

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

PROGRESS

The research magazine of Parkinson's UK
Issue 19 Autumn 2016

**Get connected, take part
and have your say**

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WELCOME

This issue our welcome comes from Christine Proctor, who shares her passion for getting involved in research as a participant.

I was 44 years old when I took myself to my GP. A year later, a trainee GP watched me walk and within minutes diagnosed a movement disorder which was soon confirmed to be Parkinson's.

I can still remember, at the moment of diagnosis, the relief that I wasn't going to die. But the relief was short-lived and quickly replaced by fear for my future and where Parkinson's would take me.

Twelve years on and the word "fast" no longer exists in my vocabulary. But despite the inevitability of progression, I feel a great sense of personal wellness. I am happier at the end of a decade with Parkinson's than I was at the beginning. I've visited places, met people, made friends for life and done things I would never have done. It's no trade-off but Parkinson's can bring positive things into your life, if you let it.

At the time of my diagnosis, I had no knowledge of Parkinson's. So I set about educating myself and with that became interested in research. My first experience as a participant was in a study exploring mood, which involved tests at home, completing questionnaires and physical exercises.

I discovered there is research out there for everyone. From surveys to surgery, everyone can contribute something that is of value in the search for a cure.

I am now fortunate to be one of the participants involved in the GDNF trial and you can read more about this groundbreaking study and my experiences on page 6.

My involvement has really helped me to understand the value of research. I want to raise awareness of the great research that is happening and urge people to actively get involved. We are the key to the cause and the path to the cure. While we look for a cure, research is helping us to live our lives with this illness better than it has ever been possible before.

Over the past couple of years I have become an active member of the Parkinson's UK Research Support Network – which you can read more about on page 14 – including setting up a research interest group in the North East and speaking about my experiences as a participant.

I would certainly encourage other people to get involved with research – I can't begin to list the benefits. It has been the most positive experience and I've enjoyed every minute of it.

parkinsons.org.uk/rsn



INTERNATIONAL NEWS ROUNDUP

We keep track of all the latest developments in Parkinson's research across the world. Here we share some of the highlights from the last few months.

Safinamide launched in the UK

In May, international pharma company Zambon and its partner Newron Pharmaceuticals launched a new Parkinson's drug called safinamide (trade name Xadago®) in the UK.

The drug gained approval in the EU last December following a two-year study in people with mid to advanced Parkinson's who were already taking levodopa.

The trial showed that safinamide helped reduce off periods (when medication stops working) without increasing the risk of dyskinesia, and also improved quality of life and mood.

Professor David Burn, Clinical Director of the UK Parkinson's Excellence Network, says:

"It is good to know that another treatment that has been shown to benefit people with Parkinson's will now be available in the UK.

"While it's very much part of the spectrum of treatments already available as opposed to completely new medication, it does give us one more tool for managing the symptoms."

We recommend you speak to your specialist for more information.

parkinsons.org.uk/researchnews26may16

Test to detect Parkinson's

Researchers in Edinburgh have collaborated with the Oxford Parkinson's Disease Centre to develop a new test that can detect abnormal alpha-synuclein – a protein known to be involved in Parkinson's.

The team tested 99 samples and detected abnormal alpha-synuclein in the fluid that surrounds the brain and spinal cord in people with Parkinson's. They did not detect the abnormal protein in people with other conditions such as Alzheimer's.

It is possible that changes in the alpha-synuclein protein happen before the development of Parkinson's symptoms. In this research study, the team found the abnormal protein in samples from people at high risk of Parkinson's who have not yet been diagnosed.

The study was featured in the media, including *BBC Breakfast*. The Parkinson's UK Research team commented:

"Although early days, the fact that researchers have developed a new test that is able to detect abnormal alpha-synuclein with remarkable specificity and sensitivity, is hugely promising.

"Further research is needed to test more samples to see if the results continue to hold true, but this could be a significant development towards a future early diagnostic test for Parkinson's."

parkinsons.org.uk/researchnews29aug2016

First drug approved to treat hallucinations and delusions

Some people with Parkinson's may experience hallucinations or delusions. This means that they may see, hear, smell or taste things that aren't there, or have thoughts and beliefs that aren't based on reality.

In April, pimavanserin (trade name Nuplazid™) was approved by the US Food and Drug Administration (FDA) as the first drug for treating hallucinations and delusions associated with Parkinson's.

The next stage for pimavanserin to be made available as a treatment in the UK is for it to be approved by the European Medicines Agency (EMA).

Dr Beckie Port, Parkinson's UK Senior Research Communications Officer, says:

"Hallucinations and delusions are difficult to treat in Parkinson's. There are a limited number of medications available, which are often prescribed with caution and require people to be continuously monitored for side effects.

"Pimavanserin has been specifically designed to treat hallucinations and delusions without worsening the motor symptoms of Parkinson's. FDA approval is a huge step forward but further regulatory approval is needed before pimavanserin will be available in the UK.

"While we don't know exactly how long it may take, hopefully there will soon be an additional drug to treat the symptoms of Parkinson's on our pharmacy shelves."

We will continue to monitor the progress of pimavanserin closely and report on any developments.

parkinsons.org.uk/researchnews03may16

News in brief

Can singing improve speech in people with Parkinson's?

A recent review has provided strong evidence to suggest singing can help with speech problems in Parkinson's. However, more research is required to investigate whether singing could also have wider benefits on communication and quality of life.

Inhalable levodopa trial results

A study published in April suggested that an inhalable form of levodopa, CVT-301, could be used to reduce off periods. Researchers are now performing larger Phase III trials to confirm that CVT-301 is a safe and effective treatment for Parkinson's.

New therapy could replace DBS

Scientists have found a non-invasive way of stimulating the brain, using small iron particles and magnets. So far this new technique has only been tested in rats – but it's hoped it could provide similar benefits to deep brain stimulation without the need for major brain surgery.

Video game to help with memory and thinking problems

A new clinical trial is looking at whether a brain-training tool could help with memory and thinking problems in Parkinson's. The MyCQ programme, developed by science-based company MyCognition, provides personalised online training to help keep brains active.

Is Parkinson's on the rise?

A new study suggests that the number of people with Parkinson's has increased over the last 30 years – and changes in smoking could help to explain it. But as this research only looked at a small number of people in America, larger studies are needed to see if the same can also be seen worldwide.

Keep up with all the latest research news as it happens by joining our Research Support Network: parkinsons.org.uk/rsn

MEET THE TEAM BEHIND THE GDNF TRIAL



GDNF (glial cell line-derived neurotrophic factor) is a special protein that is naturally produced inside the brain and supports the survival of many types of brain cells – including the cells lost in Parkinson's. To investigate the effects of GDNF, 41 people with Parkinson's are taking part in a groundbreaking clinical trial in Bristol.

In the first phase, participants received either GDNF or a placebo (a dummy drug) for nine months. Neither the researchers nor the participants knew who was receiving what, which is why this kind of study is called 'double-blind'.

This initial phase is now complete and the second phase, where all participants receive GDNF, is currently underway.

At the time of writing, the full analysis of the results from the first phase was still underway. Initial results suggested that GDNF treatment is safe but didn't show a clear cut difference between participants who received GDNF compared to those who received a placebo.

The second phase, where all participants receive GDNF, is currently ongoing and may also provide more insight into GDNF's potential.

Can GDNF treatment slow, stop or reverse the course of Parkinson's? That's the question a team made up of researchers, charities, companies and people with Parkinson's set out to answer in a unique and complex clinical trial.

[Dr Alan Whone](#), a consultant neurologist and researcher based at Southmead Hospital in Bristol, is the Chief Investigator and leader of this ambitious study. Alan says:

"When we sat down to put together the plan for this clinical trial back in 2011 I knew this study would be the most complex and challenging I had ever been involved in – but also the most exciting.

"A study of this magnitude would usually be carried out across multiple hospitals and sometimes in multiple countries.

"So the fact that we've managed to take such a large group of people with Parkinson's through this study at just one hospital is a fantastic achievement.

"It's all been down to incredible teamwork across a huge range of different groups and I feel very proud to be part of such an amazing collaborative effort."

Let's meet the team who've made this trial possible.

The company providing GDNF

MedGenesis is a Canadian biotechnology company founded in 2006 to develop new therapies for serious neurological conditions. MedGenesis own the rights to GDNF and have supplied the drug for this trial for free. They have also brought their professional expertise to support the study, as Chief Operating Officer [Lara Longpre](#) explains:

“So far in the studies we have done more than 600 infusions of GDNF and completed over 500 assessments, generating over 20,000 individual sheets of data.

“My role is to provide project management so that Alan and his team can concentrate on the participants. This means keeping track of all the different tasks and activities, and working with all the partners to make sure everything gets done on time and to the required standards. I’ve worked on many clinical trials, but this one has been one of the most challenging for a couple of reasons. There are multiple parties involved, all based in

different places and each with a critical role, so communication has been one of the things we’ve had to focus on.

“The second challenge has simply been the sheer volume of data that we are collecting. Gathering it all, making sure every piece is captured correctly and then figuring out what it means through statistical analyses is a huge task. Although it has been a complex and demanding study, it’s been a wonderful experience and I’m proud of what we’ve achieved together.”

An innovative drug delivery system

To get GDNF to the brain cells that need it, we’re using an innovative delivery system, specially designed for the task. [Paul Skinner](#) is an Operations Manager at Renishaw, the engineering company based near Bristol that has been contributing to the development of the system designed by [Professor Steven Gill](#). Paul says:

“As a company we specialise in developing systems that do complex tasks with extreme precision. In the trial we have worked closely with the hospital and lead surgeon, Professor Steven Gill, who designed a system that can deliver GDNF safely, accurately and consistently to the right parts of the brain.

“Participants had four tubes carefully placed into their brains that are connected to a small port behind their ear. This device allows GDNF to be pumped directly through the tubes to the affected brain areas with pinpoint accuracy.

“First we use brain scans to build a 3D map of each participant’s brain. This allows the surgeons to plan the safest route for implanting the device. Our specialised robot is then programmed to guide the surgeons to implant the device during the surgery.

“This is the first time this kind of delivery system has been shown to deliver drugs successfully. It has exciting possibilities for other brain conditions, which we’re already exploring.”





A dedicated team in Bristol

A team of 10 doctors, nurses and administrators at the Brain Centre at Southmead Hospital in Bristol are involved in carrying out the study. Here we talk to [Louise Hawkins](#), the Clinical Trial Manager, about her role:

“My role is to make sure the day-to-day running of the study all goes smoothly. This means everything from making sure the pharmacy provides us with all the GDNF or placebo we need, through to arranging all the participant appointments, travel expenses to be paid and managing the budget.

“On a typical week we’ll have 14 of the participants visiting the hospital for assessments and infusions, and co-ordinating all of that requires a lot of teamwork and communication.

“I’ve been working in the NHS for 13 years and I’ve been involved in running studies for the last seven. This study is the most complex and interesting I’ve ever been involved with. It’s been great to develop such good working relationships with all the other partners.

“Without a doubt the best part of my job is the participants. They’re a lovely bunch of people who are all so committed to finding a solution to this

terrible condition. If they come away from the study having had a positive experience then I’ll be happy that we’ve done our job well.”

41 incredible participants

Groundbreaking research relies on people who courageously volunteer to participate. Taking part in this study is particularly demanding as it involves complex brain surgery, frequent visits to Bristol for treatment and detailed assessments, as well as undergoing brain scans.

[Christine Proctor](#) (pictured during a GDNF infusion) is one of the 41 participants, and here she shares her highs and lows from life on the trial.

“In early 2015 I was accepted as a participant on the GDNF trial. Although part of the rigorous screening process included talking through all the potential psychological, physical and emotional consequences. Without doubt participating in this study has challenged me to my limits.

“Completing physical assessments every eight weeks while I’m off my regular medication for 24 hours is like climbing Everest, and it’s why they call studies like this one a trial. But the positives far outweigh the challenges. The nicer things are meeting the wonderful and committed people involved in the study. Although

it involves a 500 mile round trip, I look forward to my monthly visit to have my infusion. It's a very relaxed procedure during which I can enjoy a snack, read my newspaper and chat with other participants and the research staff. I have learned a lot about my Parkinson's and whatever the results ultimately tell us, I feel privileged to have been able to contribute to this study."

A way to see into participants brains

All the participants involved in the trial are undergoing detailed brain scanning. [Professor Chris Marshall](#), Director of the Wales Research and Diagnostic PET Imaging Centre at Cardiff University, says:

"My role in the study is to manage the brain imaging. We're using a type of brain scanning called PET imaging to measure how dopamine is used inside the brains of the participants. Participants have an injection of a radioactive version of dopamine and lie as still as possible in the scanner for 90 minutes. The PET scanner allows us to track the movement of the radioactive dopamine through the participants' brains.

"One of the most technically challenging parts of this project was actually manufacturing the radioactive dopamine. To make enough of it to do all the scanning we've had to develop an innovative new production method which took us nine months to get up and running. We can now make around 100 times the amount of radioactive dopamine than using the previous method, which is extremely exciting. We're the first in the UK to achieve this and I believe it's going to open up huge opportunities for future Parkinson's research studies."

Once Chris and his team have taken the brain scans in Cardiff they pass them on to [Professor Vesna Sossi](#) and her team at the University of British Columbia in Canada for analysis. Vesna explains:

"When we receive the images to analyse they are completely anonymous. We don't know which participant they are from, or whether they are receiving GDNF or a placebo. This is really important because it means we can analyse them

without being biased in any way. This type of brain imaging is tremendously powerful for helping us to understand the effects of treatments like GDNF. The radiotracer we're using helps us zoom in to see what is happening to dopamine inside the brain – and whether there are any changes in the rate at which it is made or stored – which would otherwise be totally impossible."

Two charities with a shared mission

All research relies on funding and the GDNF trial is funded by Parkinson's UK, with crucial support from The Cure Parkinson's Trust. The two charities have between them provided £2.5million to support this crucial project, as well as helping to raise awareness of the study and supporting the participants.

[Dr Arthur Roach](#), Director of Research at Parkinson's UK, comments:

"The GDNF trial is one of the most important studies Parkinson's UK has ever supported. The scale of collaboration involved in this project is really unprecedented and just goes to show what can be achieved when companies, charities, patients and researchers work together."

[Helen Matthews](#), Chief Operating Officer at The Cure Parkinson's Trust, adds:

"This trial has fostered a fantastic sense of teamwork between the scientists, clinicians and those participating in the trial. Above all else it has demonstrated the importance of effective communication between all parties and the value of uniting everyone involved. We hope that this innovative way of working forms a template for other trials in the future."

Keep up to date with GDNF

We are hopeful that full results of the first phase will be available before the end of 2016 and we'll be sharing them with you as soon as we can. In the meantime, you can find out more about the study on our website at parkinsons.org.uk/gdnf

Over to you...

We love to hear your comments, thoughts and opinions on *Progress* magazine and Parkinson's research in general. Here are some of the latest topics you've been in touch about.

A CALL OUT TO CARERS

Having just read the Spring issue of *Progress*, it occurred to me that it must be difficult to get to events if you are a current carer.

So what about former carers? Could you put out a plea to those who have lost loved ones, and who perhaps think that because their caring role is no longer required, that Parkinson's UK does not need them. Of course you do!

My daughter is undertaking a run in September to raise money for Parkinson's UK in memory of her granddad.

For myself, I will get involved in the future, so my subscription to *Progress* will continue.

I used to read it and pass it onto my dad, so he could see there were so many positive things going on.

It's not politicians that change the world... it's scientists!

Cheryl

Thank you for your letter Cheryl. People with Parkinson's, family members, carers and former carers are all very welcome to attend our events and conferences.

You can search for research and fundraising events on our website at parkinsons.org.uk/events

Please also pass on our thanks and best wishes to your daughter for her upcoming fundraising run in memory of her granddad.

PRAISE FOR PROGRESS

Taking part: Tracking Parkinson's

I have read the latest *Progress* magazine cover-to-cover. Fascinating.

I am on the Tracking Parkinson's study [featured in issue 18, page 27], and go every six months. The researchers are so friendly and grateful, and the tests are interesting. I hope the research will help my son and grandchildren.

I encourage anyone to take part in research, it's so rewarding.

Brenda

Taking part: brain donation

In the last issue I found the article about the Brain Bank interesting. My mother had Parkinson's and when she died in 2011, her brain went to your Brain Bank. It was confirmed that she had Parkinson's.

My husband and I have also registered, and I've just signed up to the 100forParkinson's project.

From our feedback survey

You can also fill in our feedback survey online by visiting parkinsons.org.uk/progressfeedback

SPEAKING UP

We have been asked to fund training for a speech therapist to deliver Lee Silverman Voice Therapy (LSVT) at a cost, I understand, of about £450 for a two-day course for our branch members.

To help us come to a decision I would be grateful for information about Parkinson's UK's opinion of this therapy and its value.

I have seen some of the comments on your website but am looking for unbiased opinion and information about any research studies particularly relevant to Parkinson's.

Committee member for a Parkinson's UK branch

Problems with speech and communication in Parkinson's can include lack of volume, hoarse voice, lack of expression and indistinct speech.

Lee Silverman Voice Treatment (LSVT) is a type of speech therapy developed specifically for Parkinson's.

It focuses on improving voice loudness to help with daily communication by thinking loud, encouraging high-effort and using many repetitions. It is an intensive treatment programme and requires daily therapy and homework.

The programme helps people with Parkinson's to recognise that their voice is too quiet and trains them to speak more loudly.

Being aware of how loud you are speaking, and how much effort to put in to sustain volume, is thought to help people maintain the benefits after the treatment.

In terms of research into this type of therapy, it's been suggested that LSVT can help with not only the loudness of speech, but articulation, facial expression and even swallowing.

However, only trained clinicians can administer LSVT, so it is not widely available through the NHS.



At the moment we don't have any research that can tell us whether this treatment is better than conventional speech and language therapy.

However, there is currently a clinical trial underway called PD-COMM to address this.

Interestingly, recent research suggests that in the future LSVT could be delivered online, as similar benefits were found in those treated over the internet compared to face-to-face.

You can find out more about speech and language problems in Parkinson's at parkinsons.org.uk/speechlanguagetherapy

Introducing...

THE COHORT STUDIES COUNCIL

Cohort studies provide vital insights into the causes of Parkinson's, and a better understanding of how it progresses. But how can we ensure these studies tackle the questions that are important to people with Parkinson's? We find out about the newly established Cohort Studies Council.



What is a cohort study?

Cohort studies are a special type of research project that help to develop our understanding of Parkinson's.

They are long-term projects that follow numerous individuals (the cohort) over many years and help researchers answer important questions, such as:

- Who will develop Parkinson's?
- Are there different kinds of Parkinson's?
- What markers can we use to monitor Parkinson's?

Over the past five years, we have spent around £7million on this type of project, making us the main funder of cohort studies in Parkinson's within the UK.

Our projects have recruited more than 5,500 participants to take part. The participants include people with and without Parkinson's, and those at risk of developing Parkinson's.

Developing a cohort studies research strategy

Cohort studies tend to last longer than other kinds of research studies. They often involve many researchers at sites across the UK who collaborate and work together.

Over the past year we have been working hard to develop a strategy for these unique and valuable studies in Parkinson's.

Our cohort studies research strategy will guide future studies to ensure they produce reliable results that contribute to the development of new treatments, and ultimately a cure.

The strategy will include recommendations for how to carry out the best, future-proofed research, and encourage the sharing of valuable data and biological samples with other Parkinson's research projects.

We have established the Cohort Studies Council to make this strategy a reality. The council consists of:

- scientists who study Parkinson's (regular members)
- scientists who study related research fields such as multiple sclerosis, stroke and dementia (advisory members).

The council will put the needs of people with Parkinson's first, by helping cohort studies address the research priorities identified in partnership with those affected by the condition.



Improved assessment for cohort study applications

The council and people affected by Parkinson's will both be responsible for reviewing applications for cohort studies.

Cohort Studies Council

All members of the council will help improve studies by identifying opportunities for co-operation, collaboration and cost savings. Advisory members and scientists from outside the UK – who are less likely to be collaborating on the research and so can provide an unbiased review – will review the final applications.

People affected by Parkinson's

Lay reviewers provide invaluable feedback on the importance of research studies from the perspective of someone affected by the condition. Our lay reviewers also comment on whether the researchers have demonstrated Patient and Public Involvement (PPI) in shaping their research. You can read more about PPI on page 18.

All this feedback is used to help decide whether the study should be funded.

What's happening now?

The next meeting of the council will be later this year to finalise the cohort studies research strategy. Once the strategy has been established, we anticipate holding a council meeting twice a year, allowing applications to be reviewed on a regular basis.

Find out more about the council at parkinsons.org.uk/cohortcouncil



GET CONNECTED,
TAKE PART **AND**
HAVE YOUR SAY



New to our Research Support Network? Or an existing member looking for more information? Here's our guide to the opportunities that the network offers and the steps we've been taking to make sure it continues to grow.

The Research Support Network connects you to all the latest Parkinson's research news and opportunities.

More than 2,300 people are now part of our online network, driven to help find a cure and better treatments for Parkinson's. And we're still growing.

Everyone is welcome to join – you can take part as much or as little as you are able. With so many research activities on offer, there's something for everyone.

A new look

The Research Support Network has been connecting people affected by Parkinson's with research for more than six years. In this time it has not only grown in number, but also in the range of research opportunities on offer.

So with your help, we've given our Research Support Network a makeover to make sure that everyone knows about its purpose and what being a member involves.

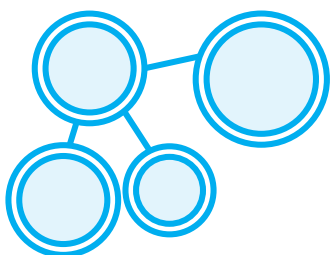
Earlier this year we hosted several focus groups and interviews to find out what the Research Support Network means to you. We asked members new and old to share their experiences and thoughts.

From this feedback we've been making some changes to the way we talk about the Research Support Network.

If you're already a member, you might have already seen some changes to our regular email updates – and we hope you'll be seeing other new and exciting developments in the future.

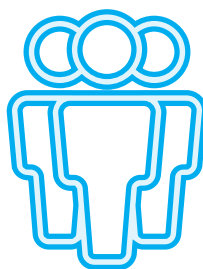
What's on offer?

Becoming part of our network means you can:



Get connected with Parkinson's research

Hear the latest Parkinson's research news and find out about events where you can meet scientists.



Take part in research studies

Find out about opportunities to take part in research studies and clinical trials.



Have your say to help shape research

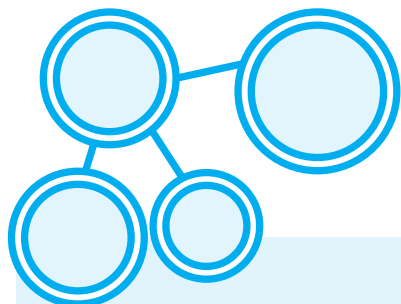
Make sure your voice is heard when it comes to our research projects, or partner with scientists to help develop their research.

Join the Research Support Network at parkinsons.org.uk/rsn. All you need is an email address and we can start sending you updates on Parkinson's research and opportunities to get involved.

Start a new journey and GET CONNECTED with research

One of the main reasons people sign up to the Research Support Network is to find out more about Parkinson's research. Our regular emails keep our members up to date with research news and information – helping to educate themselves, as well as friends and family, about current research into the condition.

We also share opportunities to meet the scientists at research events, such as our project visits and annual Research Support Network conference. These events are a great way to learn how researchers are working towards bringing new and better treatments to people with Parkinson's.



Parkinson's UK Research Interest Groups

Many Research Support Network members tell us that they want more opportunities to connect with research at a local level – with nearby researchers as well as with other people interested in research.

Local access to research is currently provided by volunteer-led groups such as the East Midlands RSN, and the Edinburgh, North East, Yorkshire and South Wales Research Interest Groups.

These groups help to:

- raise awareness of Parkinson's research
- connect local people to research
- build connections with researchers

Dr Emma Lane, researcher at Cardiff University, comments on the value of these groups:

“As an academic it has been hugely beneficial to be part of the Research Interest Group and to hear the group's thoughts and feelings about how research is presented.”

If you are interested in joining a Research Interest Group, or starting one in your local area, please contact Anna-Louise Smith at rsn@parkinsons.org.uk



My RSN journey

Marie Francis is a member of the Research Support Network Development Team

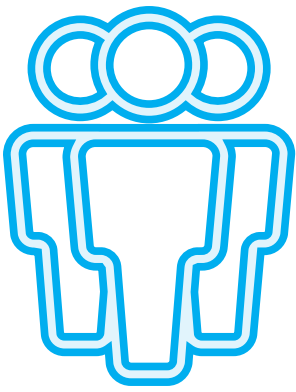
“After my husband was diagnosed, I wanted the best and the latest outlook on the future – and I wanted more than coping strategies. I wanted hope.

“I found the annual Parkinson's Research Support Network conference on the Parkinson's UK website. This seemed like a good opportunity to meet other people and learn more. It was also an excuse to visit Birmingham and discover its famous curries.

“It was a great event, and through it we discovered the Research Support Network. All we had to do was sign up and then we would receive regular emails with links to the latest research. It's also an easy way to sign up for any relevant medical trials as it gives us full information on the purpose of the trial, who is running it and what commitment it requires.

“So far my husband has taken part in one non-invasive trial analysing saliva.

“We are benefiting from looking forward in a positive way. We enjoy reading about the research and feel we are becoming part of a community that we will be more involved with in the future.”



Your questions about **TAKING PART** in research

While most people initially join the network to find out more about research, 60% of our members have told us that they've taken part in an activity through the Research Support Network. These activities include everything from attending an event to participating in a research study.

We know that many people affected by Parkinson's are interested in taking part in research, but it's often hard to know where to start. Our Research Support Network tries to make this process easier by providing information about getting involved and connecting people who want to take part in studies.

For International Clinical Trials Day on 20 May we brought together an expert panel to answer your questions about taking part in research.

Manuela Tan, Research Assistant and Study Co-ordinator of the Parkinson's Families Project, answers your questions:

What does research involve?

"This will vary depending on each individual piece of research. Some projects will involve trialling new medications or interventions, while other projects will just involve donating samples or completing questionnaires or assessments."

Can anybody take part in research?

"Each project will have different criteria for who can take part. If you find a project you are interested in you should contact the study team to find out whether you would be able to take part. There is a research study out there for everyone – it is just a matter of finding out where the opportunities are. A large number of studies need people as controls so people without Parkinson's can take part as well."

Richard Windle, member of the Research Support Network, answers your questions:

What's in it for me?

"You will be contributing towards our understanding of Parkinson's and better treatments. The great benefit is having experienced healthcare professionals who are interested in your Parkinson's. You'll get the chance to spend time with them discussing your own situation. Also, many people who take part in research feel like it gives them control over what they are experiencing."

How would I know what is the right the research study for me?

"The most important thing is that you fully understand what the research involves and how taking part would fit in with your life. You should discuss the research with your family, and also your Parkinson's doctor and nurse. Be aware that you can always choose to withdraw from a research study at any time."

Amelia Hursey, Senior Research Participation Officer at Parkinson's UK, responds:

Who should I talk to if I want to take part in research?

"You should talk to everyone about research. You never know who is taking part in research or conducting a trial. People involved in research are generally very happy to discuss their experiences and tell you where you can find out more."

See the rest of our Q&A session at parkinsons.org.uk/qaresearch



HAVE YOUR SAY in Parkinson's research

At Parkinson's UK we know that people affected by Parkinson's are the experts in living with the condition. That's why we've been working

hard to increase the opportunities for Research Support Network members to have their say in what research is done, how that research is designed and what projects we should be funding.

Partner with researchers

Patient and Public Involvement (PPI) is when researchers and people affected by health conditions work in partnership to develop research studies.

Our PPI volunteers have been helping researchers with lots of exciting projects – from commenting on written information to joining focus groups with researchers. One of our volunteers, Paula, tells us how she helped a researcher to shape their study:

“A lot of us with Parkinson's have difficulty with writing, and that may not occur to a researcher. The time of day is also important. How we are is dependent on whether our medication is working. By helping address these issues before the research starts, it means the researchers won't be wasting time because the patients in the study can't write or talk.”

Opportunities to shape research are wide-ranging and many can be done from home. Get in touch at rsn@parkinsons.org.uk to find out more about getting involved in research.

Help us review our grants

Parkinson's UK funds more than £5million in research a year. When a researcher submits an application for funding, it's reviewed by both scientific experts and people affected by Parkinson's – our lay grant reviewers. These volunteers help to make sure the research we fund reflects the priorities of people affected by Parkinson's.

Professor Peter Magill is a Parkinson's researcher based at the MRC Brain Network Dynamics Unit at the University of Oxford, and is a member of our grant assessment panel. He shares his views:

“The priorities and needs of people with Parkinson's and their carers are always evolving, and it can be a real challenge for researchers to keep updated about what is most important. On the other hand, it can be equally challenging for those outside of the lab or clinic to get to grips with all the possibilities and pitfalls of scientific research.

“This is why the opinions of researchers and lay people, and a two-way dialogue between both groups, are critically important. It is the lay reviewers who typically provide the best 'reality checks', and their feedback can make all the difference between a research application being funded or not.”

We need your help

If you would like to make a difference to Parkinson's research by using your personal experience of Parkinson's to help us decide which grant applications to fund, please contact us at researchapplications@parkinsons.org.uk for more information.





It's time for a new treatment

**WE WON'T
WAIT**

People with Parkinson's need a new treatment. The science is ready and we have the expertise. We won't wait – invest in our research today.

Parkinson's drugs aren't good enough. They don't stop, slow down or reverse the condition – they just mask it for a time. And they can have distressing side effects. Right now, we're at a tipping point. With decades of research, we've unlocked key discoveries that could transform lives.

Donations from people like you made the groundbreaking GDNF clinical trial happen. Your money allowed us to begin testing a potential new treatment in people with Parkinson's. By 2020, we want at least two to four new potential treatments for Parkinson's in the drug development pipeline, so we have a real chance of finding a better treatment and a cure.

We won't wait any longer – donate today and help us make more clinical trials happen.

**[parkinsons.org.uk/
wewontwait](https://parkinsons.org.uk/wewontwait)**





GENETICS IN PARKINSON'S

What causes Parkinson's? There is no one simple answer. In most cases it is a complex combination of environment, lifestyle and genetic factors. We asked five volunteers from our Research Support Network, along with researcher Dr Patrick Lewis, to delve into the world of DNA and genes.

Genetics in Parkinson's research

For decades, researchers thought that our genes played only a minor role in Parkinson's. However, our understanding has progressed greatly in the last 20 years.

The identification of very rare familial forms of Parkinson's, where the condition is diagnosed in generation after generation, coupled with a better understanding of what is happening inside the affected brain cells, means genetics is no longer a neglected area of Parkinson's research.

Today, genetics is recognised as playing an important role in around 10-15% of Parkinson's cases.

Finding a needle in a haystack

There are about 20,000 genes in the human genome. Trying to identify links between genes and conditions like Parkinson's is painstaking work, but the good news is that researchers have found needles in this haystack.

Recent advances in technology, for example the sequencing of the human genome, mean that it is now possible to study the genes of large groups of people, and to store and process the vast amount of data that results.

Together these technologies are revolutionising our understanding of genetics in Parkinson's.

Genes linked to Parkinson's

The first link between a specific gene and Parkinson's was discovered in 1997. The SNCA gene – which stands for 'Synuclein Alpha' – acts as the instructions for making the protein alpha-synuclein. This protein is known to play a key role in Parkinson's.

Several families worldwide are now known to have an extra alpha-synuclein gene in their DNA, causing their cells to produce extra protein and increasing the risk of Parkinson's.

Since this discovery, at least 16 different areas of our DNA code (imaginatively named PARK1 to PARK16) and 30 specific genes have been linked to Parkinson's – including gene LRRK2, which is the most common genetic cause of Parkinson's identified so far.

These discoveries are important for several reasons:

Parkinson's genes may provide us with new drug targets

Understanding how changes in genes – such as LRRK2 and SNCA – cause things to go wrong in Parkinson's could unlock new ideas for how to target and fix the problems.

Protective genes may lead to a way of slowing or preventing Parkinson's

Many people carry Parkinson's risk genes but never develop the condition. Researchers think this is because they may also have inherited protective genes. Identifying these genes could lead us to treatments that stop Parkinson's in its tracks.

More accurate and earlier diagnosis

Genetic testing can tell us about risks but it cannot yet predict accurately who will get Parkinson's. With no treatments that can slow or stop Parkinson's, many would prefer not to know about their genetic risk. But in a future where these treatments exist, genetic testing could be very valuable.

Testing treatments earlier

Genetic risk factors could help identify people at risk of Parkinson's. This could give researchers the opportunity to test new treatments that have the potential to slow or stop Parkinson's earlier in the condition, when they are likely to be more effective.

Using types of Parkinson's to improve treatment

While no two people with Parkinson's experience exactly the same symptoms, there do appear to be distinct subclasses of the condition. It may be possible to use genes to identify types of Parkinson's, which could lead to more personalised treatments.

Play your part in the future of genetic research

Better understanding of the genetics of Parkinson's promises to improve our understanding of the condition. This will help researchers develop new and better treatments, and one day a cure.

To fully understand the role of genetics in Parkinson's more people are needed. If you are interested in taking part in research, visit parkinsons.org.uk/takepartinresearch for a list of studies currently looking for participants.

Or join the 2,300 members of our Research Support Network (p14-18) to get opportunities to take part in research delivered to your inbox.



DEVELOPING THE TREATMENTS OF TOMORROW

Drugs work in a variety of ways. They fight germs, destroy abnormal cells that cause cancer, replace substances that we're lacking (such as vitamins), or change the way that cells work in the body.

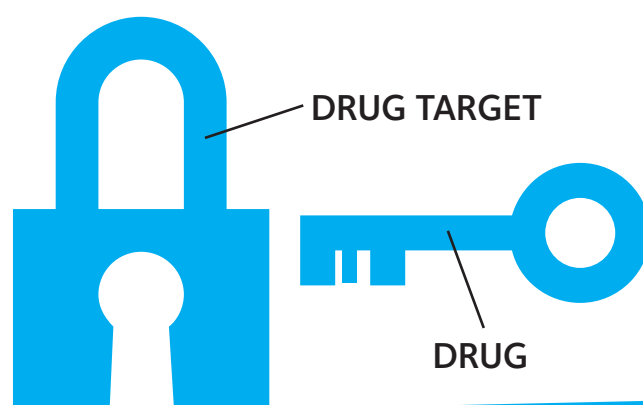
Most of the drug treatments we currently have for Parkinson's work by replacing the chemical dopamine inside the brain. But they cannot stop the loss of brain cells, which means symptoms get worse over time.

We now have a much better understanding of how processes inside these precious brain cells go awry in Parkinson's – causing these cells to stop working properly and die. And this means we are ready to develop treatments that can tackle the underlying causes of Parkinson's by changing the way the brain cells work.

The key is finding small molecules that are exactly the right shape and size – the way a key fits a lock – and that target the process that has gone wrong in the cell. And crucially, they need to do this without causing problems in other organs and tissues that could produce serious side effects.

The actual process of developing these new treatments is shown in the cartoon on the next page.

It's a long and difficult journey. Each step in the process is vital, and a drug can fail at any stage along the way. But the rewards for success are compelling – treatments that can slow, stop or even reverse Parkinson's.

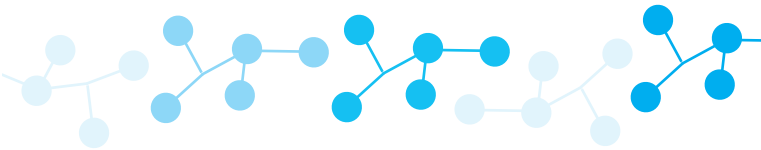


The drug development pipeline

EUREKA

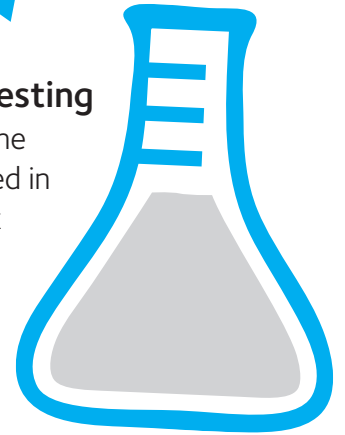
1 Find molecules with potential

The first step is to screen a large number of drug-like molecules with a simple test that swiftly identifies any that may have the desired effect. Up to 500,000 different molecules need to be screened to find a handful of molecules with potential. These can often be provided in drug libraries by companies.



2 More rigorous testing

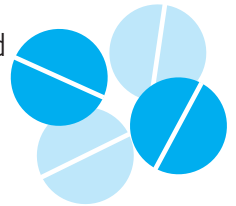
To find out more about the molecules, they are tested in a range of more complex experiments to identify those with the most promise.



3

Turn molecules into drugs

Now the group has been whittled down to molecules with real promise, it's time to start honing and developing them into drugs. This step needs skilled scientists who are specialists in drug design. They will painstakingly tweak the structure of the molecules to improve their performance. This will help to ensure the drug gets to the right place in the body and has the most beneficial effect with the fewest side effects.



4

Choose the best contenders

With a set of experimental drugs with real potential for treating Parkinson's, the very best ones are chosen to move into the next stages.



WOW

5 Intensive safety and effectiveness testing

Before any new experimental treatment can be tested in people, it first needs to be extremely rigorously tested in the lab to fully understand safety and effectiveness.



GO!

6 Testing in people in clinical trials

At last, the new drug is ready to go forward to be tested in people in clinical trials – the ultimate test of any new treatment.



Introducing the Parkinson's UK Virtual Biotech

We speak to our Director of Research, Dr Arthur Roach, about how Parkinson's UK is planning to fast-track the most promising scientific discoveries into life-changing treatments for people with Parkinson's.

What are we planning to do?

The crucial early stages of developing new drugs and treatments (described on the previous page) are often led by companies called biotechs.

They have special expertise in this vital stage in the journey from a scientific discovery to a new treatment.

But opportunities could be lost because there's not enough investment from industry to drive scientific discoveries forwards.

This is a major roadblock in our mission to develop better treatments and a cure. We believe we can step in here to bring new treatments forward faster.

We're calling this major new programme of work the Parkinson's UK Virtual Biotech because we'll be acting in the same way as a small biotech company.

But unlike commercial biotechs, we will be dedicated to developing new treatments for one condition – Parkinson's.

And instead of making money, our goal is delivering better treatments that improve life as quickly as possible.

How will the Parkinson's UK Virtual Biotech work?

This is the clever bit! We want to do the same type of drug development work as a regular biotech company, but we don't want to build our own labs, employ a huge team of scientists or buy expensive equipment.

Instead, we will work in partnership with a range of other organisations – these may be companies, universities or other charities – who have the facilities and staff to carry out the scientific work for us.

We will carefully manage these projects with guidance from a team of industry and scientific experts who are volunteering their time.

We will bring these elements together to create our own portfolio of projects – all at different stages of the drug development pipeline – in a manner similar to a commercial biotech company.

This means we can deliver new treatments at a fraction of the cost. And we can stay agile – rapidly investing in the most promising projects, and cutting off projects that turn into dead ends so that we make maximum use of every pound we spend.

Do other medical research charities do this?

We are not alone as there are a few other charities taking a similar approach, but our virtual model

seems to be fairly unique in the charity sector. Alzheimer's Research UK is actually setting up three Drug Discovery Institutes which will employ teams of research scientists at state-of-the-art facilities, so they could be a potential partner for some of our projects.

When will the Parkinson's UK Virtual Biotech start developing new treatments?

I believe it's the perfect time to be launching our Virtual Biotech.

The discoveries in the past ten years, particularly in the genetics, molecular biology and biochemistry, provide us with a wealth of promising ideas for new treatments that have the potential to tackle the underlying biology of Parkinson's.

And that means treatments that can actually slow, stop or reverse the development of the condition are within touching distance.

We hope to have new projects to tell you about in the next few months, and to build an exciting portfolio of projects over the next few years. ”



USING OLD DRUGS FOR NEW PURPOSES

We have already looked at how our Virtual Biotech aims to fast-track the most promising scientific discoveries (page 24-25), but what other strategies will help get new medicines to the people who need them quicker?

Although many drugs already exist on our pharmacy shelves, lots of time and money is invested into developing new treatments from scratch. Currently, developing an idea in the lab into an approved treatment can take up to 20 years and cost around £1 billion.

Drug repurposing involves finding drugs – that are already approved and in use for other conditions – with untapped potential for Parkinson's. This repurposing of drugs could make new treatments for Parkinson's available much more easily, quickly and cheaply. But drug repurposing isn't only about using drugs that are already available. It also allows us to take advantage of drugs that may have failed in clinical trials for one condition and test them in another.

Drug repurposing in Parkinson's

Many of the drugs commonly used today were originally developed for another purpose. Aspirin for example, one of our oldest drugs for treating fever and pain, has recently been shown to have other powerful effects – such as reducing the risk of heart attacks and stroke. And drug repurposing has already helped us to find ways to treat Parkinson's.

Selegiline

Initially developed as an anti-depressant, this drug is now available for the treatment of Parkinson's symptoms. It works by preventing the breakdown of dopamine in the brain.

Ropinirole

First used to treat high blood pressure, it's now widely used as a Parkinson's medication. As a dopamine agonist, it acts like dopamine to stimulate nerve cells.

Statins

Statins, like simvastatin, are normally used to treat high cholesterol. But their anti-inflammatory properties have led to them being tested in a new clinical trial for Parkinson's.

Exenatide

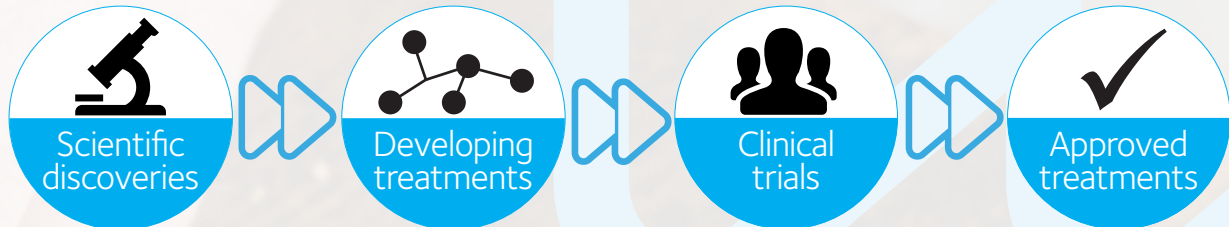
Research in animal models has suggested that this diabetes drug could help to prevent nerve cells from dying. As Parkinson's is caused by the death of dopamine-producing nerve cells in the brain, clinical trials are looking into whether exenatide could be used to slow or stop the progression of Parkinson's.

Have you ever noticed a time when taking a non-Parkinson's drug has had an effect on your Parkinson's symptoms? With so many drugs at our disposal we're convinced that there are other drugs available with hidden benefits for Parkinson's. And with your help we are trying to uncover them. Help us to find new prospects for drug repurposing by filling in our survey at parkinsons.org.uk/repurposingsurvey

How does repurposing reduce the time that drugs need to spend in clinical trials?

Developing a drug from scratch is a long, slow and expensive process. In drug repurposing, we know treatments are safe, so they can often progress more quickly into clinical trials.

1. Developing a drug from scratch



Researchers in university labs and hospitals look at the fine details of a condition – finding out what goes wrong in Parkinson’s and coming up with ideas for how to fix it.

Dedicated teams then turn the most promising scientific discoveries into potential new treatments.

Phase I tests the safety of a new treatment. At **Phase II**, new treatments are tested on people with a condition to see if it is effective. **Phase III** trials test the safety and effectiveness of treatments over a longer period of time.

Treatments need to be officially approved before being made available. Regulatory authorities check all necessary testing has been done, scrutinise the results and judge which treatments are safe for use.

2. Drug repurposing

First stages are bypassed.



Repurposed drugs have already been proven to be safe after years of use by patients, so early clinical trial phases can often be bypassed. Treatments can enter the later phases of clinical trials more quickly.

While drug repurposing can speed up the initial discovery and testing stages of new therapies, these drugs still need to be approved by regulatory bodies before they can be made available.

We're already funding several research projects testing existing drugs to see if they could have hidden benefits for people with Parkinson's. Find out more at parkinsons.org.uk/repurposing

What else is being done to speed up access to new treatments?

Many organisations, from charities to the Government and regulatory bodies, are joining forces to bring treatments to patients more rapidly.

Regulatory authorities, such as the European Medicines Agency (EMA) and the Medicines and Healthcare Products Regulatory Agency (MHRA), need to review and approve new drugs before they can be given to patients. This can take one to two years and can be a frustrating stage of the clinical trial process for patients who could potentially benefit from the new treatment.

Both the EMA and the MHRA have now adopted early access schemes that make certain promising treatments available to people before they've officially been approved.

But while drug approval is time-consuming, ultimately it's for our own protection. Treatments that are available through these early access schemes are still being investigated, and we still may not fully understand how they work or what their side effects might be.

The UK Government is also taking steps to make new treatments available to those who need them more quickly.

The Accelerated Access Review aims to speed up people's access to innovative treatments

"As much as repurposing drugs has been a breakthrough in finding and testing new treatments, it seems that a similar shake up of the approval process is required to speed up the delivery of new therapies for Parkinson's." **Member of the Research Support Network**

and technologies. Since its announcement in 2014, patients, healthcare professionals and organisations – including Parkinson's UK and our supporters – have been contributing their ideas to the review. It's hoped that the final review will address current challenges in people's access to new treatments and propose solutions to help get medical discoveries to patients as quickly as possible.

Several MPs have also put forward bills to help accelerate this process. And while they've mostly been unsuccessful – often due to patient safety concerns – they have raised awareness of this key issue.

And what about Parkinson's UK?

We are committed to getting new and better treatments to people with Parkinson's more quickly. However, we don't want this to be at the cost of patient welfare.

We've been involved in opposing and amending parliamentary bills when we've felt they could have a negative impact on patients, as well as providing briefings to help debates and attending meetings with relevant organisations such as the Department of Health.

But ultimately we want new treatments to reach people with Parkinson's as soon as possible. And we are involved in ongoing discussions with other charities, regulatory bodies and the Government so we can all work together to make this happen in the safest possible way.

RESEARCH RESULTS

Parkinson's UK-funded researchers are looking into all aspects of Parkinson's – from searching for a cure to finding ways to improve life with the condition now. Over the next few pages we update you on some of their latest findings.

Making brain cells and mimicking the brain in a dish – an interview with Professor Rosemary Fricker

Over the past six years, Prof Rosemary Fricker from Keele University has been the lead researcher on two Parkinson's UK-funded projects. We find out about the inspiration behind these two quite different projects, her successes and what she plans to do next.

What was the inspiration behind your initial research project?

I was inspired to work on treatments for Parkinson's after my grandmother was diagnosed with the condition while I was at university. I wanted to become a scientist to research a potential cure, and was fortunate to join a prestigious research group, led by Prof Stephen Dunnett, investigating nerve cell transplants for Parkinson's.

Nerve cell transplants have the potential to reverse Parkinson's by replacing the cells lost in the condition. While nerve cell transplants have shown promise in small clinical trials, we need a better, more abundant source of cells that could be used to treat many people.

Did you find the signals that make stem cells into dopamine-producing nerve cells?

We found a protein called the vitamin D receptor, which controls how cells respond to a form of vitamin D known as calcitriol. When we added calcitriol to stem cells growing in a dish, we generated more dopamine-producing nerve cells than without it.

We showed that this is at least partly because calcitriol protects the nerve cells from dying.

Off the back of this discovery we were awarded an extension for the project to investigate if vitamin D can protect dopamine-producing nerve cells and prevent the development of Parkinson's-like symptoms.

So can vitamin D protect dopamine-producing nerve cells?

We used an animal model to further explore the protective abilities of vitamin D. We gave rats vitamin D in their drinking water before injecting a toxic chemical into their brains that specifically kills dopamine-producing nerve cells – this creates Parkinson's-like symptoms.

Our results showed that rats that were given vitamin D in their drinking water could move better after being given the toxin. We also found that more dopamine-producing brain cells survived in these rats.

What does this mean? Could vitamin D be a treatment for Parkinson's?

Our results suggest that vitamin D or calcitriol could have a future use in Parkinson's treatment as it may protect remaining nerve cells in the condition – but we still need to do more research to test this.

Vitamin D could also be used to produce more dopamine-producing nerve cells that could be used for transplants.

RESEARCH RESULTS

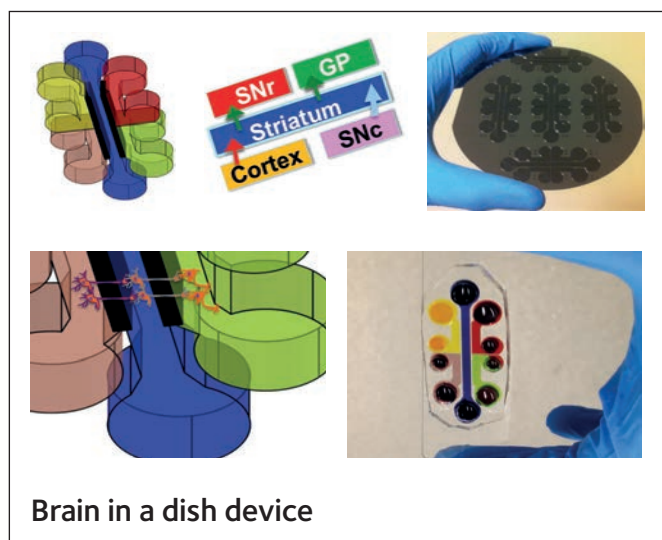
My lab is working towards developing a funding application for a clinical trial to test if vitamin D supplements can benefit people with Parkinson's.

That was just one of your projects. How did your other project come about?

I've now worked in research towards therapies for Parkinson's for more than 20 years. I am continually inspired by friends and colleagues with Parkinson's and their carers. My other project was inspired by a discussion I had with colleagues about how to overcome decades of failure to generate a model of the human brain in a culture dish that could be used to study Parkinson's. We felt compelled to pool our expertise in engineering and biology to try to make a major breakthrough in Parkinson's research.

What did you do?

Our goals were to build a device to model the Parkinson's brain in a culture dish. The dish needed to have nerve cells growing in different sections. It also had to allow the cells to connect with cells in other areas of the dish, to make a circuit that mirrors the one in the living brain.



Did it work? Have you made a brain in a dish?

We successfully built a device, small enough to fit on a microscope slide. The device can contain five different types of nerve cells in different areas, and has tiny channels that allow the cells to connect and communicate with each other.

So what can you use this device for and how will it help people with Parkinson's?

We still need to prove that our device works as close to real life as possible, and check that the nerve cells connect and function appropriately. But the next step is to use it to make a model of Parkinson's. We believe that this project will have long-term benefits for people with Parkinson's by providing a rapid method to test new potential therapies, reducing the time for new treatments to reach the clinic and reducing the need for as much animal testing.

Where can people find out more?

I gave a lecture earlier this year where I talked about my research projects. You can watch the videos at parkinsons.org.uk/fromthelab

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

Parkinson's UK-funded researchers at Toronto Western Hospital, Canada, led by Dr Lorraine Kalia, have been looking for drugs that may have potential for Parkinson's.

What they did

The team were interested in drugs that have been approved for other conditions, as these drugs have already been safety tested. This means that if they found drugs with potential for Parkinson's, they could more speedily enter clinical trials and be tested in people with the condition than drugs developed from scratch.

Lorraine's team used a worm model of Parkinson's to see whether any drugs known to target a specific Parkinson's-related protein called alpha-synuclein could stop the problems with nerve cells that happen before the cells are lost.

.....
"We believe there may be drugs that are already available and approved for other conditions that can slow Parkinson's. We wanted to use a faster, better drug screening method to identify drugs with promise for Parkinson's."
.....

Dr Lorraine Kalia

“By testing drugs that are already approved for other conditions, promising drugs can rapidly be taken forward into clinical trials.”

Dr Lorraine Kalia

What they found

The team developed a new method to measure how small drug molecules change movement in a worm model of Parkinson’s.

The method they developed is more automated than previous techniques, which will allow researchers to test drugs more quickly and more accurately.

This will be instrumental to finish testing how effective drugs used for other conditions are for Parkinson’s, and will lay the foundation to deliver new and better treatments for Parkinson’s faster.

A lifetime study of people living with Parkinson’s

Parkinson’s is a widely variable condition. So understanding how Parkinson’s affects people over time (called prognosis), and who will do well and who will do badly, would be hugely valuable. It could help to improve the management of the condition, provide those affected with more accurate information, and improve the planning of future healthcare provision and clinical trials.

Most of the existing knowledge about the prognosis of Parkinson’s comes from studying groups of people with younger onset Parkinson’s.

“Our study gives a clearer understanding of how people with Parkinson’s fare over time and what factors influence outcomes such as survival and disability. This will allow better information to be given to those with the condition and their families, so they can plan for the future.”

Dr Carl Counsell

This means existing information on prognosis may not be accurate or relevant to everyone with Parkinson’s. And there are currently no tools that predict, at an early stage, who will fare well or badly.

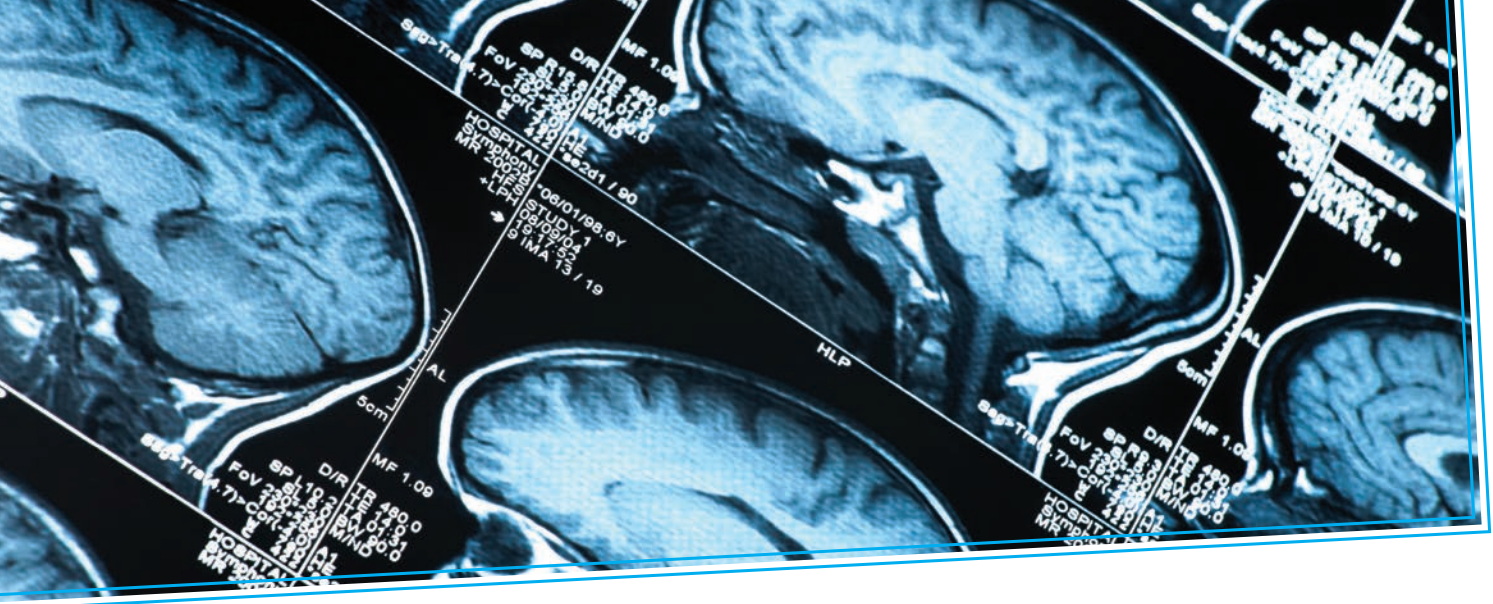
Now Parkinson’s UK-funded researchers at the University of Aberdeen have produced the best evidence yet about prognosis for people with Parkinson’s.

The team, led by Dr Carl Counsell, used data from a cohort study called the PINE study. They discovered that, at diagnosis, older age and worse scores in measures such as slowness, memory and movement were predictive of a worse prognosis. The team also developed predictive tools and showed they could fairly accurately predict prognosis.

“The predictive tools may help personalise treatment. For example, those predicted to do badly may merit earlier, more intensive treatment, or be selected for certain clinical research or trials.”

Dr Carl Counsell





HOW YOUR BRAIN COULD HELP PARKINSON'S RESEARCH

The Parkinson's UK Brain Bank helps researchers all over the world to better understand the condition. We explain how this vital resource is driving our researchers towards new and better treatments for Parkinson's.

Why do Parkinson's researchers need brain tissue?

Researchers investigate Parkinson's in many different ways – from looking at nerve cells in a dish to testing new treatments in animals and people. Animal models mimic the symptoms of Parkinson's and can help us to understand some aspects of the condition. But animals don't get Parkinson's naturally, so we need to look at humans to understand more about why nerve cells are lost in Parkinson's brains. By studying people living with Parkinson's we can improve our understanding of how the condition develops, as well as responses to new treatments – but it's difficult to study small changes in the brain in this way. So brain tissue, donated by people with and without the condition after they have died, is really important for helping us understand why people get Parkinson's.

What type of research projects use brain tissue?

Since it was set up in 2002, the Parkinson's UK Brain Bank has supported more than 100 research projects worldwide. It supports researchers involved in a number of promising avenues of Parkinson's research, including projects looking at:

- **The causes and signs of Parkinson's**
Scientists search for changes in the brains of people with Parkinson's to try and identify potential targets for new treatments. These signs could also help to improve diagnosis.
- **Developing imaging techniques to help us study people with Parkinson's**
Researchers are developing brain scans that may allow us to visualise Parkinson's. These imaging methods need to be tested in brain tissue to check if they work properly before they can be used in people.
- **Genetics in Parkinson's**
Researchers can use brain tissue to look for changes in our DNA that are linked to Parkinson's.

Looking for DNA modifications in Parkinson's

Who? Dr Nigel Williams

Where? Cardiff University

What? £232,404 over 2 years

Nigel is trying to understand how chemical changes to the DNA – known as DNA modifications – are associated with an increased risk of developing Parkinson's. To do this, he's using tissue from the Brain Bank.

We don't fully understand why people get Parkinson's – but genes, lifestyle and environmental factors are all thought to be involved.

Tiny molecules can stick to our genes like labels and affect how active they are. Nigel's team previously discovered that subtle changes to certain genes can affect the accumulation of a common type of molecular label, known as methylation, and increase the risk of developing Parkinson's.

In this study his team are looking at whether another type of DNA label, known as histone modification, could also have a role in Parkinson's, by influencing the behaviour of genes linked to the condition.

The team will use brain tissue samples donated to the Brain Bank to look for differences in histone modifications in different parts of the brain.

“Rather like a light switch determines whether a bulb is on or off, different histone modifications can act as a molecular switch regulating whether a gene is active or not. We will assess whether individuals who carry a genetic change previously shown to increase the risk of Parkinson's have a different pattern of these histone modifications in comparison to those who do not.”

Dr Nigel Williams

Drugs that can enter the brain and reverse histone modification have already been identified. If this project discovers histone modifications that are linked to Parkinson's, it could open up new avenues for future treatment.

If you're interested in becoming a brain donor find out more at parkinsons.org.uk/brainbank. If you're an existing donor, please share your email address with the Brain Bank so they can keep in touch. Contact them at brainbank@imperial.ac.uk or on **020 7594 9732**.



MY LIFE IN RESEARCH BY DR CATHERINE HURT



I have always been interested in the relationship between the body and the brain. After graduating in Psychology from the University of Manchester, I worked on an international research project testing the effectiveness of a drug for memory problems in Parkinson's.

I found the project very interesting from a research perspective – Parkinson's is a very diverse condition with so many varying symptoms and challenges. It certainly fits with my interest in the links between the brain and the body.

I also realised that public awareness of Parkinson's isn't always what it should be, even though the condition has profound effects on patients and those around them.

I met some inspiring people who had remarkable resilience and optimism. Much of my decision to continue research in Parkinson's came from my enjoyment of working with these people, and a desire to try and help make life a little bit easier.

After finishing my PhD I was lucky enough to complete my post-doctoral work with Professor Richard Brown at the Institute of Psychiatry, Psychology and Neuroscience at King's College London. I worked on his national study exploring mood states in Parkinson's. I then went onto my own research projects at City University London.

My research focuses on how people think about their condition and how this affects what they do and how they feel. I find it fascinating that people can have the same condition, with very similar symptoms, but think about them in very different ways.

One of my current projects is about supporting people with Parkinson's to seek help for non-motor symptoms. The research so far has identified that many people don't realise that non-motor symptoms are related to Parkinson's, or they think that treatments aren't available. We are developing an online programme to empower people with Parkinson's to ask for help with problematic symptoms.

My research won't find a cure for Parkinson's but I hope that it will help to improve the lives of people affected by Parkinson's. I really want to give something back to a group of people who have always been so generous with their time and experiences.

Dr Catherine Hurt is Senior Lecturer in Health Psychology at City University London. Her PhD work at the University of Manchester focused on perceptions of illness and help-seeking behaviour in people with memory problems. She then conducted post-doctoral work at the Institute of Psychiatry, King's College London, before joining City University London as a Lecturer in Health Psychology in 2012. Her main interest is in the coping, quality of life and wellbeing of people with neurodegenerative conditions.

MORE PROGRESS?

Progress magazine is our free, twice-yearly magazine focused 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 research@parkinsons.org.uk or phone **020 7963 9313**



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Your thoughts help make *Progress* magazine better. You can fill in our survey online at parkinsons.org.uk/progressfeedback, email us your comments at research@parkinsons.org.uk or call **020 7963 9313**. Or write your feedback in the space below and post it back to us at Research team, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1 1EV.

Do you have any comments about *Progress* magazine?

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Parkinson's research lecture series

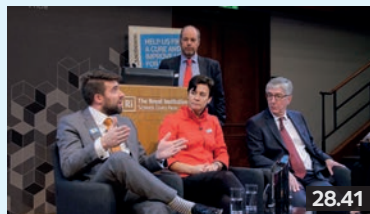


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