

Cambridge Branch Newsletter – March-April 2022

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BRANCH MEETINGS

FACE TO FACE FOR THE FIRST TIME IN TWO YEARS!



Chair of the Branch, Mark Goodridge (far right), talks to the members on Friday, February 25.

Every picture tells a story, as the saying goes, and we have been waiting two years – or actually three days short of two years – to tell the tale pictured above.

It is astonishing that we are celebrating something as simple as people getting together, even – dare we say it – shaking hands or hugging!

But that is what COVID has done to us, in one of the very few events in the whole of human history to have affected the entire planet. We call the two great wars of the 20th century World Wars but there were millions of people who remained completely uninvolved in them. As a truly worldwide phenomenon, nothing matches what we have lived through during the last 730 days – and counting.

But we are the lucky ones who have survived! And the prospects of normality resuming – at least in terms of public health – are looking good. Tragically, normality is a long way off for the people of Ukraine.

At the meeting, on the fourth Friday of February (the 25th) brief speeches were made by Keith, our Membership Secretary, and Mark, our Chair. Keith said he was grateful to all the many members who had participated in our Zoom cuppa meetings. Their success had delighted him, and they undoubtedly played a major role in making us feel that the whole concept of the Branch was being

retained. So all of us owe him a big Thank You for staging these events. (The less said about Teams the better!)

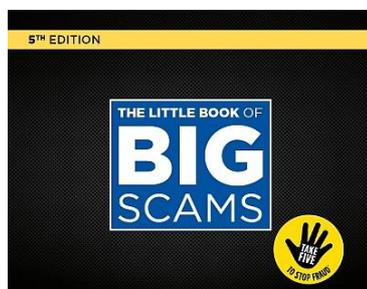
Mark, who took over the Chair in the most unusual and peculiar of circumstances, said it was great to finally be meeting the members he represents, many for the first time. Indeed, one of the really encouraging things about the meeting was the number of brand new members who came. A more than warm welcome to you all!

Finally, Caroline, our Events Organiser, told us we have several speakers already lined up for future meetings – which we plan to make ‘hybrid’, that is, available online as they happen. This makes for the largest possible audience, and also means we can ask speakers from virtually anywhere. Some of the speakers are featured in this issue but here is a summary:

- **March 25** AGM & Parkinson’s Nurses
- **April 22** Andrew Harding from AbilityNet
- **May 27** Andrew Lacey on Cambridge spies
- **June 24** Kate & Rachel on fraud & scams
- **July 22** David Short (publican): Life behind bars
- **Sept/Oct** Prof Roger Barker, Branch President

FRAUD AND SCAMS TALK SET FOR JUNE 24

Unfortunately, as those who were attempting to participate will know, the planned presentation by the police on the current rise in fraud, scams, and general intrusion in our lives, had to be postponed. This was because of technical problems with the 'Teams' app.



However, the good news is that Rachel and Kate, who would have been speaking to us, have now agreed to try again on June 24, and what's more, in person!

Meanwhile, they recommend that we all read the police document "The Little Book of Big Scams". You can do this via our website, <https://parkinsonscambridge.files.wordpress.com/2022/01/the-little-book-of-big-scams.pdf>

NEWS, EVENTS & PEOPLE

SAVE THE DATE: SEPTEMBER 2 LUNCH

In recognition of the 40th Year of the Cambridge Branch of Parkinson's, there will be a celebratory lunch on Friday, September 2. Time, place and booking details will follow. We hope to persuade Caroline Russell, the new CEO of Parkinson's UK, to join us for that occasion. It should be fun!

EARLY ONSET GROUP FORMED

"Parkinson's only affects the elderly" is a commonly held view. Unfortunately, it's not the case – there are all too many instances of people in their 30s and 40s getting it – and even in their 20s, as happened to one of the world's best known sufferers, Michael J. Fox. He was 29.

For people who can expect to have many years ahead of them, Parkinson's is arguably an even more daunting diagnosis than for older people. And the 'young onset' as they are called may have to deal with it at the same time as bringing up young children and handling a full time job.

What's more, they can find it difficult to participate in the events staged by their local Parkinson's Branch – think of our meetings on Friday mornings. In normal

times, to attend every meeting throughout the year, they would have to use at least six days of their precious annual holiday entitlement.

So that is why a new group is being formed, catering specifically for people of working age, covering the whole of Cambridgeshire. And it recently got off to a good start, with around 20 people getting together – face to face! – to discuss how to proceed.

It took place on Saturday, February 5, at the Village Hall in Hemingford Abbots, where a series of workshops enabled the participants to give voice to their expectations, their needs for social support, and anything else seen as relevant.



Organiser Julie Wilson, Parkinson's UK's Development Area Manager for the East, said: "We had a very successful morning. The group agreed to have four face to face meetings a year in different parts of the county, and also to stage regular Zoom meetings. They will come under the auspices of either the Peterborough or Cambridge branch, but this has to be decided. Following on from this a 'Parkinson's Café' (a sort of sub-branch) will be set up.

Our Chairman, Mark, attended the meeting and is proposing that our branch should 'sponsor' the group (together with Peterborough). Although he admits that at this early stage we can't be precise as to the detail of what this might entail.

One person who has offered to help with the new group, in particular to reach out to younger PWP and the newly diagnosed, is Ledia Alushi. Ledia is currently studying for a PhD at Cambridge University, and gave a talk to one of our Zoom meetings last year about a survey she is doing on exercise for people newly diagnosed.

NEW SAWSTON EXERCISE CLASS IS THRIVING

The new exercise class that started as a result of the survey of our branch members, which rated a class second only in importance to face-to-face meetings, is thriving.

Under the guidance of instructor Paul Goddard, the class is based on the Parkinson's Warrior exercise regime which specifically targets the symptoms of Parkinson's. Paul has been providing a class for a couple of years in Uttlesford, which is held in Little Easton on Monday afternoons.

Deb Liddington, a member of the Uttlesford Branch, helped set up the new class. First, she found a village hall convenient for Cambridge residents, and that also matched Paul's availability, and then handled the organisation to get it off the ground. Her connection with Parkinson's is her late father, whom she lost to Parkinson's in August 2020.



St Mary's Hall, Church Lane, Sawston.

"We have been supported initially by a grant from Sawston-based John Huntingdon's charity, which helped subsidise class fees and for which we'll be eternally grateful," she says. Now, after starting with eight people on January 4 this year, the second six-week course started on February 22. It has attracted a further four people, together with the original eight who all want to continue.

"We have also now become an official organisation – Active with Parkinson's Cambs – which means I can apply for grants to subsidise class fees to ensure accessibility for everyone who needs it," Deb says.

The class is held at 2pm on Tuesday afternoons at (CB22 3JR). "We already have some Cambridge members attending, and if any more are interested in joining us, please come!"

DONATIONS AT FUNERALS CAN GO STRAIGHT INTO THE BRANCH ACCOUNT

In recent years a number of kind families have recognised their gratitude to the Branch by asking for donations at the funeral of their loved one. This is normally done through the funeral director. These donations can go straight in to our branch account, <https://parkinsonscambridge.org/donate/> and do not need to be sent first to Parkinson's UK. If they are sent to the Head Officer, a letter specifying that they should be paid to the Cambridge Branch is required.

COVID RELAXATIONS TOO LATE FOR A TULIP RUN IN 2022, BUT THERE IS AN ALTERNATIVE

Unfortunately the relaxation of Covid-19 restrictions has come too late for us to arrange a fund-raising Tulip Fun Run in 2022. But this doesn't mean you can put your feet up for the rest of the year! One simple way to do your bit is to make 'Time to Run.' This requires you, and any others you can encourage to take part, to 'run' 50 miles in 50 days. It lasts from March 1 to April 19. Try to do as much as possible around April 11, World Parkinson's Day (WPD).

Many participants will be running for their Parkinson's hero, which can be anyone who has inspired you, gone the extra mile or supported you in any way. It could be someone in your life who's living with Parkinson's every day. Or if you have Parkinson's, your hero might be someone who makes your life a little bit easier. Together we can thank everyone who is helping to transform Parkinson's every day.

By taking part you'll be running for research. Your fundraising will directly fund the Parkinson's Virtual Biotech, to help us fast track the most promising scientific discoveries and treatments.

Get running in four easy steps:

1. Sign up and your fundraising page will be automatically set up. Give it a personal touch, tell us who your hero is and share with friends and family.
2. You'll receive a link to join our Facebook group so you can share your experience with the Time to Run community.
3. From March 1 you have 50 days to run your 50 miles. Track your progress with your running app or upload your miles manually.
4. Get a medal for finishing! You can also earn fundraising rewards for going the extra mile.

Go to www.parkinsons.org.uk/events to find out more and to register.

GUILDHALL TURNING BLUE FOR WPD

Parkinson's UK is encouraging all of us who live with Parkinson's, as PwP, supporter or friend, to colour the country BLUE on April 11, World Parkinson's Day (WPD). The Committee is working to have public buildings in and around Cambridge, including the Guildhall, lit up that evening. The Senate House and Ely Cathedral are also possibles. If you know of any building that can do this, ask them to join the country-wide effort to increase awareness of PD.



If Edinburgh Castle (above) can do it, surely we can too! Wear your Parkinson's T-shirt that day, put a blue notice in your window, or a blue light bulb in your outside light. Anything and everything will help!

GOT ANY IT PROBLEMS? DON'T MISS THE APRIL 22 BRANCH MEETING FROM AbilityNet

The meeting set for April 22 will feature Andrew Harding, who studied electronics engineering, and now works with AbilityNet, a UK charity that helps companies with digital accessibility and usability issues. Here, he gives a brief outline of his talk.

"I ended up working in marketing for a Japanese electronics company where I was on my PC from dawn to dusk. That's where I learnt all my IT experience," he says. "I was diagnosed with Parkinson's in 2013 whilst living and working in Munich. In 2018 I took early retirement and returned to the UK to be close to family. I was asked to lead a Parkinson's support group in North Norfolk just weeks before the pandemic struck and we've been Zooming ever since!

"I usually start my talks with a short video throwing fun at the challenges of IT. Then I may talk a bit about 'going further with Zoom' – having some fun with backdrops, the perils of sharing videos, how to use breakout rooms, running quizzes on zoom etc. And perhaps if anyone has any problems to solve I could be briefed on them in advance and try to solve some 'live'. Send an email marked for Andrew's attention to enquiries@abilitynet.org.uk , tel 0800-048-7642.

"I could share a bit about my experience of using the MAC (plus iPad, iPhone and PC) with Parkinson's and what I find helpful. And finally, I explain a bit about AbilityNet, which aims to ensure that websites, apps and other digital services are accessible, usable and comply with current legislation.

SCIENCE & RESEARCH

GOOGLE AND MAYO DEVELOP NEW ALGORITHM FOR BRAIN STIMULATION

A new type of artificial intelligence (AI) algorithm, developed by the Mayo Clinic and Google's Research Brain Team, can potentially enhance DBS for treating Parkinson's. Researchers say the algorithm can determine more accurately the interaction between different regions of the brain, data that will be crucial to improve the way brain stimulation devices are used for treating Parkinson's.

Knowing which brain regions directly interact with one another will help in guiding the placement of electrodes for stimulating devices. Brain network interactions are complex, but they can be explored by delivering pulses of electrical current in one area of a patient's brain and measuring the responses elsewhere. But the recorded signals are usually complex to interpret, and only a limited number of measurements can be made.



To address this problem, Mayo Clinic researchers developed a way of simplifying comparisons between the effects of electrical stimulation on the brain. Based on these, and together with collaborators at Google, they created a new type of AI algorithm called 'basis profile curve identification'.
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VIEWPOINT

Friday, February 25, will be remembered by our Branch for a long time: our first face to face (F-to-F) meeting for pretty well exactly two years.

The previous one took place on February 28, 2020, featuring a talk about Duxford Airfield from guide David Allars. The next one, which had been planned for March 27, was the day Lockdown No 1 started.

Our first post-COVID meeting wasn't quite normal: no speaker, and bring your own sandwiches! But it still felt great – and was a powerful reminder of how limiting the last two extraordinary years have been in terms of our interaction with other people. And in millions of cases, it has been much worse than limiting, but tragic, with people dying of COVID while their loved ones were unable to comfort them. A truly appalling thing to happen to anyone.

But here we are, having survived the first pandemic of the 21st century. Let's hope that the wonderful scientific achievement of developing really effective vaccines in months rather than years will stand us in good stead for any future repeats.

The dramatic success of the vaccines has been one remarkable element in the whole COVID story. Potentially, there is another one: in March 2020, the vast majority of us used the word zoom to refer to changing the focal length of a camera, or the view on a computer screen. Now, millions – maybe billions – use the word to refer to software for virtual meetings.

In the future, it may well be that the pandemic is seen as the start of a technological transformation of human interaction. It may be that within 20 years or so, ultrafast broadband (1 gigabit/sec) will make possible Zoom-like tools that are extremely realistic, dramatically better than anything today.

It could be as if people you are talking to are in the room with you. Online holography could provide totally realistic, 3D images of everyone. And you will be able to make a quick comment to the speaker without stopping them speaking. Today, that simply doesn't work very well, and it is something we do all the time when talking to people in the flesh. There will be other improvements making the whole experience far closer to real F-to-F meetings. So if and when the next lockdown comes, it may be less constraining than it has been during COVID. Not much consolation, admittedly, but a bit!

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For AI researchers, neurological data is perhaps the most challenging but exciting data to try to model. In their study, a patient with a brain tumour had an electrode array placed in his brain, to locate seizures and map brain function before removal of the tumour. This array helped generate thousands of readings for the algorithm to use.

Every reading enables the creation of 'basis profile curves' – sets of characteristic responses – that can be mapped back to the brain anatomy. These help to quantify the projection strength of each stimulated site. Ultimately, the AI algorithm allows for a more straightforward interpretation of the stimulation data.

With their research, the team presented what they call "a new machine-learning framework to probe how brain regions interact using electrical stimulation. Unlike previous studies, this approach does not assume in advance how one brain area will respond to stimulation in another area. Instead, it discovers the shape of the response in time from the data," they said. The team has made the code they developed available so other scientists can explore this algorithm and use it on their own data.

CHEERS – MAKE MINE A FLAVONOID!

Adding a few servings per week of flavonoid-rich foods to diets could improve life expectancy for PwP, according to researchers at Pennsylvania University. Flavonoids are found in richly coloured foods like berries, cocoa and red wine, and have long been associated with health benefits.

The research revealed that when people already diagnosed with Parkinson's ate more flavonoids, they had a lower chance of dying during the 34-year study period than those who did not consume as many flavonoids. Additionally, they found that eating more flavonoids before being diagnosed was associated with a lower risk of dying in men, but not in women.



The study analysed data on 599 women and 652 men, all recently diagnosed. Participants' flavonoid intake was calculated, and after controlling for things like age and several dietary factors like total calories consumed and overall diet quality, the researchers

found the highest flavonoid consumers had a 70% greater chance of survival than the lowest group.

The former consumed about 673mg of flavonoids each day, compared with only about 134mg for the latter. The researchers also analysed the effects of individual flavonoids and found that those in the top 25% consumers of anthocyanins, found in red wine and berries, had a 66% greater survival rate compared to those in the lowest 25%.

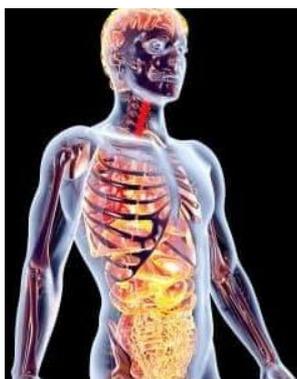
The underlying mechanisms causing this were not part of the study but the research team has proposed some theories. "Flavonoids are antioxidants, so they may be lowering chronic neuro-inflammation levels," a researcher said. "It's also possible they interact with enzyme activities and slow neuron loss, and could protect against cognitive decline and depression. Both are associated with higher mortality risk."

PARKINSON'S PATIENTS FOUND TO HAVE UNIQUE BACTERIAL PROFILE

Researchers at the biotech company Second Genome have identified specific intestinal bacteria that are either enriched or depleted in patients with Parkinson's.

Studies have indicated that alpha-synuclein, the protein that forms clumps in the brain and may be responsible for Parkinson's symptoms, could be migrating to the brain from the gut. And research has shown that specific bacterial proteins can reduce this clumping.

In what is called a 'meta-analysis' the team looked at groups of Parkinson's patients in eight different studies, comprising 992 patients and 663 individuals who served as controls, in several countries including the US, Italy and Germany.



Different kinds of bacteria are found in the gut of PwP.

After selecting and processing the DNA sequences of different versions of bacteria from the groups, the researchers ran plots that enabled them to visualise which versions were significantly increased or decreased between the control group and the patient group. Further analysis allowed them to determine which versions were most consistently associated with Parkinson's.

The team found that 168 types of bacteria were significantly depleted in PwP compared to the control group, whereas 441 were significantly enriched in Parkinson's patients.

Second Genome plans to use this research to develop predictive biomarkers and future therapies for Parkinson's, using a system it has developed that can turn what it calls "host-microbiome signals" into "precision therapeutics."

SHINING A LIGHT ON A NEW THERAPY

Could light help manage Parkinson's symptoms, have a protective effect on brain cells, and slow down the progression? Why should cells in the middle of the brain, in complete darkness, be protected, or even 'healed', by light? How do cells in the eye signal to the deepest parts of the brain? Or is it that light is being absorbed by specific components in cells, activating and providing energy for the body to promote brain cell survival, protection or regeneration?

One area of study is vitamin D, which is produced by exposure to direct sunlight. Small amounts are present in certain foods, but many doctors advise taking Vitamin D supplements, especially through the darker months in winter. It helps regulate the amount of calcium and phosphate in the body, which keep bones, teeth and muscles healthy.

Research has looked at the relation between vitamin D and Parkinson's, including exposure to sunlight and possible links with the risk of developing Parkinson's. Studies have found higher vitamin D levels decrease the risk of Parkinson's, and also that PwP with higher vitamin D levels tend to have better mobility.

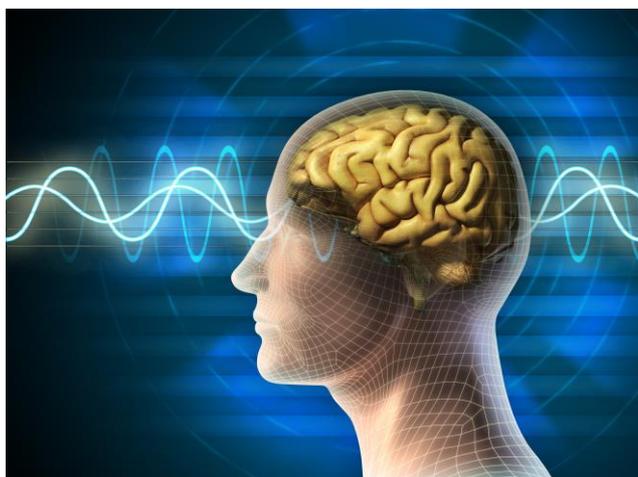
Bright light therapy uses a special lamp to mimic natural light. Intensity, duration and timing are carefully controlled. It is known for its use in Seasonal Affective disorder (SAD), a form of depression linked to the change in seasons, where decreasing levels of light in the winter triggers low mood. But controlled trials with SAD have had mixed conclusions, suggesting light therapy only works with some individuals. Similar mixed results occur when treating bipolar disorder.

However, a more consistent result is that light therapy improves sleep. That is relevant to Parkinson's, which often causes sleeping problems, alongside anxiety, low mood and depression. So, can light therapy help in Parkinson's? Some evidence suggests it can, but it is not clear cut. One study involving more than 80

patients showed no significant change in overall depression, even though mood and sleep did improve.

Other studies looking particularly at sleep showed light therapy does help, and that the benefits happen quickly. Also, it can improve movement symptoms like tremor and rigidity, but research here is limited. Some scientists suggest light therapy increases dopamine levels, which could explain why some individuals receiving it can reduce their medication. This is supported in rat models, where dopamine-producing cells can respond to light.

One problem with light therapy is that research has used different methods, such as 'doses' and duration of light, so finding a consistent method would be useful for future research. On the other hand, it could be argued that light therapy needs to be tailored to the individual to have the best results.



An alternative form of light therapy is near-infrared light therapy (NILT). The near infrared has a longer wavelength than bright light, and it is thought to be better absorbed by specific components within the cell, such as those that control the cell's energy levels. Evidence is growing that NILT has protective and restorative properties, and this does apply to Parkinson's. But it comes mainly from research on cell-based and animal models. Nevertheless, the results look promising, with NILT decreasing stress in brain cells, and protecting dopamine-producing neurons, resulting in improvement to movement symptoms.

It seems that NILT works best when applied directly or very close to target cells, which is a problem in Parkinson's as the relevant cells sit deep in the mid brain. To get round this, some researchers suggest using an optical fibre device surgically inserted into the brain. One study, featuring mice, rats and monkeys used such a technique with beneficial

results, and revealed a potential link between light therapy and an increase in the growth factor in the brain called GDNF. A clinical trial of GDNF a few years ago showed that directly infusing it into a specific area of the brain in PwP could have protective and regenerative effects on dopamine-producing brain cells. Could light therapy offer an alternative way to boost GDNF in the brain?

Investigations of NILT in PwP have so far been very limited. But 'red light helmets' are being investigated in Tasmania and Australia (see Newsletter 33 Nov-Dec 2019). These helmets were inspired by research done in mice.

So should people try NILT? "Although light therapy is thought to be safe with minimal side-effects, we don't advise people seek out this therapy as a treatment for Parkinson's," said Dr. Katherine Fletcher, Research Communications Officer. "There needs to be more research into the long term impact of NILT, and the research so far has used various techniques and each needs to be investigated in larger and longer, controlled clinical trials."

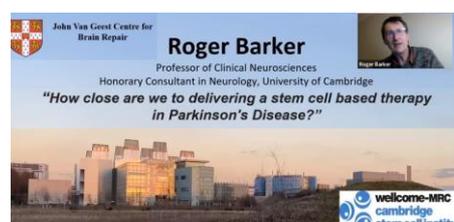
STEM CELLS: A MAJOR NEW THERAPY COMING?

A recent webcast featuring Prof Roger Barker centred on the subject of the use of stem cells as a Parkinson's therapy. His talk was part of the No Silver Bullet group, which was started by PwP, their carers and other Parkinson's specialists, and is building up a collection of interesting material.

In fact, the use of stem cells being implanted in the brain to try to replace lost dopaminergic cells already has something of a history to it. A pioneer of this form of therapy is Lund University, where trials took place decades ago. The results were variable but when the treatment worked, it worked very well. For example, one patient who was not taking any medication could walk virtually completely normally. And the point was, this was 30 years after his diagnosis!

Since then, it would be fair to say that the therapy has had its ups and downs. But increasingly it looks more like a potentially powerful treatment than it ever has before. One reason for that is a critical issue for cell-based therapies: where do you get the cells from? One source is aborted fetuses. Another option is embryonic stem (ES) cells. And the final one is induced pluripotent stem cells (IPS). This technique enables you to take adult cells, like skin or blood cells, and turn them back into ES cells.

In fact, it was never going to be feasible to use foetal stem cells as a widely used Parkinson's therapy. They are simply far too rare. But they were invaluable as a proof of concept. So the choice lies between ES and IPS cells. One crucial issue is scalability. Can we 'mass produce' the cells? A few years ago, the investment in cell-based therapies for Parkinson's worldwide was approximately zero, Barker says. Now, he reckons several billion dollars are being invested. Why?



One major reason, at least for ES cells, is that the drug companies now believe

there are real profits to be made. For example, a plate about as big as a paperback book can feature six ES cell wells. Around 16 days later, this will have produced enough dopamine cells for 500 patients.

"Equipped with a robot, and using a 1000-well plate, I could treat 500,000 people with Parkinson's. That is pretty much the population of the entire world suitable for this therapy," Barker says. "For a company, that means they can produce a therapy at quite a low cost and hence get a good return for it."

Another plus is that because it can be done so quickly, it is a highly reproducible process and minimises the problem of cells being different from batch to batch.

Barker is now leading a new project called STEM-PD and is waiting for approval from the relevant Swedish and UK authorities. The aim is to start it in the first half of this year. What about the link being forged with so-called 'Big Pharma'? It can have drawbacks, but Barker says the companies have the money and the know-how to quickly take this to market.

"I'm optimistic that if it works, we will move quite quickly through the trials, and see results." He believes this could change the whole nature of future treatment of Parkinson's. At the moment, the STEM-PD project is not recruiting participants as that has to wait for approval. But if you are interested, go to <https://cctu.org.uk> and look under contact.

IN MEMORIAM: ROBERT MILSOM

We are sorry to inform you that our member, Robert Milsom, has died. Robert and his wife Penny were long-standing members of the Cambridge Branch, even attending our Cake and Cuppa Zooms until just a few weeks ago. Robert's Parkinson's had progressed during the Pandemic, and he finally died, at home, on January 13. At his funeral on January 31, tributes were paid to a gentle family man who used his skills as an educator and solicitor not only to protest against injustice, but also to help those suffering from it.

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USEFUL CONTACTS

Parkinson's Local Adviser – 08088-000303 email hello@parkinsons.org.uk

Facebook: 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>

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