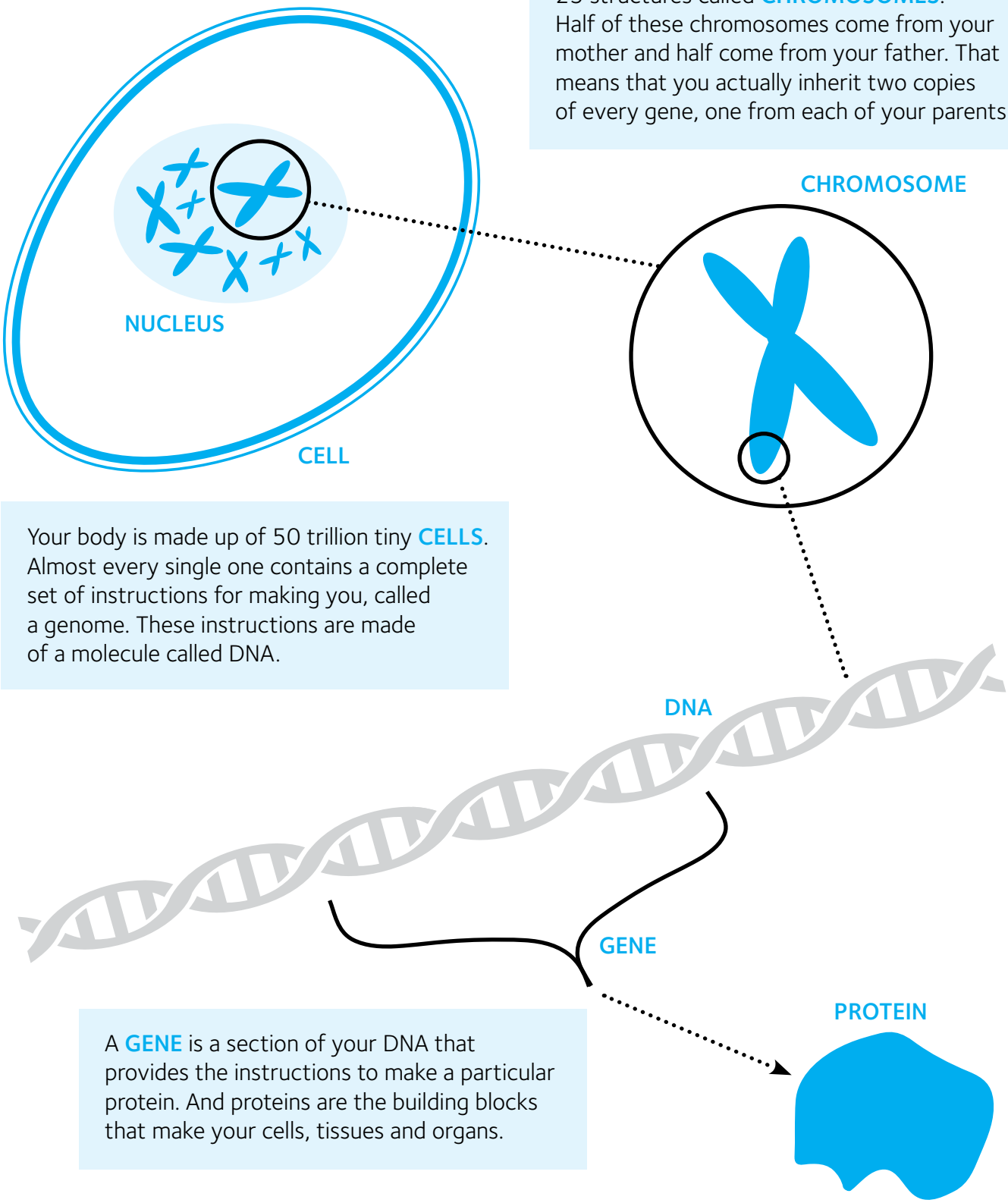
Most of these variations are harmless but sometimes a gene has a difference that means the protein it produces does not work as well as it should. These genetic differences are called variants or mutations and can increase the risk of particular illnesses.

Illnesses that are directly caused by a change in a single gene are very rare. Like most of our characteristics, our health is generally the result of a mixture of different genes coupled with other factors like diet and exercise.

What's in a gene?

Our diagram below explains what a gene is.

Inside your cells your DNA is organised into 23 structures called **CHROMOSOMES**. Half of these chromosomes come from your mother and half come from your father. That means that you actually inherit two copies of every gene, one from each of your parents.



Your body is made up of 50 trillion tiny **CELLS**. Almost every single one contains a complete set of instructions for making you, called a genome. These instructions are made of a molecule called DNA.

A **GENE** is a section of your DNA that provides the instructions to make a particular protein. And proteins are the building blocks that make your cells, tissues and organs.

CASE STUDY: This story comes from a lady who wishes not to be named. We have called her Ann. In 2011, Ann took part in online genetic testing and discovered that she has a variation in the LRRK2 gene called G2019S. Here Ann describes how she came to terms with this news and the effect it's had on her family.

I was 53 when I was diagnosed following three years of visits to the doctors, so definitely at the younger end of the spectrum. But I didn't know of anyone else in the family who had it so didn't really consider the possibility that genetics could be involved.

From almost day one I was determined to get involved in research. I wanted to help find answers and better treatments, if not for my generation then for the next.

I knew I would never forgive myself if in the future anyone in my family was diagnosed with Parkinson's and I had not helped where I could.

In 2011, a genetic testing company was advertising for people with Parkinson's because they were collecting genetic data for research purposes.

Quite a few other people I knew with the condition were doing it and I thought why not, if would help advance research?

Taking part was easy. At the click of a button I signed up and they sent me a kit in the post. I just had to spit into a tube and post it back to them and six weeks later I got an email to tell me my results were displayed on their website. Looking at my results on the screen my eyes were instantly drawn to the words 'elevated risk of Parkinson's'. I quickly clicked on the more detailed findings which said I was a carrier of a genetic mutation in the LRRK2 gene called G2019S. The shock of reading those words is difficult to explain. I just hadn't considered this to be a possibility.

It dawned on me that these results weren't just important to me but may also have implications for my children and siblings. I panicked and shut down the computer.

For a long time I tried not to think about it but eventually I read the report again more carefully then spent quite a lot of time Googling the LRRK2 gene and my particular variant, G2019S, to try and understand what it all meant. I discovered that I had a 50% chance of passing the variant on to my two sons and that there was also a chance my brother or sister could have inherited it.

The first person I told was my husband, who was incredibly supportive. We spent a long time worrying about how best to tell our sons – who by this time both had children of their own. When we eventually plucked up the courage they were both very understanding and asked lots of questions, including about whether they could take part in research themselves.

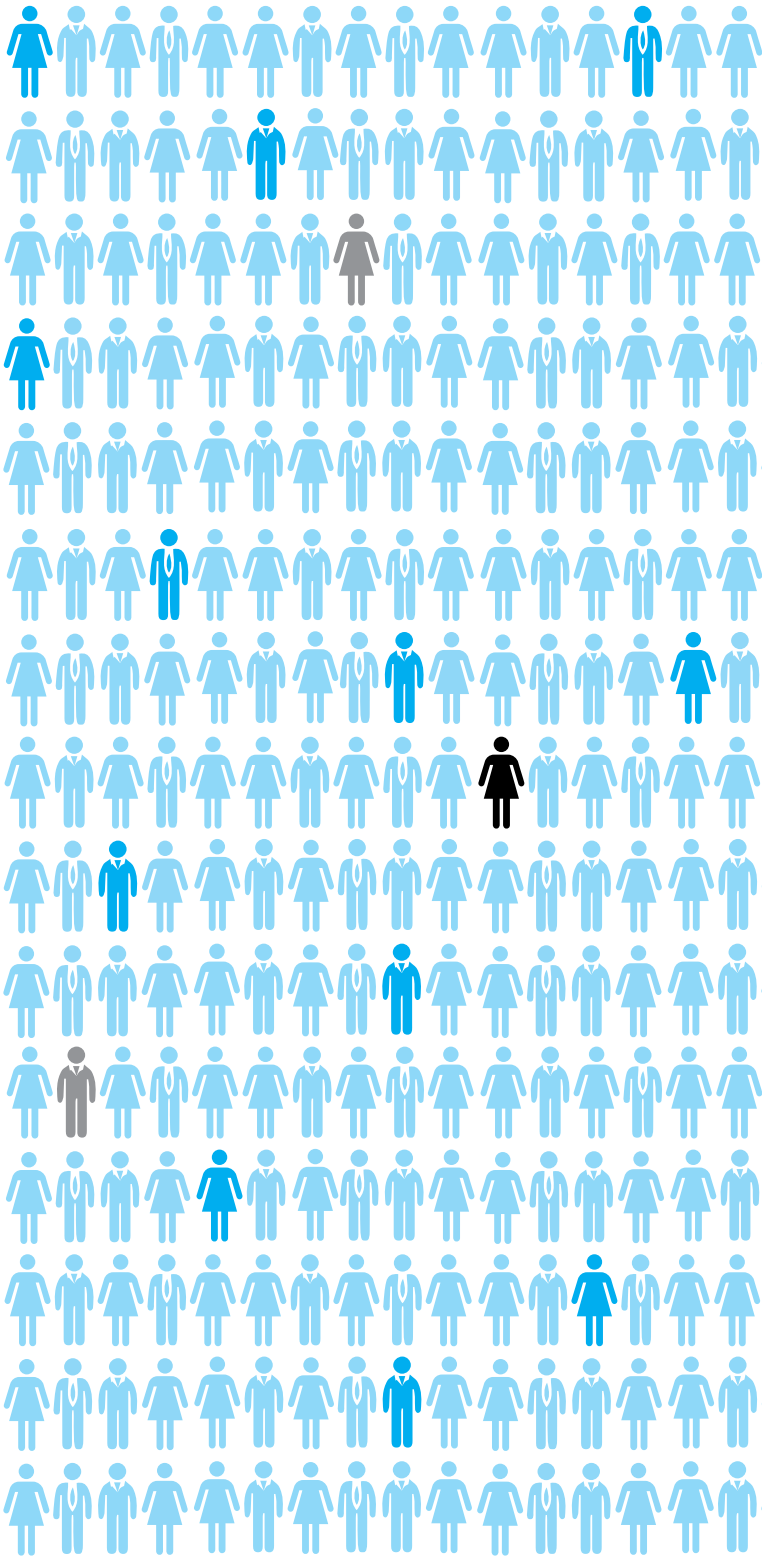
I have since told my brother and sister and they've been great too, although they haven't yet told their own children.

Looking back six years on I am glad that I know that I carry this LRRK2 variant. For one thing, I now know that specific drugs targeting LRRK2 are being developed and I may be able to participate in clinical trials.

My one regret is jumping in to the testing without discussing it with my family first. If I could go back in time I would definitely change that. ■

Parkinson's and genes – what we know so far

Parkinson's is an 'idiopathic' condition, which means that it usually isn't connected to any particular cause. However, for a small minority, Parkinson's can be caused by changes in single genes. For other people, genetic variations can play a part in increasing the risk of the condition. It's a complex and changing picture but, so far, changes in around 10 different genes have been linked to different effects on the risk of Parkinson's. Let's take a closer look.



Very rare changes with strong effects

Around 1 in 1,000 people with Parkinson's carry a very rare change in a gene that causes the condition directly. Changes have been identified in genes including alpha-synuclein, parkin, PINK1, DJ-1, ATP13A2, PLA2G6, FBXO7 and VPS35, and often cause symptoms to develop at a young age.

Rare changes with medium effects

A change in the LRRK2 gene known as G2019S is probably the most common genetic variant linked to Parkinson's. In the UK, around 1 in 100 people with Parkinson's carry it. It's more common in North African and Ashkenazi Jewish populations. People who carry this variant may develop the condition later in life and have around a 70% chance of being diagnosed by the age of 80.

More common changes with weak effects

As well as single genetic changes that directly cause the condition, we now know that there are also changes that increase risk. These changes are more common but their effects are more subtle. Carrying one of them means you are more likely to develop Parkinson's but often only very slightly. The most common of these changes was discovered in 2004 when doctors noticed that patients with a rare genetic disorder called Gaucher's disease often had relatives with Parkinson's. Gaucher's is caused by inheriting two faulty copies of the GBA gene, one from each parent. Research has shown that people who carry just one faulty copy of GBA are more likely to develop Parkinson's.

Ask the **expert**

Professor Huw Morris
Consultant Neurologist and Professor of Clinical Neuroscience at the Royal Free Hospital, National Hospital for Neurology and Neurosurgery and UCL Institute of Neurology

Huw is an international expert in Parkinson's and is currently leading several major research projects to learn more about the genetic basis of the condition.

Is genetic testing available on the NHS?

Yes, genetic testing is available but the directly inherited genetic forms of Parkinson's are very rare and there are currently no treatments that can prevent the condition. We would usually consider genetic testing for people who develop the condition early (before the age of 40) or who have a strong family history, with several people in the family affected.

If you are considering genetic testing it's important that you fully understand what it means before it's carried out. Some people may find it helpful to talk to a genetics specialist (a doctor or a counsellor) before proceeding with genetic testing. We would recommend that all patients and or families with a positive genetic test have access to genetic counselling to help them understand the possible implications.

Is it possible to be involved in genetic research?

Yes, absolutely. I believe we have a huge amount more to learn about the genetics of Parkinson's, including genetic variants that we haven't discovered yet, and there are several research studies exploring this that need people to participate.

We set up the Parkinson's Families Project to search for the next pieces in this complex and ever-expanding puzzle. In this project we're looking for people who developed symptoms before the age of 45 and or who have a family history of the condition. We're also keen to involve their close family members so that we can compare the genetic makeup of people with and without Parkinson's. Participants donate a blood sample, provide a medical history and complete some questionnaires. We can then look for new genes that may be important in Parkinson's.

As with many research studies, participants can choose to be notified if genetic testing may be relevant to them or their family. They can then have follow-up NHS genetic testing, if they wish.

How concerned should I be if Parkinson's runs in my family?

Parkinson's is a relatively common condition, so it's fairly common for people with Parkinson's to have one other member of their family who is also affected by the condition. But if your family looks like image 1 (below left) the likelihood of you carrying one of the gene variants we currently know cause inherited Parkinson's is still low – around 1 in 50. It's less common for Parkinson's to affect several members of the same family and this would increase the chance of having a single gene cause. But even if your family looks like image 2 (below right) you still only have around a 1 in 10 chance of carrying one of the known genetic variants. There are likely to be more genetic changes for Parkinson's that have not yet been identified, so this may change over the coming years.

Image 1

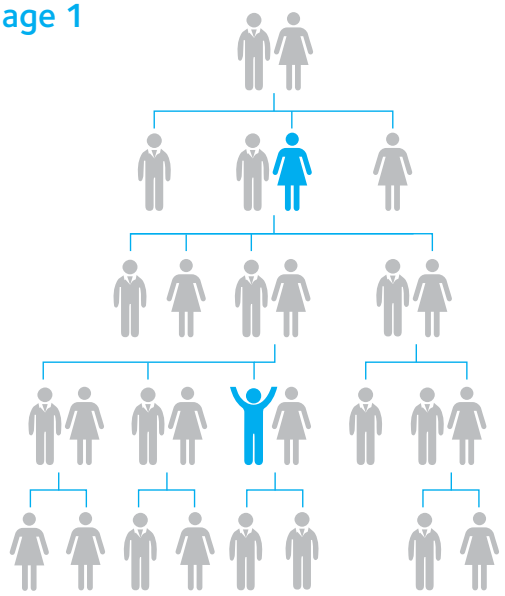
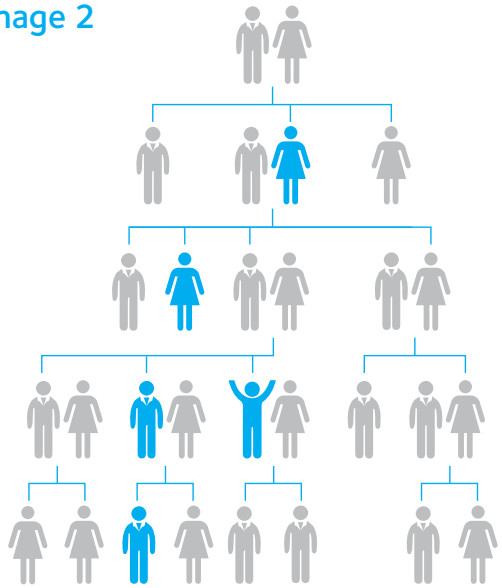


Image 2



Why is genetic research so important?

The reason I'm so passionate about genetics is that I believe that understanding the genetic variants involved in Parkinson's will lead us directly to new treatments. Many of the variations we've identified are involved in key processes and activities inside brain cells and have helped us understand more about what goes wrong with them in Parkinson's. Crucially, we think many of these insights will hold true for everyone with Parkinson's, not just those with these rare genetic changes, and this knowledge is already leading to the development of treatments that are showing significant promise. Another way in which I believe that genetics will improve life for people with Parkinson's in the future is by helping us to provide much more personalised treatments to individuals. Parkinson's is a very variable condition. People develop it at different ages, experience different symptoms, and respond differently to treatments. I think genetics may help us understand this better, and hopefully one day we will be able to look at a person's genetics to help us choose the right treatments for that individual.

TAKE PART IN GENETIC RESEARCH

Find a list of studies currently looking for participants at **parkinsons.org.uk/takepartinresearch**

Could we treat Parkinson's naturally?

We're often asked if natural forms of levodopa are the answer to side effect free treatment. Here we look at the evidence.

Levodopa – the most commonly prescribed drug for Parkinson's – works by replacing the dopamine that the brain is no longer making. It's a chemical building block that the body converts into dopamine, and the 'active ingredient' that is found in conventional Parkinson's medications.

Manmade vs natural

The levodopa in our medications is manmade and the chemical is identical to the levodopa our bodies naturally make. But levodopa can also be found in nature. Some animals and plants make the chemical, including a plant called mucuna pruriens.

The active chemical in the plant is the same that's in prescription Parkinson's medication, so it would have the same benefits but also the same side effects. However, unlike with Parkinson's medications, it's hard to control the amount of levodopa you receive when you use natural sources. This could make it hard to manage symptoms in a consistent way. But this isn't the only downside to natural levodopa.

Enhancing levodopa

Our bodies contain proteins that break down levodopa. This means that much of the drug (around 60 to 80%) is deactivated before it even has the chance to get into the brain.

To counteract this, today's medications for Parkinson's combine levodopa with other drugs – such as carbidopa and benserazide – that block this breakdown. Combination drugs mean lower doses of levodopa can be taken while still getting the same effect, which means fewer side effects and better symptom control.

But levodopa from mucuna pruriens isn't combined with these levodopa-enhancing drugs. So if you could take the same dose, less of the levodopa would get into the brain. And taking more to compensate would likely result in more side effects, such as nausea and constipation.

Protecting cells?

Some researchers have been investigating other properties of mucuna pruriens. We know that levodopa does nothing to prevent or slow the loss of brain cells in Parkinson's. But, in some cell and animal models of the condition, mucuna pruriens appears to protect cells. Researchers have suggested that mucuna pruriens may have anti inflammatory and antioxidant properties. While we don't fully understand what else is in these seeds, some point towards an ingredient in mucuna called coenzyme Q10 as being the source of these potentially protective effects. Various studies testing this supplement have shown that it seems to be safe, even at high doses, but there's still no evidence of any tangible benefit.

What's next?

We know that the current treatments for Parkinson's are not good enough, and unfortunately there is a lack of evidence that natural forms of levodopa are better than conventional medications. What we need are better drugs with fewer side effects and new treatments that slow or stop the progression of Parkinson's. ■

At Parkinson's UK we fund research into all aspects of the condition – from developing better treatments and a cure to improving life for those affected. Over the next few pages we highlight four of our newest research projects worth nearly £200,000.

NEW RESEARCH

Clearing toxic iron

Who? Dr Charareh Pourzand
Where? University of Bath
What? £50,000 over 9 months

Iron is essential for the normal function of the body and brain.

To stay healthy, cells need to have the right amount of iron – too little or too much means they struggle to work properly. Iron can also exist in different forms, some of which can be toxic.

Higher levels of iron are found in the brain areas affected in Parkinson's. And research suggests that toxic forms of iron may be particularly damaging to mitochondria – the energy-producing batteries inside our cells.

'Iron chelators' trap and remove excess iron. Iron-chelating medications are already used to treat other conditions, but existing drugs eliminate iron from everywhere.

This can lead to harmful iron deficiency. Dr Pourzand believes it may be possible to only remove toxic iron.

"Our team has developed a number of specially designed molecules that home in on mitochondria and are capable of detecting toxic forms of iron. The next step is making new compounds that can also neutralise harmful iron by binding to and removing it."
Dr Charareh Pourzand

Using analogies to overcome freezing

Who? Dr William Young
Where? Brunel University
What? £35,536 over 14 months

Many people with Parkinson's experience freezing while walking – when they stop suddenly and feel as though their feet are stuck to the ground.

Freezing episodes can create feelings of embarrassment and lead to anxiety, especially if they happen in public.

Analogy learning involves turning a sequence of movements into a simple analogy or metaphor, such as following footsteps in the sand.

The technique was originally developed to learn skills for sports, as analogies may be easier to follow when under pressure.

"With the help of a project advisory group – made up of people with Parkinson's and healthcare professionals including physiotherapists – we're hoping to develop and test analogies to help people adjust their balance and take their first step after freezing."
Dr William Young

FREEZING AND PARKINSON'S
Find out more and download or order a free information sheet from our website at **parkinsons.org.uk/freezing**

Could SUMO proteins be the key to better treatments?

Who? Professor Jeremy Henley and Dr Kevin Wilkinson
Where? University of Bristol
What? £64,711 over 12 months

Mitochondria are the tiny batteries inside cells that provide the energy they need to survive and function. Research has shown that mitochondria inside the nerve cells affected in Parkinson's become damaged, but we don't fully understand why.

"Our research suggests a process called SUMOylation may play a pivotal role in keeping mitochondria healthy. SUMO is a protein tag that cells stick on to other proteins to change their function. We're using donated brain tissue, cell and animal models to investigate how SUMOylation regulates key proteins that are involved in deciding the fate of mitochondria."
Professor Jeremy Henley

In heathy cells, mitochondria go through a constant cycle of joining together and breaking apart. This allows healthy mitochondria to repair partially damaged ones, and badly damaged mitochondria to be tagged for removal. But in conditions like Parkinson's this process can become disrupted, leading to a build-up of damaged mitochondria.

This project could reveal vital clues about how we can harness SUMOylation to protect mitochondria in Parkinson's.

Using genetics to find new drugs for Parkinson's

Who? Professor Nigel Williams
Where? Cardiff University
What? £45,903 over 12 months

Although fewer than 5% of people with Parkinson's have a directly inherited form of the condition, research has uncovered a number of subtle genetic changes that slightly increase a person's risk.

"We're making a database of all the known drugs that act upon specific genes and or pathways inside cells. We plan to use specialist mathematical tools to cross-reference the database with our knowledge of the genetics of Parkinson's. We hope this will identify groups of drugs with potential to become new and better treatments."
Professor Nigel Williams

Our understanding about how genetic changes affect the way cells work, and potentially contribute to the development of Parkinson's, is increasing.

This means researchers can look for drugs that target the relevant pathways and processes inside cells. ■

How do we SP£ND YOUR MON£Y?

We are the largest charitable funder of Parkinson's research in Europe and have so far invested more than £80million in groundbreaking projects. Our investment has led to improvements in diagnosis, treatments, care and services for people living with the condition. But we still urgently need to do more to develop better treatments in years, not decades.

Our achievements

Here are some of our major achievements since we were founded in 1969:

1970

1977 Trials funded by the charity show that the drug selegiline helps levodopa work better for longer.

1980

1980s Our researchers identify increased iron levels and defects in the tiny energy-producing batteries called mitochondria in the brain cells of people with Parkinson's.

1988 Trials funded by the charity show that the drug apomorphine can be helpful in the later stages of Parkinson's.

1990

2000 We support some of the first pioneering brain cell transplantation studies for Parkinson's, which show the promise of this new approach.

2000

2003 Initial trials of GDNF as a potential treatment produce promising results.

2004 Our researchers discover two of the most important genes – LRRK2 and PINK1 – that are linked to Parkinson's.

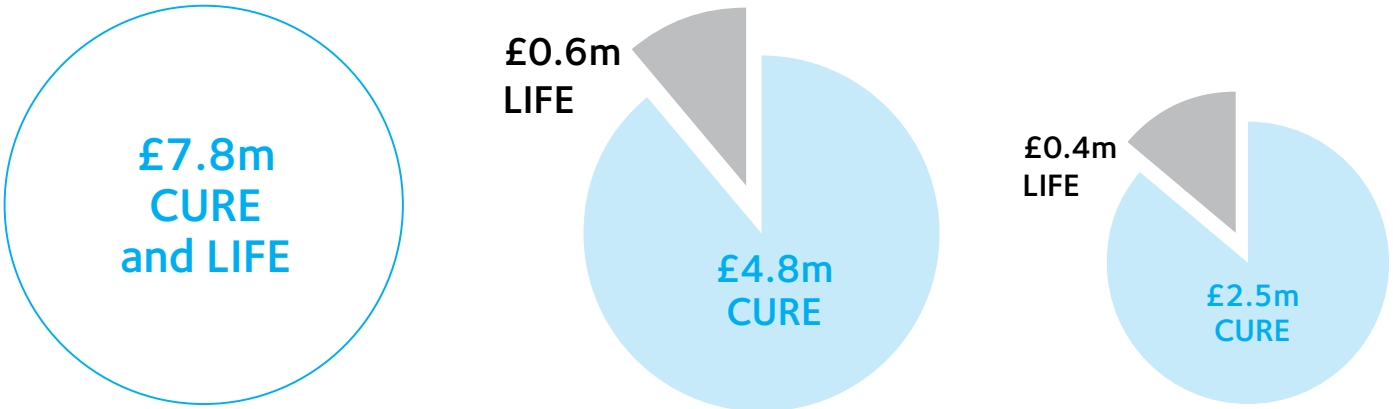
2010

2016 A phase 2 trial funded by the charity demonstrates that a common dementia drug – rivastigmine – could help to prevent falls.

Our current research

Since the start of our strategic period in 2015, we've invested £16million in research. Here we show how this is spread across the research pipeline, and how much is supporting projects aimed at developing a cure, compared to those projects seeking to improve life for people with Parkinson's.

SCIENTIFIC DISCOVERIES DEVELOPING TREATMENTS CLINICAL TRIALS



What do we mean by 'cure'?

Projects and programmes that work towards treatments and strategies that have the potential to slow, stop, reverse or prevent Parkinson's. This includes developing new treatments and improving diagnosis and monitoring of the condition.

What do we mean by 'life'?

Projects and programmes that will deliver treatments and strategies that improve symptoms and quality of life for people with Parkinson's. This includes better therapies and management for issues such as anxiety, thinking and memory problems and falls.

Current key projects

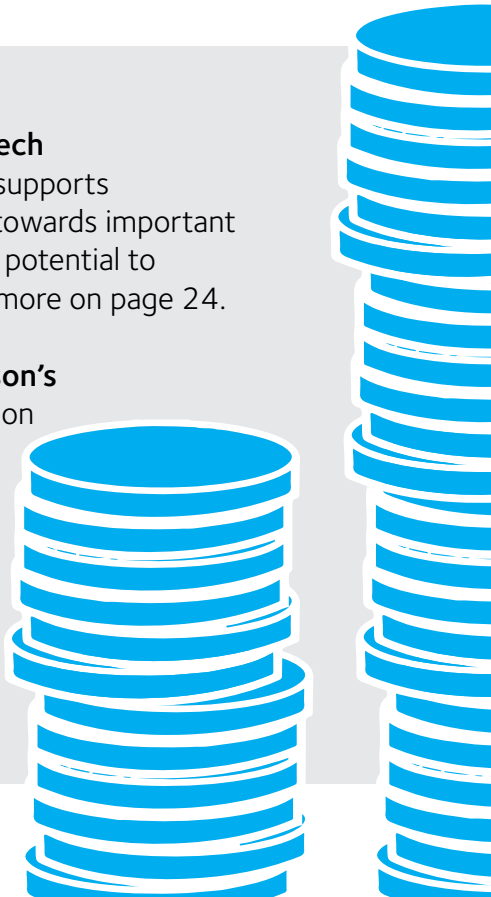
Oxford Parkinson's Disease Centre
Launched in 2010, the centre is now a world-leading research centre focused on improving diagnosis and identifying new targets for drug development.

Tracking Parkinson's
The world's largest in-depth study of Parkinson's began in 2012. We're following almost 3,000 individuals to help understand variation and identify biomarkers.

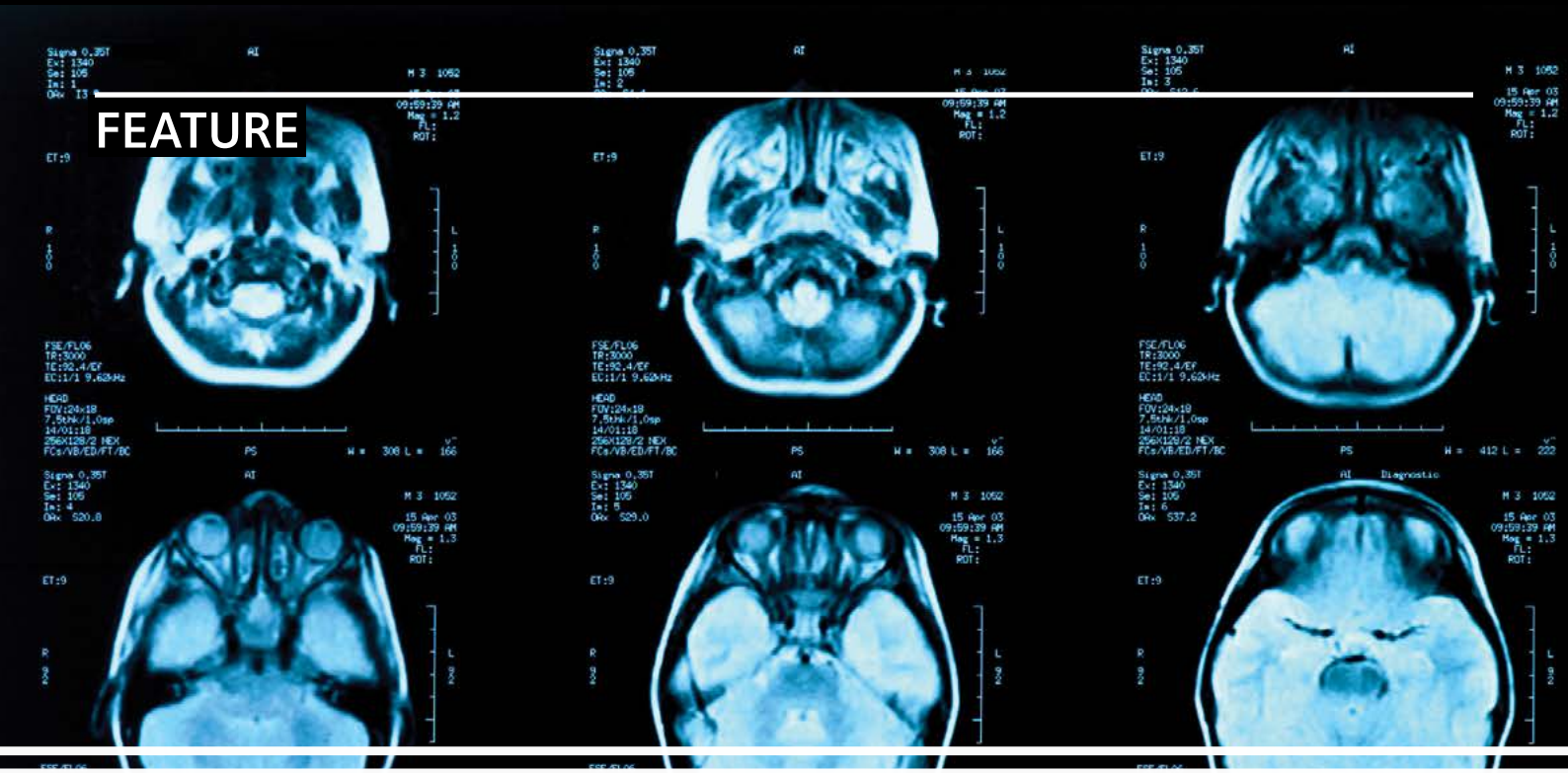
The GDNF trial
This groundbreaking clinical trial kicked off in 2013 and full results are expected later this year.

Parkinson's Virtual Biotech
This innovative initiative supports projects that are driving towards important new treatments with the potential to transform lives. Find out more on page 24.

Critical Path for Parkinson's
This is a global collaboration of charities, companies and universities working to improve clinical trials so they're smarter, more likely to succeed and meet regulatory approvals. ■

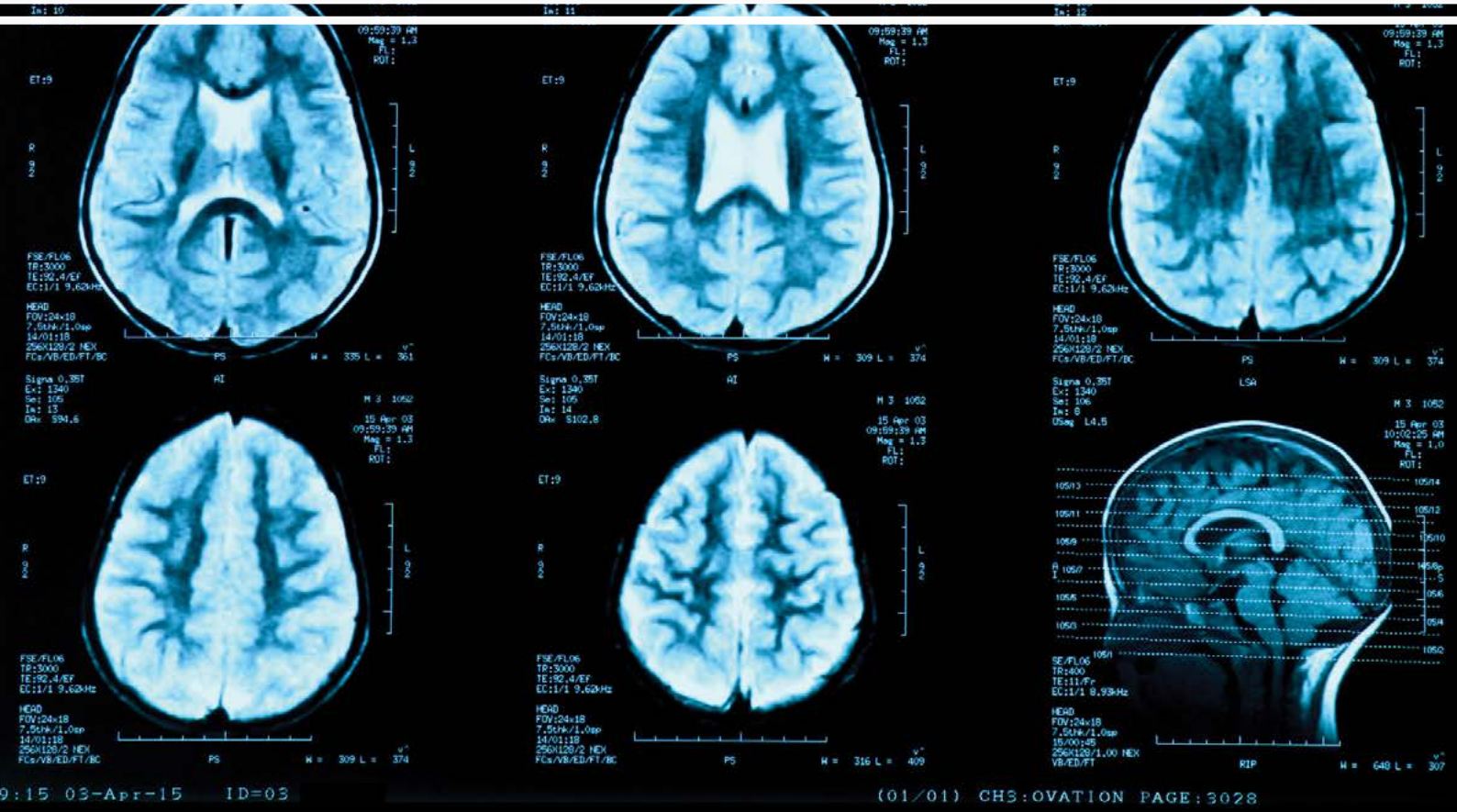


FEATURE



Could growth factors be the key to new treatments for Parkinson's?

Growth factors are molecules that support the development, growth and survival of our bodies and our brains. Their extraordinary properties make them an exciting prospect for developing new treatments that could help repair the damage caused in Parkinson's. We take a look at the story so far.



The first growth factor was identified over 60 years ago when an Italian scientist, Rita Levi-Montalcini, experimented with transferring pieces of cancerous tumours into chick embryos.

She found that it caused nerve cells to start growing like a halo around the tumour cells – it was unlike anything she had seen before.

The way the nerve cells were growing suggested to Levi-Montalcini that the tumour was releasing a substance that was stimulating the growth of nerves.

She then worked with Stanley Cohen to isolate this substance, which they later named Nerve Growth Factor (NGF). This work was recognised 30 years later when Levi-Montalcini and Cohen were awarded the 1986 Nobel Prize for physiology and medicine.

NGF is now known to be involved in a huge range of vital biological processes, including the regulation of the immune system, the survival of pancreatic cells and even in the biological basis of romantic love.

Since this discovery, an expanding family of growth factors has been identified. And research has shown that a whole range of these factors seem to be crucial for the growth, development and survival of the brain cells that are affected in Parkinson's, including:

1. **GDNF** (glial cell line derived neurotrophic factor) and its close cousin neurturin
2. **BDNF** (brain derived neurotrophic factor)
3. **CDNF** (cerebral dopamine neurotrophic factor)
4. **MANF** (mesencephalic astrocyte derived neurotrophic factor)

Growth factors are often described as fertilisers for the brain because of their abilities to nourish and revive brain cells, and to stimulate new growth. These properties have made them a target for the development of new treatments for Parkinson's.

What are growth factors?

Growth factors are a family of remarkable molecules that play a range of important roles in our bodies.

These multi-talented molecules play critical roles in the development of our brains during childhood and the ability of our brains to change and adapt during adulthood.

They ensure that our nervous systems are wired up properly by guiding cells to grow in the right directions and connect correctly with other cells.

If we can boost the levels of some of these key molecules in the brain areas that are affected in the condition, perhaps they could prevent further damage or loss of cells, or even help struggling cells to regrow.

The challenges of delivery

Unfortunately it's not quite as simple as popping these molecules into a pill. They are usually large and complex proteins, which means that getting them to where they need to be, deep inside the brain, is a major challenge.

Different approaches have been tried to overcome this hurdle with varying levels of success:

1 SURGERY

The first and most direct approach is to insert tubes into the brain and then pump the growth factor straight to the cells that need it.

This approach has been tried several times with GDNF in people with Parkinson's but has produced mixed results. However, the variation in these results may have been, at least partially, due to differences in the way it was delivered.

The most recent clinical trial of GDNF in Parkinson's, which finished in early 2017, used a specially

designed device involving four separate tubes. These tubes were carefully placed into participants' brains using robot-assisted surgery. Once in place, participants visited the hospital every four weeks to have GDNF pumped directly through the tubes and into their brains.

Results are coming soon – but encouragingly this approach appears to be safe and acceptable to people with Parkinson's, despite the huge commitment it involves.

2 GENE THERAPY

Other studies have tried another route called gene therapy. In this approach, rather than pumping the growth factor directly into the brain through tubes, the idea is to use genetic instructions to encourage brain cells to start making the growth factors themselves.

Scientists have done this by engineering viruses to carry the key genetic instructions required for manufacturing these growth factors. The virus can then sneak into target brain cells and insert the instructions.

The main advantage of this approach is its potential to produce a longer lasting effect.

Individuals would have an operation to have the gene therapy carefully injected into the right brain areas, but then their brain cells should start producing growth factors naturally without the need for repeat doses.

This innovative approach has already been used by a company called Ceregene. They developed a gene therapy called CERE-120 to insert the genes required for cells to produce neurturin (the close cousin of GDNF). CERE-120 initially showed promise in early stage clinical trials but sadly failed to deliver the hoped-for benefit in later studies.

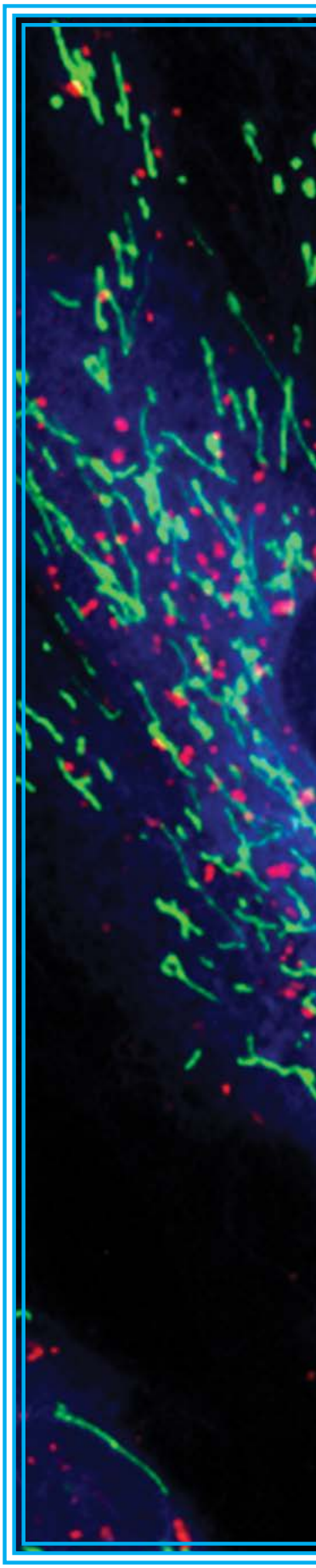
Is there another way?

Both of the previous approaches involve complex brain surgery to get growth factors to where they are needed, but could there be another, less invasive, way to boost the levels of growth factors in the brain?

One possible way may be a little unexpected: exercise. Studies have shown that physical exercise triggers an increase in the natural production of BDNF.

A recent review suggests that every time we exercise it stimulates our bodies to produce a 'dose' of BDNF, and that regular exercise helps to increase this 'dose' over time.
As a result, there are now studies under way exploring whether exercise regimes can help to improve memory and thinking, and how exercise could be harnessed as a tool to prevent dementia.

Researchers are also investigating if drugs can stimulate the brain to produce more growth factors. One recent attempt was a pill called Cogane that was designed to promote the release of both GDNF and BDNF. Despite showing exciting promise in lab studies, Cogane ultimately failed to deliver the same beneficial effects when it was tested in people with Parkinson's. Despite this disappointment, there are ongoing efforts to develop these types of therapies.



What does the future hold?

Despite the challenges of delivering them to the right parts of the brain and some setbacks in clinical trials in recent years, growth factors still hold genuinely exciting promise for Parkinson's. And there are several studies currently under way to keep an eye on.

A gene therapy approach to GDNF

This study is testing a newly developed form of gene therapy that aims to reprogramme brain cells to produce their own GDNF.

The study is taking place in the US and will include 24 patients divided into four groups who will receive different doses of the therapy.

The participants will then be followed closely for five years to assess the long-term safety and effectiveness of this experimental treatment. Read about GDNF at **parkinsons.org.uk/gdnf**

The first trial of CDNF for Parkinson's

In December 2016, the Finnish company Herantis Pharma announced that they had successfully secured funding to carry out the first clinical trial using CDNF in people with Parkinson's. The new trial will use the same delivery method that was developed for the recent GDNF trial in the UK.

A combined therapy to stimulate BDNF

Finally, a research team in New York is interested in combining exercise with non-invasive brain stimulation called transcranial magnetic stimulation (TMS). This is a noninvasive procedure that uses magnetic fields to stimulate particular brain areas.

The US team is carrying out a small trial in people with Parkinson's to find out whether this combined therapy can boost the natural production of the growth factor BDNF.

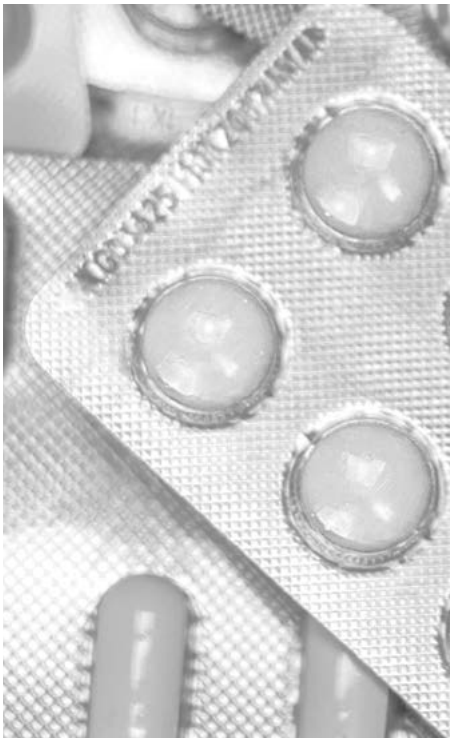
We'll be keeping a close eye on these studies and reporting on any major developments.

GET CONNECTED TO THE LATEST RESEARCH

You can keep up to date with all the latest news on treatments in development by joining our Research Support Network. Find out more at **parkinsons.org.uk/rsn** ■

What happens **after** the clinical trial?

After the research is finished there are still more hurdles to making new drugs and therapies available, and this could be slowing down the process of getting treatments to those who need them. That's why our campaigning activities are looking for ways to overcome these hurdles – and asking you to help us get new and better treatments to people faster.



We know that health and care budgets across the UK are going to be tighter in the years ahead.

However, we want to ensure all our investment in research leads to people with Parkinson's getting better treatments and a cure, faster.

In order to achieve this, we're developing an active group of people who can add their voices to our campaigns to ensure vital treatments get to people with Parkinson's when they need it.

And we're asking people from all over the UK to get involved.

What is campaigning?

Campaigning is asking for change – whether that's vital improvements to health and social care, better transport services in your area or access to a treatment.

Campaigning activities can be anything from sending an email or signing a petition to meeting with your local decision maker to make your case. You really can make a difference – as our case study on the Parkinson's drug Duodopa highlights.

CAMPAIGNING WORKS: DUODOPA

Duodopa is a vital treatment for controlling the advanced symptoms of Parkinson's when all other medications have been exhausted. In 2014 we became aware that people with Parkinson's in England weren't able to easily access Duodopa. We lobbied NHS England to fund Duodopa. However, it was only when we involved our fantastic campaigners that we managed to get NHS England to agree to fund the treatment. Our campaigners wrote to their MPS, encouraging them to sign an early day motion (like a petition for backbench MPs) and attend a briefing with prominent neurologists.

With the treatment now being funded in England, you helped pave the way for the Scottish Medicines Consortium to agree to fund Duodopa in 2016 and Northern Ireland to confirm they would fund it this year. But we're still not finished – Duodopa is not available in Wales yet, but a proposal to fund the drug is being submitted.

HOW CAN I GET INVOLVED?
Campaigning with us can really help to make a difference to people living with Parkinson's. There are loads of ways to get stuck in and get involved. Find out about all these opportunities at **parkinsons.org.uk/campaigns** or contact us by emailing **campaigns@parkinsons.org.uk** or calling **020 7963 9349**.

How new treatments are made available

Licensing new treatments

1 Once a treatment has been through clinical trials, and been shown to be safe and effective, the pharmaceutical or medical device company must get a licence for their product.

While no treatment is completely risk free, a licence indicates all the proper checks have been carried out and the benefits of a medicine are believed to outweigh the risks.

At the moment, authorisation of drugs and treatments for use in the UK happens through the Medicines and Healthcare products Regulatory Agency (MHRA) or the European Medicines Agency (EMA).

Appearing in the guidelines

2 After a licence for a new treatment has been granted it does not mean people will have immediate access to the treatment.

The benefits of new medications and technologies are evaluated by independent bodies and incorporated into guidelines. These guidelines act as recommendations for how best to treat conditions such as Parkinson's.

The main guidelines for the UK are the NICE guidelines. Northern Ireland usually adopts the main principles of the NICE guidelines. In Scotland, the clinical standards are called SIGN.

Funding approved treatments

3 This final stage of how new treatments are funded, and made accessible to people with Parkinson's, varies in different parts of the UK. This means that not every Parkinson's drug is easily available across the UK.

In England, the decision to make a treatment available through NHS England ultimately rests with local decision makers. They decide if they want, or can afford, to fund new treatments through the NHS. And this means different treatments may be available in different parts of England. In Scotland, Wales and Northern Ireland funding decisions are made more centrally. ■

SPARKING A TREATMENT REVOLUTION

In April, we launched our We Won't Wait campaign during Parkinson's Awareness Week to raise funds for research into new and better treatments. But how is this money driving new treatments closer?

One of the key areas we're investing in is the development of new treatments through our Parkinson's Virtual Biotech. A biotech is a company that uses the latest technology and expertise to take the best science discoveries and develop new medical treatments. Now we're doing the same type of drug development work as a company. But instead of doing it for profit, we are doing it for people affected by Parkinson's.

What's 'virtual' about it?

Our biotech is 'virtual' because we won't build our own labs, employ a team of specialist laboratory scientists or buy hi-tech equipment, all of which would be incredibly expensive. Instead, we work with partners – such as universities, companies or other charities – who already have these facilities and can do the work for us. We've put together a team of industry and scientific experts to help us identify and select ideas with the greatest chance of delivering new treatments for people with Parkinson's. This collaborative approach means we can develop new treatments at a fraction of the cost of a traditional biotech. And, like a company, our in-house staff will take a hands-on role in managing the projects to ensure they deliver.

Director of Research at Parkinson's UK, Arthur Roach, says: "Due to the funding gap in early stage drug discovery, there are promising scientific breakthroughs for Parkinson's happening every day that are not being picked up and developed by commercial companies. This major new programme of work will allow us to act in a similar way to a small biotech company. However, unlike a commercial company, our primary goal is the creation of new treatments to improve the lives of people with Parkinson's, regardless of commercial considerations."

What's next?

The greater number of ideas we can take forwards, the greater our chances of delivering new treatments to people living with Parkinson's.

So we're aiming to create and invest in many more projects through the Parkinson's Virtual Biotech and hope to announce further projects before the end of 2017.

VIRTUAL BIOTECH
Visit **parkinsons.org.uk/virtualbiotech** for more information and videos.

Introducing our first project

Protecting brain cells against oxidative stress

We've launched a new £1million project to develop exciting new drugs that can combat oxidative stress, a process that is believed to play a key role in Parkinson's.

Oxidative stress happens when there are too many damaging molecules called free radicals inside our bodies. Our bodies constantly produce free radicals and, unchecked, these molecules can cause damage to our cells and tissues.

The project will build on more than a decade of research at Sheffield University's Institute for Translational Neuroscience (SITraN), where researchers have pinpointed a way to trigger a possible in built defence system that helps protect brain cells from oxidative stress. Dr Richard Mead has discovered a new type of molecule that can activate the brain-cell defence system.

We are now working with Richard and the company Sygnature Discovery to further develop these molecules, which could eventually become new drugs that can slow or stop the progression of Parkinson's. To carry out this collaborative project we have formed a company, Keapstone Therapeutics, which will combine world-leading research from the university with funding and expertise from the charity to help develop revolutionary drugs for Parkinson's. ■

How do you design a new drug?

We investigate the science of designing new drug molecules and how scientific advances are making it easier to develop better drugs.

Researchers are working hard to understand the causes of Parkinson's. It is through this understanding that we learn what is going wrong and come up with new treatments. This concept of 'find and fix' is fairly familiar to us – much of our world works this way. For instance, if your car breaks down, a mechanic will first identify the cause of the breakdown before attempting to fix the faulty part. But when it comes to fixing problems with our bodies, the process of identifying what is going wrong and coming up with a fix is not as simple.

Current treatments for Parkinson's

We know that the symptoms of Parkinson's are due to the loss of dopamine-producing cells in the brain. This small molecule is needed for the brain to communicate messages about movement.

Current treatments aim to replace the dopamine that the brain is not making so that it can continue to communicate. But these drugs do not slow the progression of Parkinson's. And while they work well for a time, ultimately the side effects of these medications become problematic. The trouble is that we don't truly understand the cause of the cell loss. What we need to do is find out what is going wrong because, when we find the fault, then we can design a fix.

And fixing the problems that are happening inside these dopamine-producing cells will help us protect them.

Finding the fault

At the scientific discovery stage of the research pipeline, the problems in the cells are identified. We already know a number of processes in the cells are changed in Parkinson's. The batteries of the cells, waste disposal and even protein production are all affected.

Proteins are at the heart of everything that happens in our cells. They are the workers of our cellular factories and there are more than 21,000 different types. Many types of proteins are involved in the different processes that happen inside our cells, but a single faulty protein can have a significant impact on how well a cell performs. And, if a cell is not able to carry out its normal functions well enough, it will die.

Researchers have already made headway into identifying the proteins at the heart of the processes affected in Parkinson's – the proteins that new drugs should target to change the fate of the cell. And, if drugs can be developed to help these proteins work better, then it may be possible to slow or even stop Parkinson's.

Developing new drugs

The first stage of drug development is to find molecules with the potential to interact with your protein of interest. In the past, the traditional starting point was to test natural products for their ability to treat human conditions.

There are many examples of where this strategy has produced drugs that are still in use today:

➢ Fungi that help your heart

Statins are a group of medicines that help to lower the risk of cardiovascular disease by reducing blood cholesterol levels. The first promising statin drugs were originally found in the 1970s. One in particular, called lovastatin, is still in use today. The chemical in this drug was discovered as a natural product of a type of fungus, and tests showed that it could reduce the body's production of cholesterol. Today the chemical in lovastatin is synthesised by chemistry specialists rather than being isolated from fungi.

➢ Anti-cancer trees

A cancer drug called paclitaxel is another example of natural products being used for treating human conditions. After discovering its potential anti-cancer properties, from 1967 to 1993 almost all paclitaxel (trade name Taxol) came from bark of Pacific yew trees. But harvesting the bark kills the tree and the Pacific yew is relatively scarce.

Chemistry specialists struggled to make the complex molecule

in the lab, but it was clear that an alternative, sustainable source would be needed.

Fortunately chemists were able to find a semi-synthetic way to produce the molecule using the needles from another type of conifer, the English yew, which removed the need to kill trees to produce the drug. Nowadays the drug – which is still used to treat a number of cancers – can be made in the lab.

The era of man-made molecules

Today the most common method of finding potential drug molecules to develop is to use 'drug screening'. This involves working through (or 'screening') a library of hundreds of thousands of diverse manmade molecules to find those that show promise. As all proteins have slightly different shapes, the trick is to find a molecule that can interact with a protein because it has a complementary shape. In this way, drug screening is similar to looking for a key that fits a lock. But instead of unlocking a door, these chemical keys can change the way that a protein works.

Finding potential drugs in this manner is like finding a needle in a haystack, and often only a handful of potential molecules are found in a drug library. But the companies that do this type of discovery have developed tools and techniques to automate and speed up the process.

A new way to develop drug molecules

Drug screening can help to discover molecules of interest, but it relies on a promising molecule being part of your library. And, when it comes to developing this molecule, screening doesn't give you much information about how the key and the lock fit together, or where this fit could be improved.

So researchers have developed a new way to identify promising drug molecules. Instead of testing pre-existing molecules, in the hope that a good fit already exists, they want to build molecules that specifically fit the protein locks. The technique they use is called fragment-based design and involves using parts of molecules or 'fragments' to design new drugs that fit the lock.

First the researchers figure out what the protein looks like. Small molecule fragments are used to explore the space inside the protein.

Special techniques are used to see how and where these fragments bind – giving the researchers a good idea of what the space inside the protein looks like. And from this they can develop a chemical key that fits perfectly.

There are advantages to this new method of finding potential molecules to work with. Fewer molecules need to be tested than in traditional drug screening approaches and scientists develop a good understanding of how molecules actually fit in the protein – a key insight for the next stages of drug discovery. And this method of designing new drugs has already been fruitful for finding promising drugs to treat cancer and kidney disease.

Developing new treatments for Parkinson's

We're learning more about how to develop new and better drugs every day, and our Parkinson's Virtual Biotech means we're in a position to make the most from these scientific advances.

Our virtual approach means we don't need to build expensive laboratories and pay for all the latest equipment. We can stay agile – working with the companies and organisations that have the right skills and techniques to take our projects forward. This means we can benefit from the latest technologies, such as fragment-based design, and help deliver new and better treatments faster. ■

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PARKINSON'S UK
CHANGE ATTITUDES.
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We hear from Parkinson's UK-funded researchers about their latest results, and find out what it means for people with the condition.

RESEARCH RESULTS

A step forward for ethnicity research

We often get asked whether Parkinson's affects people from different ethnic groups in different ways. But until we awarded a one-year grant of £33,233 to Professor K Ray Chaudhuri and his team at King's College London, very little research had been carried out.

We know that Parkinson's varies hugely between individuals, but we don't understand exactly why. Research has already uncovered variations between people from different ethnic groups living with conditions including diabetes and multiple sclerosis. And, based on their experience at their London clinic, the team thought the same may be true for Parkinson's.

Their preliminary findings suggest that people with Parkinson's of black African, Caribbean or South Asian heritage may respond less well to Parkinson's medication, and experience a greater range of non-motor symptoms, compared to white Caucasians.

Support from Parkinson's UK enabled Professor Chaudhuri to develop work he originally started in the early 2000s.

Now the team have secured funding from the Kirby Laing Foundation to expand the study and investigate the significance of these findings. They have also established collaborations with centres in India, Malaysia, Nigeria and Thailand, making this the largest study of its kind ever attempted.

The researchers are continuing to recruit people with Parkinson's from different ethnic backgrounds, and explore their experiences of the condition.

They are collecting information from each group about the range and severity of motor and non-motor symptoms. They are also investigating how people of different ethnic backgrounds respond to Parkinson's treatments, and looking at the impact of the condition on their quality of life.

Some participants are being invited to have a brain scan and provide blood samples, which will be vital for future genetic studies of ethnic groups in Parkinson's.

"Understanding the differences in types of symptoms and response to medication will ultimately help clinicians to provide the right care for individuals of different ethnic backgrounds."
Professor K Ray Chaudhuri

Speaking with your hands

A PhD project at the University of Manchester has shed new light on the communication difficulties experienced by people with Parkinson's.

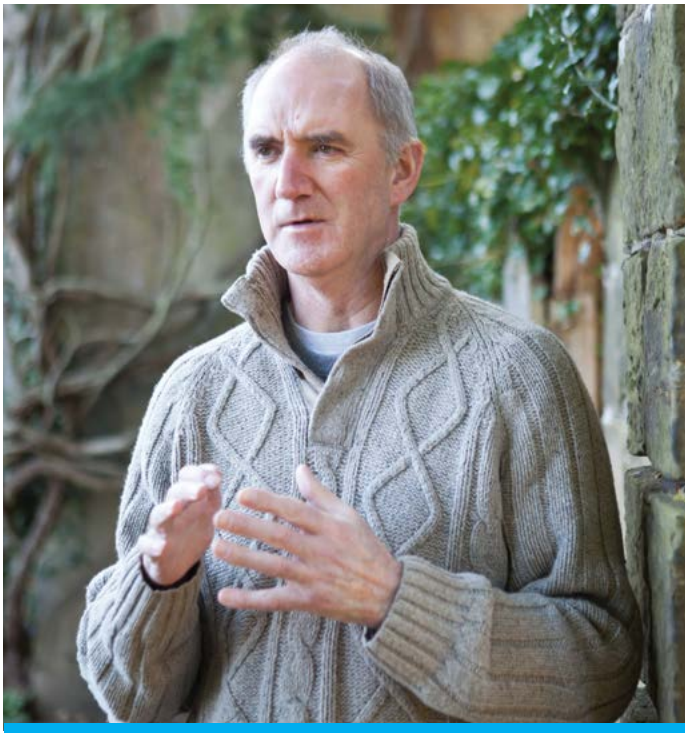
When we speak we also use subtle non-verbal signals to get our point across – body movement, facial expression and eye contact all play an important part in helping people understand what we're saying. People with Parkinson's can experience problems with both verbal and non-verbal communication, which can be frustrating and isolating. Student Stacey Humphries, her supervisor Dr Ellen Poliakoff and their colleagues showed that people with Parkinson's tend to use less complex hand gestures when communicating about actions compared to healthy people of the same age. And this might make it harder for them to be understood.

"People with Parkinson's may be more likely to gesture about an action from a third-person perspective, rather than from a first-person perspective – which would involve depicting how the action was actually performed. For instance, when describing a picture of someone skiing, someone without Parkinson's might gesture using ski poles. But someone with the condition might gesture an s-shaped path of the skier going down a slope. We think this might be due to differences in how people imagine actions when talking about them."
Dr Ellen Poliakoff

The team filmed people with and without Parkinson's as they described an event, and compared the way they used hand gestures to help tell the story. They discovered that the rate at which people produce gestures isn't really affected in mild to moderate Parkinson's. But people with the condition include less precise information when communicating about actions. For example, they may communicate what someone did but be less able to communicate information about how they did it.

Research Support Network member Dr Matthew Sullivan, who has Parkinson's, helped to shape the project by providing guidance and suggestions. The team hope their research will help to provide a more in-depth understanding of some of the communication problems faced by people with Parkinson's. And ultimately lead to possible interventions or strategies to overcome them.

They published some of their findings last year – Humphries S et al. 2016. A third-person perspective on co-speech action gestures in Parkinson's disease. *Cortex*. 78: 44-54 (open access) – and have further papers in the pipeline. The study was supported by a studentship of £65,318.



COMMUNICATION AND PARKINSON'S
Find out more and download or order a free information sheet from our website at **parkinsons.org.uk/speechtherapy** ■

New potential drugs identified

Researchers at the University of Bristol have identified four molecules that may help repair mitochondria – the tiny, energy-producing batteries inside cells that become damaged in Parkinson's.

Professor James Uney and his team worked with drug company Takeda UK, who provided a library of molecules that easily pass from the bloodstream to the brain. This is an important first step, as many drugs are not able to cross the protective blood-brain barrier to reach the affected nerve cells.

With the support of a small grant of £34,655, they developed a system that quickly 'screens' hundreds of molecules by measuring their effects on mitochondria in cells grown in a dish. They then showed that their four 'hits' are involved in the waste disposal system inside cells.

Without healthy mitochondria, cells struggle to produce the energy they need. This may play a part in why nerve cells are lost in Parkinson's. Current treatments for Parkinson's can be very effective at masking the symptoms, but they don't protect the vulnerable nerve cells. Studies like this bring us a step closer to the next generation of treatments that could slow, stop or reverse the progression of the condition.

"We're excited about our results as we have identified key pathways that can be targeted by drugs and may form the basis of a future treatment for Parkinson's. Our next steps are to test the molecules we discovered in human cell and rodent models of Parkinson's. This will help us understand if they could be used to treat the condition in people. We're also hoping to screen a larger library of molecules targeting the same pathways. Finally, we're looking for ways to improve our screening system to test thousands of drugs at once."

Professor James Uney

Dogs to help sniff out a test for Parkinson's

Trained sniffer dogs are to join the scientists leading our pioneering project to find out if skin odour could hold the secret to diagnosing Parkinson's.

The study, which hit headlines around the world when it was launched in 2015, was sparked by one Parkinson's UK member's intriguing ability to identify people with Parkinson's by their smell.

Joy Milne's husband Les was diagnosed with Parkinson's at the age of 45, although Joy noticed he had developed a 'musky' scent about six years earlier. But it wasn't until Joy joined Parkinson's UK and started meeting people with the same distinct odour that she made the connection.

"When I attended a Parkinson's UK research event I mentioned that I thought I could smell Parkinson's to one of the scientists from Edinburgh University. He decided to put me to the test!"
Joy Milne

Professor Perdita Barran from the University of Manchester believes that Parkinson's may cause changes in the sebum (an oily substance in the skin) of people with the condition. This could result in a unique and subtle odour only detectable by people with a keen sense of smell. Her team, funded by a small grant of £49,459, is using cutting-edge mass spectrometry technology to try to pinpoint these changes.

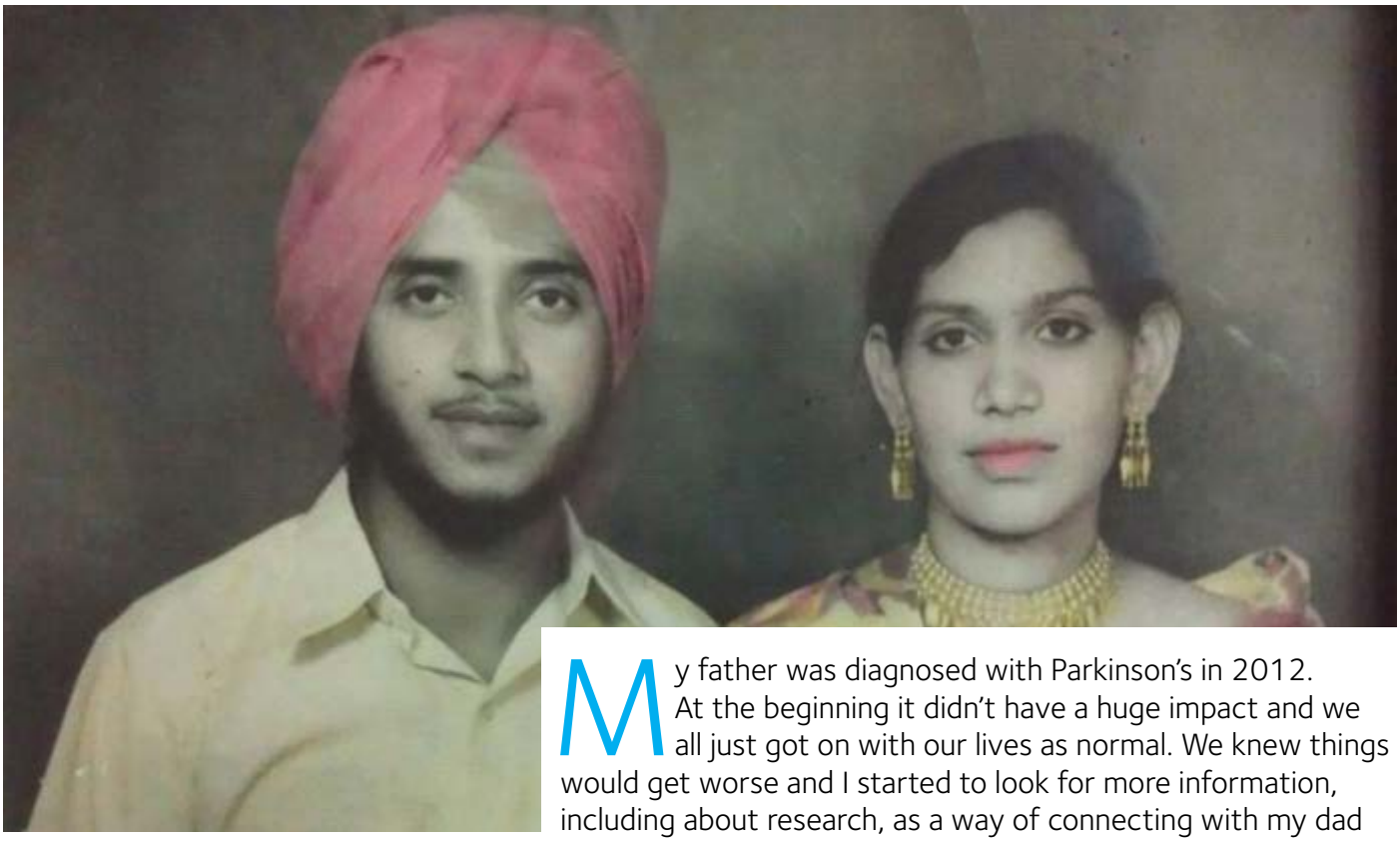
So far, they have taken skin swabs from more than 350 people with and without Parkinson's from across the UK. They have also finetuned their techniques to extract molecules from the samples and look for differences.

"In our experiment, Joy correctly identified 11 out of 12 T-shirts worn by six people with Parkinson's and six without the condition. Incredibly, the 'control' participant, who we thought Joy had 'mis-smelled' as having Parkinson's, went on to be diagnosed eight months later."
Dr Tilo Kunath, Parkinson's UK fellow

Now, additional funding from the Michael J Fox Foundation will enable a team of 'medical detection dogs' to be trained to help the scientists narrow down the exact molecule or group of molecules responsible for the distinctive odour.

If this project is successful, it could lead to the development of a simple, non-invasive test that could be used to accurately diagnose Parkinson's in the very early stages. Not only would this end uncertainty around diagnosis, but it would be a huge breakthrough for testing new treatments to slow or stop the progression of the condition.

It seems Joy isn't the only person who can 'smell' Parkinson's. Since we first publicised the study, several people have come forward to tell us that they have also noticed this phenomenon.



SHAUN'S STORY

Shaun talks about his experience of getting involved in research to help people with Parkinson's, including his dad, stay independent.

My father was diagnosed with Parkinson's in 2012. At the beginning it didn't have a huge impact and we all just got on with our lives as normal. We knew things would get worse and I started to look for more information, including about research, as a way of connecting with my dad and empowering myself. Research felt positive.

My first experience of research was far from perfect. I went along to an event to hear from researchers with my sister and my girlfriend. I'm a health professional, my sister is a computer programmer and my girlfriend does psycholinguistics, so we're all pretty intelligent people, but we could barely understand half of what was being said.

It was supposed to be an event for people affected by Parkinson's but the researchers were talking as though they were speaking to fellow academics. It was disappointing and frustrating but it motivated me to get more involved. I felt that events like this should be better and maybe I could help.

I joined the Research Support Network at Parkinson's UK and immediately felt welcomed and listened to. In early 2017, the team invited me to get involved in the launch event of a major new research project.

The project is called 'Self-Care Advice, Monitoring, Planning and Intervention' or SCAMPI for short. It aims to develop new technologies for people's homes to help them manage better with everyday life – so sensors that can detect falls and things like that.

By this point life had changed a lot for my whole family as dad's condition had progressed. The idea of finding ways to use technology to help him stay more independent was exciting. The event itself was in London and not too far away from where we live so it felt like a real opportunity for the whole family to get involved. We said yes.

The day itself did not start well. Even though we didn't have far to travel it was still a major undertaking to get dad, who is now in a wheelchair, to the venue. We got lost and had to make a toilet stop on the way so we were pretty late getting there and by the time we arrived we were all pretty exhausted. I admit that at this point I was wondering why I agreed to do it in the first place.

Before it was our turn to speak, there was someone talking from another charity. They were giving all the statistics and the facts about why better technology is needed. Their presentation was very factual and professional so when I got up to speak afterwards, looking dishevelled, I'm sure the audience were wondering what to expect.

I talked about the everyday reality of living with Parkinson's as a family. Just a few years ago my father was a local councillor and a significant person in the local community, always attending meetings, giving presentations and helping others.

Now his Parkinson's has taken away so much – his mobility, his voice and a lot of his independence. But he can still do a lot if he has the right support. He is still the same person with the same abilities and he desperately wants to stay independent.

I wanted to show the researchers the human beings behind the statistics and labels, and how the technologies they are working to develop could change lives.

One example I gave was using technology to alert families when someone like my dad has a fall. My mother is deaf, so if my dad were to fall she wouldn't be able to hear him shouting for help. Dad has one of those emergency alarm pendants but he hates wearing it and would be very reluctant to use it even in an emergency. How could technology – such as sensors in the home – help to alert my mum and the rest of the family?

> "Shaun presentation electrified the launch event. Not only did the presentation highlight the need for better solutions for care in the home, but it also demonstrated the potential emotional impacts that SCAMPI might have, and galvanised the research team to deliver effective solutions quickly."
>
> **Professor Neil Maiden, lead researcher on the SCAMPI project**

Dad is quite vulnerable to infections and can become ill quite quickly. We have spent a lot of time in A&E over the last few years. But, often, these crises could be prevented if we knew that dad's condition was deteriorating. Could smart technologies help monitor key things like heart rate and hydration levels and give us a warning if dad was starting to get poorly? If we could spot problems and intervene earlier, it could stop us ever reaching that crisis point.

By the end of my talk my mother, father and sister were all quite emotional. My dad, who now rarely talks much because his speech is quite difficult to understand, actually took over and spoke for several minutes, more clearly and coherently than he had in years. It was like having the old dad back – he was so passionate and motivated.

People saw through his Parkinson's and listened because what he was saying was important and interesting. I think he felt he had his voice back.

It can feel hard to get involved in research for all sorts of reasons. Even the word 'research' can be a barrier and people might feel that it's too technical or complicated for them to make a contribution.

We need to break down these barriers so that everyone feels able to get involved and that's what the Research Support Network is all about. ■

Every hour, someone in the UK is told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

Together we can bring forward the day when no one fears Parkinson's.

Parkinson's UK
215 Vauxhall Bridge Road
London SW1V 1EJ

Free confidential helpline **0808 800 0303**
(Monday to Friday 9am–7pm,
Saturday 10am–2pm). Interpreting available.
Text Relay **18001 0808 800 0303**
(for textphone users only)

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