## **PROGRESS** The research magazine of Parkinson's UK | Spring 2018

## Improving clinical trials

To deliver better treatments

## SEARCHING FOR MEANING Research into

Research into hallucinations

## PERSONALISED TREATMENTS

How to treat people as individuals

## INSIDE INVOLVEMENT

How partnerships can benefit research

PARKINSON'S<sup>UK</sup> CHANGE ATTITUDES. FIND A CURE. JOIN US.

## WELCOME



trained as a neuroscientist and spent 30 years at the bench, trying to understand the brain. I studied conditions like Alzheimer's and Parkinson's and tried to make medicines that matter for the people in such urgent need.

For most of my career, I worked in the lab with teams of brilliant scientists to come up with the ideas to develop new treatments that could make a difference.

But despite working for 25 years at three large companies, none of the drugs that I worked on ever made it to patients.

Then, seven years ago when I was at a large pharmaceutical company working on Parkinson's, my younger brother was diagnosed with young onset Parkinson's and my life changed. I left my job at the largest pharmaceutical company in the world because I knew that it was taking too long to bring new treatments to people like my brother. I needed to find another way to bring hope to my family.

So, I joined the Critical Path Institute, a non-profit organisation based in Arizona, which exists to make it faster, cheaper and more efficient to get new therapies to patients.

We all know that it costs far too much and it takes far too long to get new treatments to those who need them.

Our goal is to act as a neutral third party to bring all the right stakeholders together – companies, patient organisations, patients, government agencies, researchers and regulatory agencies – to create better, faster ways to develop new treatments.

In 2015 we launched the Critical Path for Parkinson's in partnership with Parkinson's UK.

We're now two years in to the project and with eight major companies, five patient organisations, four universities and global regulatory agencies all working together, we're making exciting progress to speed the development of better therapies.

I hope you enjoy reading more about the Critical Path for Parkinson's on pages 6-9 of the magazine.

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*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 **research@parkinsons.org.uk** or phone on **020 7936 9313**. Cover @Kritchanut P6 @YakobchukOlena P9 @LUHUANFENG P13 @Highwaystarz-Photography P17 @PeopleImages P18 @5xinc P24 @xubingruo P32 @Michał Chodyra P33 @media point inc

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## **NEWS**

# Research into flu and the onset of Parkinson's

study from the US has highlighted a link between certain types of flu and the risk of Parkinson's.

The team investigated the combined effects of flu and a toxin that specifically damages dopamine producing brain cells. The results, published last year in the scientific journal *npg Parkinson's Disease*, show that mice infected with the H1N1 strain of flu had a 20% greater loss of these cells when treated with the toxin called MPTP.

They also showed that this increased loss of brain cells, due to the combined effects of flu and toxin, could be reduced by vaccinating the mice against flu. Professor David Dexter, Deputy Director of Research at Parkinson's UK, comments:

"This study supports anecdotal evidence that major viral infections, such as the flu, can act as a tipping point, or speed up the onset of Parkinson's for those who have the condition but don't yet know they have it.

"This study also shows that a flu injection, for some, may reduce the damage that could be caused by multiple factors acting alongside each other.

"While a lot of exciting research is happening in this area, we still do not fully understand the causes of Parkinson's and for most people, it is unlikely that a single factor is to blame. Rather, various lifestyle, environmental and genetic factors combine to bring it about."

# NEWS ROUNDUP

## Research on caffeine to diagnose Parkinson's

esearchers in Japan have discovered that people with Parkinson's may have lower levels of caffeine in their blood after drinking tea and coffee.

The results, published in the online journal *Neurology*<sup>®</sup>, suggest that caffeine may be processed differently by those with the condition.

The study looked at the blood levels of caffeine, as well as the by-products the body turns it into, in 139 participants.

The researchers found that, despite drinking about the same amount of caffeinated

beverages, the levels of both caffeine and by-products were lower in those with Parkinson's. They also suggest that the test might work in the early stages of the condition.

Professor David Dexter, comments on these results:

"We have known of a link between caffeine and Parkinson's for some time, but up to now this was only related to the risk of developing the condition. Here, for the first time, researchers suggest an entirely new association with how caffeine is processed in the body. "However, due to the lack of participants with other conditions in this study, there is no evidence that this test could distinguish Parkinson's from other neurological conditions.

"The authors also point out it is unclear if the levels of caffeine in the blood were due to a change in metabolism, or simply because the caffeine was not absorbed in the gut.

"As such, further research is needed before we know if this test holds any promise for making diagnosis more accurate, quicker and less stressful."

#### **READ OUR BLOG**

Find out the latest research news, and go behind the headlines, in our new research blog **parkinsons.org.uk/blog** ■

## **FEATURE**

# IMPROVING CLINICAL TRIALS TO DELIVER **BETTER** TREATMENTS

Despite decades of research and major breakthroughs in our understanding of Parkinson's, a cure always seems to be 5, 10 or even 20 years away. Today there's a wave of exciting treatments coming through the pipeline that hold genuine potential for slowing, stopping or even reversing the condition. That's why we're working to make sure clinical trials are smarter, faster and more likely to succeed. Il potential treatments need rigorous testing, and clinical trials are the most costly and lengthy part of the whole research process. In recent years, several promising new treatments for Parkinson's have failed to show benefit. We believe the problem may not be that the drugs don't work, but that we're testing them in the wrong way. So we may be throwing away potentially effective drugs because we cannot test them properly.

Parkinson's is a phenomenally complex and varied condition. Different people experience different symptoms, and the condition can develop in varied and unpredictable ways. This makes choosing the right people to participate in trials, and finding the right ways to measure success, extremely difficult. That's why the international community is joining forces to improve clinical trials for Parkinson's.

## Right treatment, right patient, right time

To give new treatments for Parkinson's the best chance of success, we need to test them in the right group of people at the right time.

This is the mission of the **Critical Path for Parkinson's** consortium – an international collaboration, led by Parkinson's UK, bringing together pharmaceutical companies, regulatory agencies, universities, charities and people with Parkinson's to share data from major studies and trials. Our expert partner, the Critical Path Institute, is a world-leading expert in bringing together clinical data and using it to create new tools for clinical trials. They work closely with regulatory agencies like the Food and Drug Administration (FDA) in the US and the European Medicines Agency (EMA).

This is vital because these agencies are the gatekeepers for the development and approval of new treatments, so any new tools need to be accepted and endorsed by the FDA and EMA before they can be used in clinical trials of potential new therapies.

### How it works

This ambitious project is built on 'big data'. Many studies and trials have been conducted in Parkinson's over the past few years – some testing potential new treatments, others collecting detailed information about the condition over time.

Each individual study produces important insights, but if all the data could be combined and analysed together it becomes far more powerful.

This is exactly what the Critical Path for Parkinson's is doing – building a huge and highly sophisticated database that can be used to understand the condition and develop the tools the community needs to improve clinical trials.

The database already includes information collected from

more than 3,300 people with Parkinson's from around the world – including from Parkinson's UK-funded studies like Tracking Parkinson's and the Oxford Parkinson's Disease Centre.

It also includes data collected during unsuccessful clinical trials – so even though these studies did not result in a new treatment, the data generated still has huge value.

## New tool to select people for clinical trials

In early 2018, the Critical Path for Parkinson's project achieved its first major success. Researchers and drug companies have the go ahead from regulatory agencies to use a new tool – a brain scan – that can be used to select the right people for clinical trials. This is an important step in the search for better treatments for Parkinson's.

Research suggests that up to 15% of individuals taking part in clinical trials may not have Parkinson's. They are extremely unlikely to benefit from the new therapies being tested and their inclusion can affect both the trial results and ultimately the future of the potential treatment.

Because Parkinson's is a progressive condition, caused by the gradual loss of cells in the brain, the best chance to intervene with treatments that can slow, stop or reverse the damage is during the earliest stages of the condition. However, during these early stages, symptoms tend to be mild, which makes selecting the right people to participate in trials very difficult. Using this brain scan can produce a picture of how dopamine-producing cells – which are destroyed by Parkinson's – are functioning inside the brain.

It can help distinguish between people who have Parkinson's (or a similar progressive condition) and those with a condition like essential tremor, which is unlikely to worsen over time.

These brain scans are sometimes used by doctors to help them reach a diagnosis, but until now they could not be used to select people for clinical trials of new drugs. The use of the brain scan in this way is now encouraged by the regulatory agencies.

### Diane Stephenson, Executive Director of the Critical Path for Parkinson's consortium, which led this work, comments:

"These brain scans in themselves are not new, but until now there has not been a clear consensus that they can and should be used to select participants for clinical trials in this way. Through our global project we've been able to bring all the data and expertise together to make a powerful case, so we're delighted that this endorsement from the EMA will improve the quality and chances of success for all future trials. This success is hopefully just the first in a suite of new tools that we hope to deliver for Parkinson's."

## Next steps for the Critical Path for Parkinson's

Our mission with the Critical Path for Parkinson's is to take the guesswork out of planning clinical trials. This first success is a great step forward but there is still much more work to do.

Next, we plan to use all the data we've collected to build sophisticated computer models that can be used by researchers across the world to make the right choices when planning clinical trials for Parkinson's.

These choices include things like how many and what kind of people to recruit to Parkinson's trials, as well as deciding on the best dose and how long to run the trial for.

Ultimately we hope to create a computer platform that functions like a flight simulator – but for trials.

Researchers will be able to testrun their trials using our platform to predict outcomes, fine-tune plans and maximise chances of a successful outcome.

All the tools we create through this groundbreaking collaboration will be shared with the global community so that all clinical trials for Parkinson's can benefit, and have the best possible chance of producing new treatments.

## Measuring new treatments against what matters most

As well as being able to ensure that the right individuals take part in studies, we also need to make sure that the way we assess treatments is meaningful and truly reflects the experience of people with Parkinson's.

The main way we measure Parkinson's and the effects of treatments in clinical studies and trials today is using a scale called the Movement Disorders Society Unified Parkinson's Disease Rating Scale (MDS-UPDRS).

This assessment is composed of 50 questions about both movement (motor) and nonmovement (non-motor) symptoms.

Each question is rated from O (normal) to 4 (severe), and then the marks are added up to give a total score, which is intended to provide an overall indication of the severity of the condition.

Although this assessment can provide a helpful snapshot of symptoms, it does not allow for variation and can struggle to capture the real impact on everyday life.

#### Lesley Gosden, a person with Parkinson's and clinical trial participant, comments:

"Research into Parkinson's needs to move up a gear, improve clinical trial outcomes and focus



on treatments in years not decades. Those of us unfortunate enough to have the condition do not have the luxury of time on our side. I recently took part in a trial and found the assessments used to measure my Parkinson's frustratingly inadequate and artificial.

"The severity of symptoms varies enormously in response to stress, constipation, general health and many other triggers. Assessing participants can only accurately reflect the efficacy of the treatment under trial if all factors are identical on each occasion – but this is clearly not reproducible.

"Therefore, participants need to be monitored more frequently with provision for recording symptoms and reactions not covered within the rigidly defined assessment scales. Asking me to assess my walking ability generally is meaningless – it can vary from immobility or a slow shuffle to a brisk walk. In my Parkinson's there is no general state.

"One of my most debilitating symptoms is dystonia – cripplingly painful muscle spasms in my feet and legs that have a huge impact on my ability to do things like drive or walk. The trial assessments failed to test the factors that most adversely affect my daily life while concentrating on symptoms that I do not experience. Multiplied across the test group this will clearly distort the overall result.

"Everyone's Parkinson's is different and variable and we need assessments that acknowledge improvement in quality of life, which is ultimately what we are all striving for."

## Creating better ways to measure Parkinson's

First and foremost, if we want to develop better ways to measure the impact of treatments, we need to work with people affected by Parkinson's to understand what benefits they value most.

This year we plan to work with people affected by Parkinson's who have taken part in clinical trials, like Lesley, to hear their feedback and ideas on how we can better capture their experiences.

To get clinical trials right, people with the condition need to be

involved in developing and testing all these new methods and scales to ensure they measure the right things and that they are practical to use in clinical trials.

The development of new technologies represents a huge opportunity to develop better ways to monitor Parkinson's much more objectively and in real time.

Wearable technologies, like pedometers and wrist sensors, are being developed that can collect and analyse vast amounts of data around the clock to produce a much more meaningful and comprehensive picture of Parkinson's symptoms.

We plan to work towards standardised and accepted ways to use these technologies to monitor and measure Parkinson's in clinical trials – and input from people living with the condition is crucial to this.

We are taking all of these issues into account when reviewing the way we fund clinical trials and we are determined to make sure that we support only studies that are designed in the best possible way to deliver treatments to people who need them as quickly as possible.

## **FEATURE**

# Searching for meaning: research into hallucinations

A hallucination is seeing, hearing, feeling, smelling or tasting something that isn't really there. We find out more about halluncinations in Parkinson's, and how and why researchers are studying this symptom.



Example of pareidolia – 'The Troll' in the rocks of Geiranger, Norway

allucinations can be a difficult symptom for people with Parkinson's and their family members to cope with.

They may be threatening, scary or upsetting, as described by one Parkinson's UK forum user:

"My husband thinks there are people in the house and talks to them and gets upset. I try to keep calm and not confrontational – he will ask me what I am going to do about the tall man in his chair or will I be giving the assorted people in our sitting room some tea! I will just say that although I know they are real to him, I can't see them."

## An unusual way to study hallucinations

We don't fully understand what causes hallucinations in Parkinson's. One barrier to this understanding is the difficulty of studying visual hallucinations in a clinical setting.

Pareidolia is a phenomenon where we see patterns, shapes, faces or objects where they do not exist (like in the photograph to the left).

This helps us to understand the world around us – our brain is constantly sifting through visual information and trying to make sense of what we see. Usually we do this very accurately. But sometimes we assign meaning where it is not there.

So how is this naturally occurring phenomenon helping us to understand hallucinations?

Researchers in Japan asked people with two different dementias, as well as those without dementia, to take a pareidolia test.

They found that people with dementia with Lewy bodies were most likely to report meaning in ambiguous images.

This suggests that there may be an overlap in visual hallucinations and pareidolia, which could be exploited to study hallucinations.

Dr Alan Bowman, a clinical psychologist at Teeside University, was interested in using the pareidolia test to find out if an ambiguous environment affects people who regularly report hallucinations differently to those who do not hallucinate.

#### The study

Alan and his team recruited people with Lewy body disorders (either Parkinson's, dementia with Lewy bodies or Parkinson's dementia) who did not hallucinate and those who did, as well as people without these conditions.

They were interested in:

- sensitivity how well the participants detected images that were there
- response bias the tendency to report the presence of an image, regardless of if it was there or not

The team measured this using pareidolia images like these:



a) Pareidolia image with signal

b) Blank pareidolia

#### Did you see the teapot in image a?

In participants with a Lewy body disorder, those who reported experiencing hallucinations found it much trickier to separate the 'signal' (image a) from the 'noise' (image b).

A second key finding was that when presented with ambiguous visual noise (like image b), participants prone to hallucinations tended to see illusory objects more frequently than participants who did not hallucinate. Alan suggests that although perceptual problems contribute to hallucinations, an ambiguous environment also plays a role by encouraging the brain to compensate. He explains:

"Imagine a radio with a broken aerial that does not receive signals well. There is a lot of white noise, and it is hard to hear what is being said among all this information.

"To compensate, the user turns the volume up. The consequence is that the poor-quality radio signal becomes a little easier to hear.

"However, the white noise also becomes very loud, so that some of it starts to sound like music, or a voice, when in fact it is nothing.

"In other words, there is a cost for this compensation – meaningless, ambiguous sensory information is wrongly perceived as meaningful.

"Research has shown that people with Lewy body disorders have impaired visual perception.

"We are suggesting that the brain compensates for this by turning the volume dial up and therefore becomes more likely to perceive things."

#### Priming

Alan also wanted to establish if people's responses to the images were affected by something called priming.

If you read the words *lunch, bread and cafe*, what do you think of when you see the following word?

## so\_p

Most likely, what came to mind was soup. That's because the words lunch, bread and cafe primed you to think of soup.

But the words *shower, towel and wash*, would have primed you to think of soap instead.

And images can also be used to prime people.



- a) Pareidolia image with signal (teapot)b) Blank pareidolia
- c) Priming image
- d) 'No prime' image

In Alan's experiment, the image of the teabag could help to prime the participants to see the teapot in image a. Alan explains the effect this had on participants:

"A prime reduced the overall number of illusory objects that hallucinating participants saw in each trial, although even with a prime, hallucinating participants still reported significantly more pareidolia than control groups did."

## What's next for this research?

Alan says: "There is a growing body of research to suggest that the pareidolia test can be useful in discriminating dementia with Lewy bodies from Alzheimer's.

"The test also appears to be good at discriminating people who hallucinate from non-hallucinators."

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In the last issue of *Progress*, we investigated the genetics of Parkinson's. Here we highlight four new projects that aim to turn our understanding of genetics into new treatments, and one project investigating the role of the gut.

NEWS

# RESEARCH



## Understanding the Fbxo7 gene in Parkinson's

Who? Dr Heike Laman Where? University of Cambridge What? £200,683 over three years

Ten years ago, researchers identified changes in a gene called Fbxo7 in people with an early-onset form of Parkinson's.

Although mutations in Fbxo7 are very rare, understanding what this gene does could be important in all forms of the condition.

Heike and her colleagues have created a mouse that lacks the Fbxo7 gene in the part of the brain primarily affected in Parkinson's.

These mice develop some of the same problems and symptoms, which makes them a fantastic new tool for studying why cells are lost in patients and for uncovering clues to develop better treatments.

"I believe that Fbxo7 may be essential for keeping brain cells healthy so the goal of this project is to understand how and why Fbxo7 is so important for these brain cells. If successful, this project could lead to the development and testing of new treatments, potentially using our Fbxo7-deficient mice, which could provide an important new tool in the search for better treatments." **Dr Heike Laman** 

## Finding drugs that combat alpha-synuclein

Who? Professor Maria Grazia Spillantini Where? University of Cambridge What? £364,620 over three years

Alpha-synuclein is a protein that was first linked to Parkinson's 20 years ago, a discovery that Maria Grazia is responsible for.

It is one of the main proteins found inside Lewy bodies – sticky bundles of proteins that appear inside the brain cells of everyone with the condition.

Maria Grazia's team have produced mice which carry an altered version of the gene that makes alpha-synuclein.

They develop the same kind of sticky clumps of alpha-synuclein inside their brain cells as you see in the human condition, and crucially they also develop Parkinson's-like symptoms including problems with walking.

"Understanding how alpha-synuclein is involved in the processes that ultimately cause Parkinson's, and finding ways to combat this rogue protein, could be the key to new treatments. In this project, we will continue to develop and study our mice, and use them to test potential drugs that could be helpful for Parkinson's."

Professor Maria Grazia Spillantini

## Targeting GBA – the most common genetic risk factor for Parkinson's

Who? Professor Anthony Schapira Where? University College London What? £319,324 over three years

Variations in a gene called GBA are the most common genetic risk factor for Parkinson's identified to date. This gene makes a protein called GCase which plays a role in regulating the amount of alpha-synuclein – a protein which builds up inside brain cells in the condition.

Changes in the GBA gene mean GCase doesn't work properly and alpha-synuclein levels increase. Therefore, finding ways to restore or increase GCase may reduce alpha-synuclein levels and ultimately help to protect the brain cells affected in Parkinson's.

"In this project, we will investigate how GBA mutations and low GCase result in increased levels of alphasynuclein, and how these changes may be involved in the spread of problems through the brain. Our ultimate goal is to develop drugs that can reduce alpha-synuclein by targeting GBA, which can both improve symptoms and have potential to slow or stop the development of the condition." **Professor Anthony Schapira** 

### Understanding LRRK2 in fruit flies

Who? Dr Chris Elliott Where? University of York What? £49,441 over two years

Changes in the gene that makes the LRRK2 protein are emerging to be a crucial player in the development of Parkinson's.

Recent evidence suggests that LRRK2 interacts with another important protein called Rab10, which is involved in many crucial processes including brain cell growth. This is something that seems to be affected in cells with LRRK2 mutations.

"Understanding how changes in the LRRK2 protein cause problems for brain cells that lead to Parkinson's may hold the key to developing new treatments. Drugs that target these processes might slow the progression of the condition rather than just improving symptoms. If we are successful in identifying the interactions between LRRK2 and Rab10 that cause problems, we hope to rapidly take these insights forward to develop new potential drugs with with international pharmaceutical company Lundbeck who are already close collaborators on the project." Dr Chris Elliott

## Understanding gut bacteria to deliver better treatments

Who? Dr Maria Doitsidou Where? University of Edinburgh What? £243,128 over three years

The human intestine is inhabited by a diverse community of bacteria called gut microbiota.

Some of these bacteria are beneficial, others are harmful, but for the most part, we know very little about their effects on human health.

Recent research has shown that gut bacteria in individuals affected by Parkinson's differs from that of healthy people and scientists now believe that harmful gut bacteria may produce chemicals that are important in the development of Parkinson's.

We've funded a new project at the University of Edinburgh to investigate the complex and mysterious interaction between the gut and the brain.

To investigate how different types of gut bacteria influence the brain, Maria and her team will use C. elegans, a microscopic transparent worm.

They have engineered the worm to produce high levels of human alpha-synuclein (the major protein thought to be involved in Parkinson's) in its dopamine-producing nerve cells, which causes them to die.

They will systematically feed their worms with over 100 different types of bacteria that are thought to be present at higher or lower levels in people with Parkinson's. And study how different bacteria affect the dopamineproducing cells using specialist technology.

Once the researchers have identified beneficial and harmful bacteria, they will study their genetics to look for clues as to what might be causing the damage to dopamine-producing cells.

Maria's team have already identified bacteria that seem to have a protective effect on dopamine-producing cells in their worms.

They will study these bacteria further and hope to identify the signals and chemicals they produce that cause these protective effects.

"Gut bacteria are crucial to human health so eliminating them completely is not an option. But if we can figure out what type of bacteria are beneficial or harmful for Parkinson's this could open up vital new opportunities for treatment. Therapies that can rebalance gut bacteria, reducing the harmful ones and encouraging the beneficial ones could be an important treatment in the future. And if we can identify the protective chemicals produced by beneficial bacteria, these could be harnessed to develop new drugs that directly deliver the effect." Dr Maria Doitsidou

## CAMPAIGNING



## FAST TRACKING NEW TREATMENTS

The government's new fast-track route could shave years off the time it takes for people with Parkinson's to benefit from new and better treatments.

rom April 2018, the new accelerated access pathway will mean products with the greatest potential to change lives could be available up to four years earlier.

The pathway aims to reduce the time it takes for people to access key new medicines and technologies. It will do this by reducing the time it takes to negotiate evaluation and financial approvals before NHS England can purchase the products. Under the scheme, a number of products each year will receive breakthrough designation. This will help to accelerate clinical development and open up a fast-track route through the NHS's approval processes.

As well as improving how quickly and easily innovative products make the journey from the lab to the bedside, the pathway will help ensure future collaboration between the life sciences sector and the NHS post-Brexit. The government is also providing an £86million package to help innovators of all sizes gain access to the NHS market, to get their products to patients. This hugely important development is the result of the accelerated access review. This initiative – for which Parkinson's UK provided evidence – sets out how people could get quicker access to innovative new diagnostic tools, treatments and medical technologies.

### **Driving improvements**

Laura Cockram, Head of Policy and Campaigning at Parkinson's UK, comments:

"Our researchers are working hard to deliver new and better treatments faster. But without processes to ensure these new treatments can be accessed, there can still be huge delays to these developments improving people's lives. This is understandably a key concern for people affected by Parkinson's. We are pleased that the government is supporting ways to get new technologies and medicines to the people who desperately need them. We will continue to share the experiences of people affected by Parkinson's with the government to drive improvements to the management and care of the condition."

#### How can I get involved?

Campaigning with us can really make a difference to people living with Parkinson's. There are loads of different ways to get stuck in and get involved. Find out about all these opportunities at **parkinsons.org.uk/campaigns** or contact us at **campaigns@parkinsons.org.uk** or on **020 7963 9349**.

## FEATURE

## Towards more personalised treatments

Understanding why people with Parkinson's differ has the potential to transform the way we treat the condition now and accelerate future developments.

he era of personalised medicine is already well under way. It's the move from a one size fits all approach to treatment and care, to using new approaches to better manage health, and targeting therapies to achieve the best outcomes for an individual. It can cut down unnecessary and often expensive treatments that don't have benefits and might even cause harm. It can also ensure that the right treatment, care or support is given to the right person at the right time.

#### Better understanding = better medicine

Today, with more granular diagnostic techniques, better understanding of risk factors and the discovery of measurable changes in the body that can predict certain conditions, we are on the verge of transforming how medicine is approached and new treatments are developed. Technological advances in genetics and a better understanding of human biology have already allowed for great strides in the treatment of cancer. Now, rather than treating tumours based on where they grow in the body, doctors can choose the correct treatment based on the genetic fingerprint of the cells inside the tumour.

At the same time, research has taught us a lot about how the brain works and what goes wrong in neurological conditions like Parkinson's and Alzheimer's. But, in these conditions, we are a little further from personalised treatments.

### Personalised medicine for Parkinson's

In Parkinson's, brain cells that produce the chemical messenger dopamine are slowly lost over time, causing problems with movement as well as a multitude of non-motor symptoms – such as pain, sleep problems, anxiety and dementia. However, the condition affects each individual differently and no two people with Parkinson's will have exactly the same symptoms. As well as different symptoms, people with Parkinson's also differ in how they respond to drug therapies and how the condition progresses over time. This incredible diversity presents major challenges, but research is closing in on the answers.

If we can understand how and why people with Parkinson's differ, we can start to sort out which people will benefit from different treatments and therapies. Identifying the different types of Parkinson's has the potential not only to transform the way we care for people with the condition now, but also how we develop and test future treatments. "Science has been a bit slow in catching up on the concept that Parkinson's is probably not simply one condition, but instead an umbrella term for many different types of condition." Martin Taylor, person with Parkinson's

## **Types of Parkinson's**

The first step towards delivering truly personalised treatments for Parkinson's is to work out what different types of the condition there are, and how they present and progress. With a complex condition like Parkinson's, this means you need a huge amount of carefully collected data. And that's exactly what we're gathering through two major studies – Tracking Parkinson's and the Oxford Parkinson's Disease Centre. Both are closely monitoring people who have recently been diagnosed and collecting information about every aspect of the condition as it develops over time.

Together, these and other studies are gathering a comprehensive picture of Parkinson's through detailed clinical assessments, gene tests, brain scans and analysing proteins in the blood. The breadth and depth of the data being collected will allow researchers to spot patterns in the illness that have never been seen before.

## Progress so far

The Oxford Parkinson's Disease Centre team have found that the people with Parkinson's in their study fall into five broad categories based on their symptoms:

- Mild movement and non-movement symptoms (25%).
- Changes in posture, memory and thinking (23%).
- 3. Severe tremor (21%).
- **4.** Poor psychological wellbeing, and sleep problems (19%).
- severe movement and non-movement symptoms, poor psychological wellbeing (12%).

This research is still at an early stage and the team are now continuing to study how these groups develop to see if early symptoms might predict how the condition progresses over time. They also want to compare their findings to those from Tracking Parkinson's, to see if the same patterns emerge in a different group of people.

And, more recently, data from the Tracking Parkinson's study has highlighted a possible connection between cardiovascular health and Parkinson's symptoms such as walking and memory. The finding suggests improving cardiovascular health in some may help these aspects of the condition.

#### More personalised future

Our knowledge of the different types of Parkinson's is far from complete, but researchers are making huge progress. With focused effort, alongside guidance and support from the Parkinson's community, we are on the way towards better, more personal treatments.

## **MY LIFE IN RESEARCH**

Dave Cassy visits the Sheffield Institute of Translational Neuroscience

Everyone is welcome to join the Research Support Network. Here some of our members explain why they joined and what they've been up to.

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Diagnosed in 2004 at the age of 43, and with two sons aged 11 and 13, I was desperate to find out what the future held. Yet the volume of information available online was misleading, inaccurate and terrifying, and I soon resigned myself to the fact that there were no answers.

Since then, I have realised that the main source for realistic, down to earth and reliable information is Parkinson's UK. Their commitment to improving the lives of patients and carers, while searching for the elusive cure, was apparent.

With symptoms increasingly affecting my ability to perform everyday tasks, resulting in ill-health retirement in 2015, I was determined to take part in research. Following many smaller studies, I discovered the GDNF trial in November 2014 and had brain surgery to insert the delivery device that would infuse an experimental protein with the potential to slow down, stop or even reverse cell death.

My last infusion took place in December 2016 and despite feeling more alive than for some time, the trial has struggled to demonstrate that the treatment works.

It is my firm belief that this is not because GDNF does not work, but that the assessments carried out are artificial, open to misinterpretation and judged against a standard scale that has not evolved in decades.

"Joining the Research Support Network has given me the opportunity to understand research, how it works, why it isn't always successful, but most importantly to live with the certain knowledge that Parkinson's UK is listening and acting on the views expressed by members."

While the inability to tap our noses or the way we walk without swinging an arm may indicate the presence of Parkinson's, they have little impact on our everyday lives.

Yet in clinical trials these tests and measures form the basis of our overall score – whereas severe cramps, which can render us immobile, are not assessed.

Joining the Research Support Network has given me an insight into the tireless efforts made by Parkinson's UK to improve lives, and the opportunity to understand current methods of assessment.

It has also given me opportunities to become involved in shaping more relevant and realistic tests, which could turn inconclusive trials into real hope for the future.

There is no regular commitment, no pressure to contribute, just the opportunity to voice an opinion. Singularly we will struggle to be heard but as a

group we can demand change. The failure to find that elusive cure has to be addressed and while scientists know the in depth structure and workings of the brain, patients know what living with this condition really means. Until these two unique perspectives are working in harmony, trials will continue to fail.

WHY DID

OU JOIN THE

NETWORK?

# CONTRACTOR OF STATES

In 2010, at the age of 43, my son was diagnosed with Parkinson's. He'd had symptoms for the previous five years.

I didn't know much about Parkinson's back then, but I felt devastated. I started to look for information – I read books, searched online and spoke to anyone I could.

The most surprising thought that hit me was that nothing much had advanced in finding a cure for Parkinson's over the 200 years since James Parkinson published his first essay in 1817. Levodopa, the main medication, was developed nearly 50 years ago and has limited effects long term, with lots of side effects once maximum dosage is reached. My son became a member of the Research Support Network after taking part in many research studies, including the TRANSEURO study at Cambridge. I also joined the charity to find out everything they were doing.

"Since my son's diagnosis, I have visited research centres around the country to learn what is happening to find a cure."

I was particularly enthusiastic when the Sheffield Institute of Translational Neuroscience opened in 2010. I have since attended many research talks and open days at the institute and I started attending the Parkinson's UK Yorkshire and the Humber Research Interest Group meetings that are also hosted there.

Today, I am feeling more optimistic – the latest projects and trials seem to be moving towards finding a treatment that can slow down Parkinson's. Being part of the Parkinson's UK Research Support Network is a great way to keep up to date with what is happening in the research world. It also gives me the opportunity to hear from other people in a similar position and exchange views on finding a cure. I feel most people would benefit from joining Parkinson's UK and the Research Support Network.

I always spread the news about Parkinson's and now, at long last, there is light at the end of our 200 year battle to find a cure. Watch this space!

## CARROLL SIU TO GET STUCK IN

I was diagnosed with Parkinson's two years ago, and these last couple of years have been interesting. I am from a healthcare background, so I should have recognised my symptoms. However, when something shocking happens, it is natural to bury one's head in the sand. I suspected that my tremors were to do with something sinister, but I didn't seek help until three months after I noticed the signs.

The news of a potential Parkinson's diagnosis was distressing, but when the diagnosis was confirmed my emotions went on a rollercoaster ride. There were periods of numbness and despair when I thought about my Will and how my husband would cope with me when I am stuck in a wheelchair! And I have seen myself going through the early stages of the grieving process, denying or being angry with information that I was given. But the reactions I've received from my children and friends give me a sense of happiness and warmth. Their love and reassuring words have been heartfelt and this has given me strength to fight on. I found Parkinson's UK quite by accident when I was referred to a trial on Fox Trial Finder and got linked up with the charity. I was very fortunate to be selected to join the Research Support Network Development Group.

"Since joining I've been able to get stuck in with some really interesting and worthwhile projects."

I became a Patient and Public Involvement Volunteer, which has allowed me to look at research projects before they are even submitted for funding and help make improvements.



This is very much a personal interest of mine, as I had been teaching research methodology at a university before I retired. This role is intellectually challenging and rewarding, and I hope that I am making a difference in how participants are recruited for research in Parkinson's.

I also decided to put myself forward for several research studies. Some involved tests and scans and most recently I have taken part in a UK-wide drug trial. Meeting other members of the Research Support Network has had such a positive impact on me. Sharing stories and being empathetic with others has made it possible for me to open up and examine my own feelings about my condition.

I know that the best way to deal with this condition of mine is to face it head-on, there is no getting away from it.

Each day I feel thankful that I am still the person I was two years ago, that deep down I am no different. My physical body may be deteriorating, but I am going to fight it, slow down the progression and be hopeful for a cure in the future!

## **JULIE ADBY** TO MAKE A DIFFERENCE

Buying shoes – is this ever not obsessive for us girls? Well, for me, I was the exception to the rule.

Until I was 55 years old, I hated buying shoes. It was the thought of trying on shoes that were never as comfortable as old, well panned in favourites.

So, what changed? Well, I was diagnosed with Parkinson's, and was prompted to start looking for shoes that could accommodate my toes scrunching up, but that I still liked.

It became a routine, always taking an interest in shoes wherever I was. Perhaps it was something to do with having a range of shoes, in a range of colours, and in a range of different styles. I went from about eight pairs of shoes to 50! Maybe this is not a lot for many women, but for me this was a new pattern of behaviour. I had moved into late night internet shopping, and became tangled up in the enticing adverts on the side bar of the webpage, regardless of what I was originally looking at.

Having become aware of impulsive behaviour linked with Parkinson's, and following a discussion with my Parkinson's nurse, I recognised that I needed to take control of this behaviour. So obviously research in this area was of particular interest.

The Research Support Network has led me to get involved in research into impulsive behaviour at the University of Manchester.

Jade Pickering and her team are investigating if an intervention that involves practising stopping behaviours can help people to control their impulsive behaviour.

I attended a focus group where we discussed our ideas with the research team – they really listened and the plans for the research have changed and developed because of input from people with Parkinson's.

"It is really worth getting involved in research, as this is our opportunity to tailor it to achieve outcomes that make a difference to people with Parkinson's."

#### JOIN THE RESEARCH SUPPORT NETWORK Sign up to our Research Support Network to receive regular emails about how to get involved in Parkinson's research. You'll receive our monthly Research Roundup, as well as opportunities to take part and have a say in research in your local area. Join today at parkinsons.org.uk/rsn ■

PARKINSON'S VIRTUAL BIOTECH

# EXPANDING THE VIRTUAL BIOTECH PORTFOLIO

The Parkinson's Virtual Biotech is the drug development arm of Parkinson's UK. Our mission is to invest  $\pounds 2-4$ million per year – totalling  $\pounds 11$ million by 2020 – to fast track projects to rapidly develop and test treatments with the potential to transform life for people with Parkinson's. Last year we funded our first project, worth over  $\pounds 1$ million, which aims to protect brain cells. Here we talk about two new projects that have been added to the portfolio.

## Driving forward a better treatment for dyskinesia

Levodopa-induced dyskinesia is a common side effect experienced by people with Parkinson's who have been taking levodopa-based medications for several years. This side effect causes involuntary movements that can affect various parts of the body, such as the arms, legs and upper half of the body.

Dyskinesia was voted the third most important issue to be addressed by research in a survey of people affected by Parkinson's on quality of life. The main medication available to manage dyskinesia today – amantadine – is helpful, but it can have serious side effects and does not work for everyone who experiences dyskinesia.

There is evidence to support targeting serotonin receptors to reduce dyskinesia. It is believed that as dopamine-producing brain cells are lost in Parkinson's, some serotonin brain cells may start taking on their job. They take up the drug levodopa, convert it into dopamine and release it – but do so in an erratic manner which contributes to the development of dyskinesia. NLX-112 is designed to act on the serotonin cells to reduce the amount of dopamine they release, and in this way, reduce dyskinesia.

#### Project details

US based bioscience company Neurolixis is driving forward research into NLX-112 as a new treatment to combat dyskinesia. NLX-112 has so far proven to be highly effective at treating dyskinesia in animal models. It was originally developed as a pain medication. While clinical trials found that it was not effective for treating neuropathic pain in people with diabetes, these previous studies mean that we know a lot about the safety of the compound. This means that Neurolixis does not have to spend time on some early steps in the development of a new treatment, potentially speeding up the delivery of a new drug to people with Parkinson's.

But before it can progress to be tested in people with Parkinson's in clinical trials, some crucial steps are required:

• Final preclinical testing: In particular, we need to know whether NLX-112 can be taken alongside amantadine, which is sometimes used to help control dyskinesia.

**2** Tableting and packaging: The compound needs to be made into the 'final product', along with placebo tablets of identical appearance so it can be easily given to people with Parkinson's in a clinical trial.

**3** Examination and approvals: Discussions with regulatory authorities and other bodies must take place to ensure everything is in order to begin clinical testing.

To get these critical final stages of development completed swiftly, Neurolixis is partnering with the Parkinson's Virtual Biotech and King's College London.

If the project is successful, NLX-112 could advance to clinical testing within 12 months.

## Creating multitasking molecules with potential to both improve symptoms and slow progression

This project aims to develop molecules that increase the activity of a wide range of genes that have could have two key beneficial therapeutic effects:

#### **1** Boosting dopamine production

Current drugs help to artificially top up dopamine levels, but become less effective over time and can cause significant side effects.

Increasing the activity of genes that help remaining brain cells make more of their own dopamine could significantly improve control of symptoms with fewer side effects.

#### Protecting brain cells

Many processes may contribute to the damage and loss of brain cells – from problems with energy production and processing waste, to the build-up of toxic iron and other chemicals.

Increasing the activity of genes that protect against several of these damaging processes simultaneously may provide the best hope for slowing, stopping or even reversing the condition. Like a switch, these vital genes can be turned on by one protein and off by another.

The protein that turns these genes off has been found to be overactive inside dopamineproducing cells in studies using post mortem brain tissue from people with Parkinson's. This project aims to develop drugs that target and reduce the activity of the protein that turns the system off.

By doing so, we hope to keep the switch turned 'on' and to boost the activity of these genes to enhance their beneficial and protective effects on brain cells affected in Parkinson's.

#### **Project details**

Parkinson's UK is partnering with the drug discovery company Selcia Ltd to develop novel new molecules which could have multiple beneficial effects for Parkinson's.

There are already potential drugs that work via the same mechanism that are being tested in clinical trials for other conditions.

However, these molecules would not be effective in Parkinson's because they are not able to cross from the bloodstream into the brain.

Therefore, in this project we will attempt to use the findings from these existing potential drugs to create completely new drug-like molecules that work in the same way, but can enter the brain.

If successful, this project will produce candidate molecules that can be rapidly progressed into pre-clinical testing, and ultimately towards clinical trials.



## **RESEARCH VISION**



## INVOLVEMENT: AN INSIDE STORY



At Parkinson's UK, we believe that involvement is key to ensuring that research meets the needs of those affected by Parkinson's. As experts in the condition, it makes sense to bring together people affected by Parkinson's and researchers to develop and plan research projects, and share research findings. Here's the inside story about why this work is so valuable.

## JOHN AND SUE WHIPPS

Ten years ago, John was a successful research scientist, studying plants and microbiology, and a professor at the University of Warwick.

After being diagnosed he connected with the Research Support Network and, with his wife Sue, started to get involved with local research.

Now John and Sue play an important role rallying other people affected by Parkinson's to start their own research journey.

## DR CAMILLE CARROLL

Camille is a Lecturer in Clinical Neuroscience at the University of Plymouth Peninsula Schools of Medicine and Dentistry and an Honorary Consultant Neurologist at Plymouth Hospitals NHS Trust. Her current focus is on early detection and clinical trials of interventions that may slow or stop the progression of Parkinson's. She is currently the chief investigator of a multi-centre clinical trial of simvastatin (PD–STAT), and also has an interest in the use of technology, such as wearable sensors and apps, in Parkinson's.

## John, what first got you interested in research?

"I was already a research scientist, but in a completely unrelated field.

"I was interested in Parkinson's research because I wanted to give something back, but I have been given the chance to learn not only about the research but about how the condition affects me.

"Lots of people think that research is just about testing drugs, and they are concerned about their safety during trials.

"But research is not just testing a load of old tablets – there are many other opportunities.

"For example, you could fill in a form as part of a research study, or get involved in research by answering a survey about research priorities, or help to shape ongoing research projects."

#### John, how did you first get involved in helping to shape research projects?

"Around nine years ago, when I moved to Cornwall, I had a consultant who was keen on research. He suggested I signed up for ProDeNDRoN – a register of people with Parkinson's across the south west willing to get involved in research – and this started my direct involvement in a number of research projects.

"Then, a few years ago, when there was some shuffling of consultants in the area, I was fortunate to be transferred to Camille – we hit it off straight away.

"We now work closely with Camille helping to shape her research. I think it's important to connect with Parkinson's researchers, like Camille, as they know what is happening on the ground and that's where we can make the biggest impact."

### Sue, do you think it is important for carers, friends and family to also get involved? Is there a special role you've played?

"When John was first diagnosed our family scoured the internet for information and cures. They felt helpless and in fact they very soon became as well informed as us. Rather than being sidelined, family members can help research in many ways. They can leave their brains to the Brain Bank, raise money, join in trials that need people without the condition and review plain English summaries of research proposals.

"We've always felt that research brings us hope of a cure and improved treatments. It is the 'light at the end of the tunnel' but people need to be aware that it is happening. All along, we've tried to engage with both other people affected by Parkinson's and the researchers to try and bring the light of a cure a bit closer."

#### Camille, what's your experience when you first meet people affected by Parkinson's?

"When I meet people with Parkinson's, they are nervous about their diagnosis and what the future may hold. Some of their questions I am able to answer, and some I am not.

"Offering the opportunity to take part in research offers hope and a means by which patients can contribute to what we know and understand about their disease. Many people start their research journey by taking part in a study.

"It is important to appreciate that there really is a study for everyone, and I would encourage people to use the Parkinson's UK website (**parkinsons.org.uk/ takepartresearch**) to look for studies near them that they might be interested to take part in. John and Sue are more involved in research than simply taking part in one of my studies.

"When people with Parkinson's become involved in research it is so valuable and rewarding for us as researchers.

"It's a vibrant, open, honest, two-way dialogue that is invaluable for the research community, in both clinical and lab-based research, and that can ultimately change lives.

"It helps us set our research priorities, shapes what we do, ensures that the way that we plan and carry out our studies is acceptable to patients, and that our findings are communicated in the most effective way to have the most impact."

## Camille, what role do John and Sue play in your research?

"When I have an idea for a new research study, I readily turn to John and Sue for advice. They give me honest and critical feedback that is absolutely invaluable in helping to shape and develop these ideas and ultimately the research project itself.

"I speak to John, Sue and other people with Parkinson's most weeks about my work. It's such an important part of what I do as a researcher and has definitely made me better at my job to have them as a sounding board. They also provide fantastic support with things like setting up focus groups to dig a bit deeper into a topic.

### Camille, why do you feel it is important to involve people affected by Parkinson's in research like this?

"Having people who live with the condition every day around the table when we were planning and designing our simvastatin trial was crucial. They helped to make sure the research would work for those who would later take part. But involvement can also happen at the earlier planning and prioritisation stages.

"For example, when people with Parkinson's collaborate with

### JOIN US

Join our Research Support Network to hear about opportunities to take part and have your say in Parkinson's research. Sign up at **parkinsons.org.uk/rsn** 

researchers they can also pitch ideas to take forward as research questions, which can drive activity and progress. Volunteers like John and Sue help to shape my studies so they address the needs of people with Parkinson's.

"They also feed back on the language used in my applications. This helps me be successful when applying for funding, but it also makes my research understandable for other people who may be interested."

### Camille, what would you say to someone who thinks they don't have the skills to make a difference?

"Everyone has done something prior to developing Parkinson's – if you can write a sentence in plain and simple English that already sets you apart from most of the scientific community!

"One of the key things everyone can help researchers with is making sure that research is clearly understandable to you, because if you don't understand it others won't and that needs to be fixed.

"I think it is important that people are involved in research that is local to them. As a researcher, I want to involve people locally, build on the interactions and enthuse volunteers by showing them they are making a difference."

# RESEARCH RESULTS

## Studying mitochondria in skin cells

NEWS

Previous research has provided insights into why nerve cells die in Parkinson's. We know that the mitochondria – the tiny power stations of our cells – and the lysosomes – the rubbish disposal systems – can stop working properly in people with Parkinson's.

Professor Oliver Bandmann and his team at the University of Sheffield previously identified changes in the shape and function of the mitochondria and lysosomes in people with inherited Parkinson's.

They wanted to see if these same problems occurred in people with non-inherited, or 'sporadic', Parkinson's.

The team looked for changes in the mitochondria and lysosomes in skin cells from people with sporadic Parkinson's.

They found that some people appear to have mitochondria that work too hard and might wear themselves out. Other people's mitochondria did not recover well after exposure to toxins. And others seem to have too many lysosomes.

They also found that treating the skin cells with a drug improved the function of the mitochondria.

More and more research is suggesting that different mechanisms are causing nerve cells to die in Parkinson's, rather than Parkinson's having one cause. Studies like this bring us a step closer to developing more personalised treatments.

"We are extremely excited about the results of our study. For the first time, the field may have a tool to identify individual mechanisms leading to sporadic Parkinson's. We acknowledge, however, that more work is now required, such as determining the mechanisms that lead to problems with the mitochondria and lysosomes."

**Professor Oliver Bandmann** 

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



Pain is a common non-motor symptom of Parkinson's. We don't know exactly what causes chronic pain in Parkinson's, but we do know it can have a huge impact on quality of life.

Research has suggested that many people do not report pain as a specific symptom to their specialist and there are no specific guidelines for its management.

This is what inspired Professor Chaudhuri, and his team at King's College London, to create a Parkinson's-specific pain scale.

Measuring pain is the first step towards understanding what causes it.

The scale created by the team is designed to be used by healthcare professionals to establish the severity and frequency of the different types of pain people with Parkinson's experience. There are 14 questions to complete, which gives an overall score reflecting how much of a burden the pain is for the person with Parkinson's.

The team hopes that a standardised tool to assess pain in Parkinson's will help to manage and alleviate pain better in the future.

Better understanding of non-motor symptoms like pain will help to develop better, more personalised treatments.

"The scale has already been used to assess pain in a number of clinical studies including the PANDA study, which is looking at whether a drug called oxycodone can be used to treat pain in Parkinson's and which type of pain specifically responds to this drug."

## Professor K Ray Chaudhuri

## Gene therapy approach to treating Parkinson's

We don't yet know what causes Parkinson's in most people. But we have learned that genetic changes in a protein called alpha-synuclein can lead to Parkinson's in a small number of cases.

Alpha-synuclein is found in Lewy bodies, which may be related to the death of the dopamineproducing nerve cells. If we can find a way of decreasing the amount of this protein in the brain, we may be able to stop nerve cells from dying. A Parkinson's UK-funded research project in Spain has made steps towards making gene therapy a reality for people with Parkinson's.

Genes are the instruction manuals that tell different cells around the body what to do to keep us alive. Gene therapy is a way of reprogramming cells.

Delivering gene therapy to the brain is a major research challenge. A few clinical trials are in progress in Parkinson's but they rely on surgical injection into the brain. Dr Lydia Alvarez and her team have developed a new delivery system for gene therapy that is based on using small capsules released by cells, known as exosomes. Exosomes have a specific molecule on their surface that is recognised by brain cells, so they can be injected into the blood without the need for surgical injection into the brain.

The exosomes contained genetic molecules that reduce the amount of alpha-synuclein that cells produce. The team then injected these exosomes into mouse models of Parkinson's. Mice that had received this gene therapy had fewer clumps of alpha-synuclein and performed better in movement tests.

"Our results highlight the potential for the use of exosomes as gene therapy vehicles for long-term treatment. We aim to continue the development of this state-of-the-art technology for clinical trials for Parkinson's." **Dr Lydia Alvarez** 





## Mapping the 3D structure of the PINK1 protein

Inherited changes in the PINK1 protein were first linked to Parkinson's in 2004. They are now known to be one of the most common causes of earlyonset Parkinson's.

Dr Miratul Muqit and his team at the University of Dundee have solved the 3D structure of the PINK1 protein by using a technique called x-ray crystallography, which involves making crystals of the protein and then using an x-ray machine to determine the 3D structure of the crystal.

The PINK1 protein plays a key role in protecting brain cells against stress by detecting damage to the mitochondria, which are the power stations of cells. Switching PINK1 back on could protect nerve cells – but designing drugs to target PINK1 has been impossible without understanding the structure of the protein. The researchers also found that PINK1 has unique control elements that allow it to interact with two other proteins, ubiquitin and Parkin.

Drugs that can switch the PINK1/parkin pathway back on may be able to slow, stop or even reverse nerve cell death, not only in people who have rare inherited forms of the condition, but also those with non-inherited Parkinson's.

"Solving the structure and workings of PINK1 gives us crucial insights into how it exerts a protective role in Parkinson's. That knowledge can lead to the development of new drugs that could be designed to switch on PINK1." **Dr Miratul Muqit** 

## **EVENTS**

# RESEARCH EVENTS IN 2018

Bringing research closer to you



ast year we asked the Research Support Network to tell us what they wanted from research events in 2018.

The results were clear – members want more regional events and opportunities to participate in events from home (either through livestreaming or catching up on video recordings in their own time). We've heard what you said, and this year we'll be bringing you many more opportunities for engaging with researchers close to you. We will also be streaming three 'Research Roadshow' conferences in 2018, so you can join in a research event from the comfort of your living room.

There's a partial list of Parkinson's UK events on the next page, but we'll also be sharing Parkinson's research events from research centres and universities across the country.

So make sure you keep checking the research events page on our website at **parkinsons.org.uk/ researchevents** 

Or join our Research Support Network at **parkinsons.org.uk/ rsn** – we'll email you when events are happening in your area.



#### Livestreaming events

This year we will be livestreaming more events to help bring research closer to you. Livestreaming is the live broadcast of an event on the internet.

Our events are completely free and anyone with a computer and internet connection can tune in.

You can ask questions, participate in discussions and even watch a recording later in your own time.

Catch up on our previous live streamed events: **parkinsons.org.uk/live** 





## Research events in 2018

- Gretchen Amphlet Lecture Cambridge • Tuesday 17 April
- Parkinson's UK Research Roadshow Cardiff • Wednesday 23 May
- Parkinson's Today: Research, treatment and management Canterbury • Tuesday 12 June
- Northern Ireland Research Event Belfast • Wednesday 4 July
- **5.** Parkinson's UK Research Roadshow York • Friday 20 July
- 6. Edinburgh Parkinson's Lecture 2018 Edinburgh • Autumn
- 7. Parkinson's UK Research Roadshow Durham • September
- 8. East Midlands Parkinson's Research Forum Loughborough • Saturday 29 September

#### Research talks in 2018

- **9.** Chelmsford Branch Friday 11 May
- **10.** Fareham and District Branch Monday 21 May
- **11.** Inverclyde Support Group Friday 25 May

Every hour, two people in the UK are 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. NGT Relay **18001 0808 800 0303** (for textphone users only)

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