

## Cambridge Branch Newsletter – November-December 2020

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### BRANCH MEETINGS

#### **KATE TELLS THE LIFE OF HER REMARKABLE AUNT, FOUNDER OF THE HOSPICE MOVEMENT**

Our Cuppa, Cake and Two Speakers virtual meeting on October 23 gave everyone a real treat. The first speaker was Amanda Eady, one of our local Parkinson's nurses. She updated us on how the team is being put back together after being co-opted for COVID. To watch her, use this link: <https://youtu.be/-4RSjjgPcto>.

The second video features Dr Kate Kirk (pictured), Chair of Trustees at the Arthur Rank Hospice in Cambridge. She told us the remarkable story of her aunt, Dame Cicely Saunders, founder of the hospice movement. Cicely's medical career began in WW2, when she worked as a nurse at St Thomas's Hospital in London from 1940-44. But a bad back forced her to give this up, so instead she qualified as a 'lady almoner', effectively a medical social worker.



However, she soon realised it was vital she got a medical degree – to be taken seriously by male doctors! Already aged 32, she did this, qualifying in 1957,

and then working in the care of the dying. But she decided a dedicated building was needed to combine the nursing, medical and research work, all of which she saw as vital for true 'palliative care.' So, she bought land in South London and eventually in 1967, St Christopher's Hospice opened to put into practice Cicely's true aim: caring for the 'total pain' that can be associated with dying: physical, social, emotional and spiritual.

Her success since has been a worldwide phenomenon. Today, there are hospices or care teams in 136 countries. The UK has more than 200, and 40 for children, while in the US, there are more

than 5100. No wonder her work was described as a "catalyst for a paradigm shift in global healthcare." Palliative care is now recognised as a medical speciality, with its own dedicated journal, and in the 1990s was made a mandatory element of medical study at Oxford University. Cicely received many honours, including what is regarded as the ultimate, the Order of Merit. Kate's recounting of her remarkable story is available on our new YouTube channel, at <https://youtu.be/GDNbTz8N7qw>.

#### **SEE MEETINGS ON OUR YouTube CHANNEL!**

As we are now regularly having guest speakers, we have created a YouTube channel to store the recordings of the meetings for easy access. The channel's title is Parkinson's UK Cambridge Branch, (link: [https://www.youtube.com/channel/UCRmcdJpFbvM4XC6\\_4i93QQ](https://www.youtube.com/channel/UCRmcdJpFbvM4XC6_4i93QQ)). But we are open to suggestions for a catchier title. Email our membership sec Keith with ideas! Our next Cake and Cuppa is November 6 – watch your inbox for details.

#### **CEO MAKES BRANCH A VIRTUAL PRIORITY**

Such has been the success of our virtual Branch Meetings, word has reached head office with the result that we were one of the first branches to be visited by the CEO of Parkinson's UK, Steve Ford. Steve (pictured), who has been the CEO of our charity for 15 years now, is doing a nationwide 'tour' of local branches. As he said, the aim is to try and avoid everyone feeling isolated – applicable to his own situation, with head office closed and everyone working from home.



His 'visit' on Friday, September 25, was more a Q&A session with members than a set speech from

him. And understandably, as the song title puts it: there were more questions than answers! Caroline Bent raised the first one, about fundraising,

something she has been very actively involved in. And her question was particularly relevant: is the collecting of contributions from outside places like supermarkets something that is going to continue? And how are we – and every other charity – going to deal with the slow disappearance of cash as the use of cards becomes ever more common? Card use has been greatly accelerated by COVID and there are a growing number of places that operate a card-only policy.

Other questions concerned the availability of medications, exercise groups, mental health – particularly anxiety and lack of confidence – and how to get more members to take an active part in the branch, even at the most basic level: for example, to open emails we send out!

These were hardly questions that Steve could easily answer. Nobody can. One thing he did say he would look into was a query raised by Barry Perry (see Viewpoint page 5), who suggested the national website should contain a list of research projects Parkinson's UK is involved in. Encouraging pharmaceutical companies in the development of new drugs, via the Parkinson's Virtual Biotech organisation, and the stated aim to get a new treatment into the clinic and actually being used by 2024, were two instances of what is going on in terms of research related activity, Steve said. Another area of the website to look at for research info was the Take Part Hub.

Well done to everyone who took part – I'm afraid your Editor was relaxing on a Corfu beach at the time! And particular thanks to our Membership Secretary Keith for getting the whole Zoom-based operation going in the first place. The virtual-only era is far from over.

## NEWS, EVENTS & PEOPLE

### NEW BRANCH SECRETARY BADLY NEEDED

Trish Carn, who has been our Branch Secretary for the last few years, has taken on the vital role of Treasurer, so we badly need a new Secretary.

The Branch Secretary gets involved in various tasks. These include: helping to organise the group's activities; creating the agenda for committee meetings, and taking and circulating the minutes of the meetings (held every two months); encouraging other volunteers to get involved; monitoring news

coming from Parkinson's UK, and sharing it with members; and ensuring the group runs according to Parkinson's UK governance procedures – ie, follows the rule book!

You will need good administrative, communication and IT skills. People with Parkinson's (PwP) can have quite widely differing views and concerns and you will need to reflect these to the group, to ensure the support provided by the Branch is what members actually want. And what is in it for the Secretary? They play a crucial role in the local Parkinson's community, and one benefit you can gain is making new friends and building connections.

If anyone is willing to consider this, Trish will be more than happy to talk about what is involved, how much time is needed, and so on. She will also be available to help the new Secretary, as they get to learn the ropes. So it is not too daunting a task! If you are interested, or know someone who might be, please contact Trish ([trishc.parkinsons-cambridge@gmail.com](mailto:trishc.parkinsons-cambridge@gmail.com)) (07815-541111). She is currently doing both tasks, which is too much for anyone.

### CHRISTMAS MEETING WITH GUITARIST TOM

We may not be able to get together in person for our Christmas lunch, but our meeting on Friday, December 11, will still hopefully be an enjoyable virtual event.

One highlight should be some fine live music from a local musician and singer-songwriter, Tom Bryans (pictured), from Cambridge. Tom has been playing a range of musical instruments for more than 40 years, covering many different genres, especially Irish, Scottish and English folk music. These combine with his favourite instrument, the classical guitar, which he aims to play with "heart, soul, technical proficiency and of course experience. Book me :) because I'm worth it." We have taken him at his word!



Two factors have made a virtual meeting inevitable: first, the arrival of a second wave of COVID-19 infections, which have been increasing everywhere – even though our region is thankfully still much

lower than many. But any relaxation of the government restrictions on the size of groups allowed to meet is currently extremely unlikely. Second, refurbishment of the David Rayner Building means it will not be available by December.

However, we will have a Christmas Cake and Cuppa virtual meeting with suitable festive entertainments. So please make sure the mince pie and drink you have are definitely not virtual.

On a brighter note, we anticipate the DRB will be available fairly soon in the New Year and who knows? By then we might be able to stage a lunch. If we can, it will be a celebration of getting back together again.

### CONSULTANTS SEEING PATIENTS VIA VIDEO

Next time you have a meeting with your consultant, the odds are it will be via a video link – unless it's not for many months, and COVID-19 has faded. Maybe you have already had a video consultation?



The NHS is using a system called AttendAnywhere, which is a web-based platform that makes it possible to provide secure video appointments for patients, so that consultants can continue seeing their patients during the COVID-19 outbreak.

“All you need is an internet-enabled device, like a smartphone or tablet, or a computer that has a webcam, microphone and speakers (as virtually all laptops now do), a reliable internet connection, and either the Chrome or Safari web browser,” it says. Plus a quiet, private spot for the appointment.

Find out more by [visiting the AttendAnywhere information page](#). A short video is available to help people understand how their video appointment will work. Go to <https://www.youtube.com/watch?v=o-64JK4nLuE>. Before an appointment, you are asked to

click on a link like this  to check your equipment is working. If this test call doesn't work for any reason, you are advised to contact the department that made the appointment for you. To attend your appointment, you must select the clinic you are due to be seen in from a list, and you will then be asked to complete some checks, before

being directed to the clinic waiting room. When you are ready to start your video appointment, click 'start video call'. You will be asked to undertake your checks again. Make sure you complete all details including your date of birth and a telephone number you can be called on if there are any difficulties. Don't forget to tick the small box at the bottom of the registration screen. The NHS will not store the details you submit and any personal data will be transferred securely.

### NERVOUS ABOUT ZOOMING? DON'T BE!

We have had some very enjoyable virtual meetings since the virus first emerged several months ago. But there must still be lots of members who are online but have not yet taken part. If so, why is that?

If you haven't joined a meeting, one thing that certainly shouldn't discourage you is the feeling that it might be too complicated and difficult to use the meeting software, called Zoom. There really is very little that you have to do to join a Zoom meeting. The person acting as the Zoom 'controller' – in this case, our Membership Secretary Keith – sends out an invite by conventional email to everyone who is a potential joiner. This contains a link, plus a passcode and a meeting ID. Here is an example from the most recent branch meeting that took place on Friday, October 23:

To join the Zoom Meeting please click on the link below:  
<https://us02web.zoom.us/j/83078922983?pwd=Nk05Z2RBQk1HKy9KVnZBM2EvWW9Sdz09>

You will be asked to enter the Passcode: 40351  
 Meeting ID: 830 7892 2983  
 You will be entered into the waiting room and I will let you into the meeting as soon as possible.

And that is it! There is no need to worry about having to install Zoom on to your computer. As long as you are online at the time – which of course you have to be to take part in the meeting – Zoom will load automatically. The only thing you need is a system with a video camera, which all laptops now have, and a microphone and sound system that is turned on. If it isn't, Zoom will alert you and make it easy to switch them on. Also remember that you can just listen – there is no pressure to say anything!

### Still a bit apprehensive? Here is Branch member Margaret Steane's view:

ZOOM! Not long ago this word conjured up motor bikes revving up before a race, or perhaps a close up of a photograph. Nowadays we constantly hear about Zoom that is nothing to do with these: Zoom

meetings, conferences, family quizzes, discussion groups and more. At first I thought this was not for me – too complicated. I mostly use my computer for email, websites and Googling. But I began to feel left behind and wonder if I was missing out. Maybe I needed to find out more.

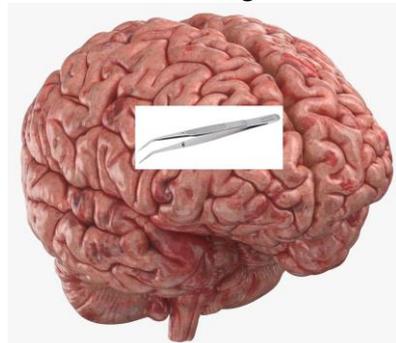
And then our branch Cuppa and Cake meetings started. That settled it, I had to get involved. With some help from membership secretary Keith it really wasn't too difficult and now apart from the occasional hiccup I easily join the meetings, take part in friendly chat and catch up with what is going on. Recently, we have had some speakers, from Parkinson's UK and elsewhere. Of course these fortnightly virtual get-togethers are not the same as meeting in person. But I think they are very much better than nothing, and for people who could not in any case travel to the David Rayner Building they are an extra benefit of Branch membership.

So if you are wary about tackling the mystery of Zoom, grasp the nettle and explore this new way of keeping in touch with fellow Branch members. You will probably soon be involved in other groups too. I hope to see new faces at future meetings and that you will enjoy them. Just one snag: you have to provide your own cuppa and cake!

## SCIENCE & RESEARCH

### MOLECULAR TWEEZERS PULL PROTEIN APART

A study led by the Oxford Parkinson's Centre has shown that drugs known as molecular tweezers could be a disease-modifying therapy. They work by pulling apart toxic clumps of protein that form in the brain during Parkinson's. The therapy has already done the same thing in Alzheimer's.



The molecular tweezer, called CLR01, was tested to see if it could reduce formation of protein clumps in cell and mouse models of Parkinson's. It worked: CLR01

stopped clusters of alpha-synuclein forming, and prevented the death of human neurons made from stem cells.

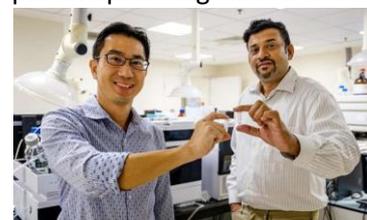
In the mice, CLR01 reduced the emergence of motor problems and toxic protein clusters. The study showed that in older animals with more advanced Parkinson's, CLR01 treatment was less effective. So using protective therapies early on is essential.

Professor Richard Wade-Martins, Head of the Oxford Centre and the study's senior author, said this was exciting as it showed that drugs can unpick toxic protein clusters, and thereby save neurons in Parkinson's. "Our work is focused on saving neurons when they start to lose function early on, but before they die later on. It should give encouragement to those hoping for protective therapies."

Dr. Beckie Port, research manager at Parkinson's UK, said the findings showed the innovative 'molecular tweezer' approach has exciting potential in the lab. "We need to take the therapy to clinical trials – only then will we know if it can do the same in PwP."

### ONE-PILL-A-DAY MEDICATION?

Scientists in Singapore have developed a new pill that can deliver medication for PwP over 24 hours. They hope this will help manage symptoms associated with 'off' periods, and have other benefits. The university's start-up company LiberaTx is commercialising the pill and planning clinical trials. By encapsulating the drug in a floatable micro-capsule, it stays in the stomach for an extended period, and its release rate is controlled. With a slow but continuous delivery into the upper intestine, the drug's concentration in the blood, and hence dopamine levels in the brain, are kept constant over prolonged periods rather than fluctuating, which is the case for current tablets.



Assoc Prof Joachim Loo (left) and LiberaTx Chief Operating Officer Dr Shashi Kesavapany (right) holding their new drug microcapsules.

Patients now on L-dopa may take up to six pills a day, and often experience 'wearing off' effects between medications. Also, after taking it for a long time, some encounter the side-effect levodopa-induced dyskinesia (LID), when their limbs jerk or they experience other involuntary spasms. The new pill could also help prevent patients failing to take the correct number prescribed: average non-adherence rate for complex medication regimens is put at 50% (*continued 2<sup>nd</sup> column page 5*).

## VIEWPOINT

**Barry Perry comments on the recent Edinburgh lecture on Genetics and Parkinson's by Professor Christine Klein (see page 7), and follows it up with an intriguing fund-raising idea.**

Professor Klein's lecture was informative and well presented. But probably with many others, I am only interested in how we can get to a cure as quickly as possible. Mapping out the genetics underlying Parkinson's is a wholly valid scientific endeavour. But the question that really matters to us is what the genes encode and what the encoded proteins do!

So for me, there was too little molecular and biochemical integration of the genetics data, which could point us towards a possible cure. Ultimately, that will only come from some suitable biologically active molecule and simple delivery mechanism, or a form of auto-transplant of genetically modified cells: namely, putting back in to your brain your own cells, after suitable genetic modification. These could be derived from a skin biopsy, for example. Professor Klein did say this was happening in her own laboratory, in cooperation with others. (Editor's note: this is also being studied by the Brain Repair Centre at Addenbrooke's).

I have also been thinking about how, as a community of sufferers, we could potentially do more to help. Charitable donations are fine, but in general they don't raise enough money, unless the target is of sufficient national/international interest to become a 'cause celeb', like the Ethiopian famine, for example. I wonder if it would be possible to raise more money to fund R&D for Parkinson's by getting an investment manager to be brave enough to establish a form of specialised global unit trust into which people could **invest – not donate!**

Surely there are some high-profile personalities with Parkinson's who could help with such a project? Apart from being a form of self-help that could mean investors potentially make money, or at least keep some savings, this would give companies – particularly academic start-ups – an incentive to find a commercially patentable and marketable cure for conditions like Parkinson's. Areas already funded to a much higher general level, like cancer, would be specifically excluded.

I would like to stress that these comments are purely personal, and in no way a criticism of any individual.

(from page 4) Special materials are used to make the micro-capsules, which metabolise into carbon dioxide and water in the human body. They are loaded with Parkinson's drugs, localised in both the hollow cavity and the shell of the micro-capsules. Being hollow, they float on top of the gastric juices in the stomach, and stay there.

Recent studies analysing drugs in the body showed the new formulations had longer residence times – how long molecules stay in the body – than current tablets. Researchers believe the technology will also work with new chemical compounds needing better 'oral bioavailability' – that is, improving the amount of a drug taken orally that reaches its target.

## SPINAL CORD STIMULATION REDUCES PAIN AND IMPROVES MOTOR SYMPTOMS

Spinal cord stimulation (SCS) reduces pain and improves Parkinson's motor symptoms, both as a therapy on its own and as a 'salvage therapy' after deep brain stimulation (DBS) has been ineffective.

This is the conclusion of US researchers at the University of California in San Diego, who worked with 15 PwP. The patients had had Parkinson's for an average of 17 years, and were all experiencing pain not alleviated by previous treatments. Eight had undergone DBS, while the other seven had received only drug treatments.

Electrodes were implanted through the skin, and then three forms of electrical stimulation were given: continuous, on-off bursts, or continuous bursts of varying intensity. After treatment, all patients reported significant improvement in pain reduction, averaging about 60%. Nearly 75% also improved slightly in the 10m walk, a test that assesses functional mobility and gait.



More than 60% improved in a Timed Up and Go (TUG) test, which measures how long it takes a person to rise from a chair, walk 3m, turn round, walk back to the chair and sit down. TUG assesses physical balance and stability, both standing and in motion. Average TUG improvement was around 20%.

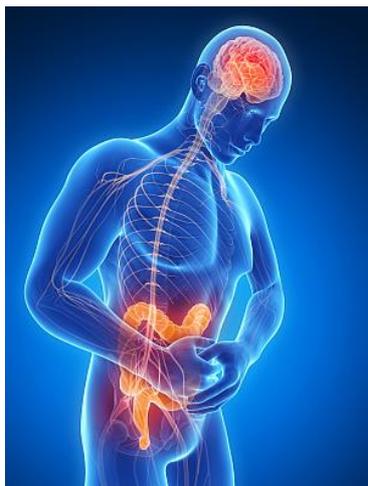
The authors said the findings suggest SCS may help treat PwP for both pain and motor symptoms. Further studies are needed to determine whether improved motor function is due to neurological changes caused by SCS, or simply decreased pain.

“We are seeing growing data on novel uses of SCS and specific waveforms in areas other than chronic pain management, specifically in Parkinson's,” said Krishnan Chakravarthy, a pain management specialist at UC San Diego. “The potential ease of access and implantation of stimulators in the spinal cord compared to the brain makes this an exciting area for future exploration.”

### NOT ONE, BUT TWO: BRAIN & GUT

Parkinson's is not one but two conditions, starting either in the brain or in the intestines. This explains why symptoms vary so much, and points towards personalised medicine as the way forward for PwP. This is the conclusion of a study by researchers in Denmark, published in the leading neurology journal *Brain*.

Using advanced scanning techniques, they say they have shown that for some PwP, Parkinson's starts in the intestines and spreads from there to the brain. For others, it originates in the brain and spreads to the intestines and other organs such as the heart. The discovery could be very significant for treatment, which should be tailored to the individual's condition.



Advanced PET and MRI imaging were used to examine both PwP, and people not yet diagnosed but with a high risk of developing Parkinson's, such as those with REM sleep Behaviour Disorder (RBD). The study showed that some patients suffered damage to their brain's dopamine system before problems occurred in the intestines and heart. In others, scans revealed the nervous systems of the intestines and heart were damaged, before anything untoward in the dopamine system became visible.

Until now, it has been puzzling why there is such a big difference between patient symptoms, they say.

With the new data confirming two versions, body-first and brain-first, this makes more sense. For the body-first, the researchers say it will be interesting to study the composition of bacteria in the intestines known as the microbiota.

“It has long since been demonstrated that the microbiomes of PwP are different to those of healthy people, without us truly understanding the significance of this,” said Professor Per Borghammer, of Aarhus University. “Now we can examine the risk factors and possible genetic features that may be different for the two types. The next step is to examine whether body-first Parkinson's can be treated with fecal transplantation or in other ways that affect the microbiome.”

Treating brain-first Parkinson's presents a bigger challenge, he said. This is probably relatively symptom-free until movement disorders appear, and by then patients will have already lost more than half of the dopamine system. So it is harder to find patients early enough to be able to slow the condition.

“Previous studies have indicated there could be more than one type of Parkinson's, but this has not been demonstrated clearly until this study, which was specifically designed to clarify this question,” Borghammer said.

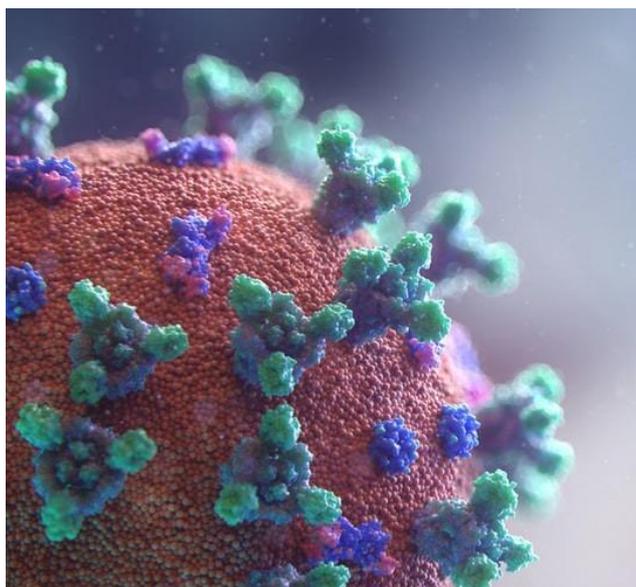
### COULD COVID-19 CAUSE PARKINSON'S?

Stories in the press have suggested the COVID-19 pandemic could cause a rise in neurological conditions like Parkinson's. Claire Bale, Head of Research Communications and Engagement at Parkinson's UK, assesses the evidence, such as it is.

“COVID-19 is a new disease and we're still in the earliest stages of understanding it,” she says. “The most acute effects are usually seen in the lungs, but there is growing evidence that it can trigger a wide range of neurological effects.”

The most common is a loss of sense of smell, which also often happens in Parkinson's. But the reasons in the two cases may be quite different. Research suggests smell loss in COVID-19 may be caused by damage to cells that support the cells for smell, rather than attacking the actual nerve cells themselves. As these are unharmed, smell loss with COVID-19 is mostly temporary, and passes when the infection is over. After all, it is quite common for

people to lose their sense of smell when they get flu or nasal infections.



It's not clear why some PwP lose their sense of smell. One theory is that Parkinson's may originate in the olfactory bulb, the brain area that processes smell. A 2017 study of post-mortem brain tissue showed the olfactory bulb was significantly smaller than usual in PwP. Other neurological issues caused by COVID-19 can include memory and concentration problems, confusion, delirium, hallucinations, fatigue, seizures and in extreme cases stroke.

So far, there is no evidence that the virus causes Parkinson's directly. To date, there have been only a handful of people diagnosed with Parkinson's following COVID-19, and this could simply be a coincidence. However, previous research has suggested that some viral infections may raise the risk of getting Parkinson's in the longer term. In the years following the last major global pandemic, the 1918 Spanish Flu, Parkinson's-like disorders increased significantly.

How some viruses may damage the brain and increase susceptibility to Parkinson's is still an active area of research, and different viruses may cause different problems. Some seem to be able to invade nerve cells and cause clumps of protein to form, while others may trigger brain inflammation. Inflammation is how our bodies respond to invaders like viruses, but it can also cause damage, especially if it is long-lasting.

"It's too soon to know if COVID-19 will increase Parkinson's in years to come," Claire says. "But clearly, as the pandemic continues, it's vital that its

long term effects on the brain are a research priority."

### GENES AND PARKINSON'S: PROFESSOR KLEIN PAINTS A COMPLEX PICTURE

The idea that genes 'cause' a particular disease is nearly always a huge over-simplification. There are actually very few cases in which having certain genes mean you will definitely get a condition. One example is sickle cell anaemia. Another, closer in kind to Parkinson's, is the neurological condition Huntington's Disease – if both your parents have the faulty gene, you have a 75% chance of getting it.

Nearly always, it is the **probability of contracting a condition** that is affected by genes, and this is so with the instances of Parkinson's where genes play a role. Even these are relatively rare, probably under 10% of all cases. That is why most people's Parkinson's is 'idiopathic' – meaning the cause is unknown.

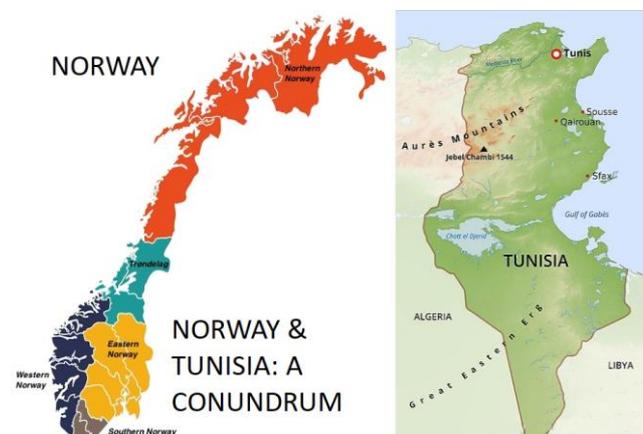


Nevertheless, genetics is an important element in Parkinson's research, one reason there is an annual lecture on the subject, held in Edinburgh. This year it was given on October 6 – virtually – by Professor Christine Klein of the Institute of Neurogenetics at Lübeck University in Germany (see the Viewpoint column for one member's comments on the lecture).

She presented a complex picture – perhaps somewhat over technical at times – but with interesting elements. One that demonstrates how difficult a subject genetics can be is called 'penetrance'. This describes how likely it is that you will develop the condition if you carry the genetic mutation(s) linked with it.

Of those with the mutation(s), some may remain free of the condition for their whole lives, while some who get it do so much later than others. Two genes linked with Parkinson's, Parkin and PINK1,

have a high degree of penetrance but having both these is very rare. With more common mutations, LRRK2 and VPS35, penetrance is much lower.



patients with the LRRK2 mutation, around 60% developed Parkinson's by the age of 60. In a similar group of Norwegians, only 20% did so. The question is why?

There is as yet no definite answer to this conundrum. Possibilities Professor Klein mentioned include effects caused by the cells' energy centres (mitochondria), levels of brain inflammation, or the environment. It is important to find out as it could result in treatments more tailored to an individual's condition. Genetic analysis should also help to detect earlier those at risk of developing Parkinson's. Prof Klein said this approach is already being used successfully with diabetes.

Another unexpected factor is that 'genetic' Parkinson's varies in different populations. For example, one study showed major differences between Tunisians and Norwegians! In Tunisian

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#### USEFUL CONTACTS

Parkinson's Local Adviser – 08088-000303 email [hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)

Facebook: [www.facebook.com/parkinsonsukcambridge/](https://www.facebook.com/parkinsonsukcambridge/)

Twitter: <https://twitter.com/CambBranchPUK>

Help Line 0808-800-0303 (free phone call) Specialist advisers can answer questions on any aspect of Parkinson's

Parkinson's Nurses in our area: for help and information contact the Parkinson's Nurse Team on 0330-726-0077

Addenbrooke's Hospital Parkinson's Nurses 01223-349814

Branch Website: <https://www.parkinsonscambridge.org.uk>

Parkinson's UK 020-7931-8080 [enquiries@parkinsons.org.uk](mailto:enquiries@parkinsons.org.uk) [www.parkinsons.org.uk](http://www.parkinsons.org.uk)