

Cambridge Branch Newsletter: March-April 2023

Editor

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BRANCH MEETINGS

CAREY COOK, SPECIALIST PHARMACY TECHNICIAN in the Domiciliary Medicines Management Service at Cambridge & Peterborough NHS Foundation Trust

This a free bespoke service offered by the NHS to people in Peterborough and Cambridge to assist people with their medicines. Residents in Cambridgeshire with a Cambridgeshire GP can access the service. Patients can self-refer, be referred by families or friends, surgeries, or surgery nurses.

The small team will assist, in the home, with drug usage, timings, with or without food, etc. They take an holistic approach to the patients situation in the home. They will consider prescription ordering, over supply and disposal of out of date medicines. The team will look at the way you store medicines and provide equipment to assist the patient to take the correct medicine at the correct time. They will also look at the medicines currently used and the relevance to your condition and communicate with your surgery as necessary.

Carey demonstrated a Rosebud reminder, dossett boxes, pipatel alarms, amongst other devices.

The members were astonished that this service has been in place for over a decade but none of the members were aware of its existence!

A lively Q&A ensued at the end of which Carey had a queue of people asking individual questions and self-referring.

To self-refer in Cambridge and surrounding areas Carey can be contacted on 07966 894044.

THE RAF'S FIRST HUNDRED YEARS

Our January branch meeting featured David Taylor as the speaker, whose subject was 100 years of the RAF.

In fact, we have now reached 120 years of flying history, as it is generally accepted that the first powered flight was achieved in the USA by the two Wright brothers, Orville and Wilbur (pictured). On December 14, 1903, they tossed a coin to see who would pilot the first flight and Wilbur won. But after only three seconds in the air, the plane stalled and crashed.



However, only minor damage occurred, so three days later it was Orville's turn, and at 10.35am he flew for 12 seconds at a speed of just 6.8mph. The next two flights covered around 200 at an altitude of 10 – feet in both cases! But in the final flight of the day, they flew a distance of 852 feet and stayed in the air for 59 seconds.

In England, there are probably two planes that compete for the “most famous” title: Concord and the Spitfire. The Spitfire was actually first named the Shrew. But it was decided – surely correctly – that a name with a bit more threat to it was needed!

Three of the most famous planes in the history of flight and warfare were biplanes, the Gloster Gladiators. Developed in the early 1930s, by 1940 they were already obsolete. But they helped defend the island of Malta against far superior Italian aircraft. Only three could take to the sky at any one time – the other three being used for spare parts – and the trio became known as Faith, Hope, and Charity. Amazingly, they managed to shoot down several Italian planes, and only one Gladiator was lost.

Later in the war, in 1942, the Luftwaffe bombed Malta to such an extent that Valetta, the capital, became the most heavily bombed place on earth. Famously, the entire island of Malta was awarded the George Cross for its resistance to the Germans.

Another classic plane was the Wellington, which was the most mass produced bomber plane of WW2. When the bomber offensive against Germany started in 1942, Wellingtons comprised about 60% of the first thousand raids. But it only had two engines, inciting the comment that if one engine failed, the other would definitely “get you to the crash site.”



David Taylor speaking at the Branch Meeting.

One of the most difficult tasks in the whole of flying is refuelling planes as they fly. This was achieved to great effect with the Vulcan bomber that played a vital role in the Falklands War. The islands are so remote that it had to be re-fuelled as it flew. One famous comment describes this as “like getting a wet piece of spaghetti into a dog’s backside”!

No one knows for sure what the future will bring for the RAF. But it is distinctly possible that its second hundred years will involve far fewer pilots actually in the planes – perhaps even none. The importance of unmanned drones in the current Ukraine conflict and elsewhere is surely a sign of what is to come.

NEWS, EVENTS & PEOPLE

YOGA CLASSES STARTING

Weekly yoga classes intended for branch members start on March 9. They will be led by an experienced yoga instructor, Rebecca Khabiri. Rebecca teaches a blend of styles of yoga and has learnt how best to teach them therapeutically. She is excellent at adapting to the needs of individual classes, and can also include Qigong, which is a good method of improving coordination and helps people to relax.

Initially, there will be 12 sessions, each lasting an hour. They will take place at the David Rayner Building, starting at 1pm on Thursdays. There will be a maximum of around 14 participants, so if you are interested now is the time to sign up.

Some of the cost is being borne by the branch, and the first four lessons will be free of charge.

Thereafter, the fee for each person will be just £5 per session. To book a place, contact Rebecca on ckhabiri@hotmail.com.

SIMON A PARKINSON'S PRIZEWINNER

Simon Stott, now working for Cure Parkinson's but known to us from his time at the Barker Lab in Cambridge, has won this year's Parkinson Prize.

There are in fact two prizes, which are given by the Journal of Parkinson's Disease (JPD), for articles it has published. One is for an outstanding contribution to the advancement of research into Parkinson's, and the other for an article on clinical research. Simon won the latter prize.

These papers were selected by members of the JPD Editorial Board from among 392 articles published in 2020 and 2021. Winners will receive a commemorative trophy and a cash award of \$1,000 per article. The Parkinson Prize will continue as an annual award.

Simon's winning paper was titled 'Parkinson's Disease Drug Therapies in the Clinical Trial Pipeline'.



It was featured in a special section of the JPD called Clinical Trial Highlights. This provides the Parkinson's community – including patients, clinicians and researchers – with an overview of the drug

development pipeline for new therapies. It is among the most widely downloaded and read papers published by our journal.

The team involved in the article, which includes people living with Parkinson's and care partners, hopes that this will stimulate further engagement and interest in the clinical trial process, resulting in greater patient involvement and faster future developments.

“My co-authors and I are extremely proud to have won the Parkinson Prize,” Simon said. “We would like to thank the editorial team at the JPD for this honour. We are very pleased that the drug development pipeline report has garnered the attention that it has.”

Simon, a Kiwi by birth, first developed an interest in Parkinson's while working for an Auckland-based biotech firm called NeuronZ. At the time, Parkinson's struck him as a very solvable problem. That interest took him to Lund in Sweden in 2002 where he did a PhD, and then took up an MRC Career Development Fellowship at the National Institute for Medical Research in London.

In 2011, he joined Professor Roger Barker's lab in Cambridge, where he worked on models of Parkinson's and also volunteered to help in the weekly Parkinson's clinics. These exposed him to the patient community for the first time. The human side of the condition opened his eyes to the true complexities of Parkinson's, but also made him aware of the lack of information being communicated about research to the patient community. So in 2015, he started a blog called the Science of Parkinson's, devoted to explaining interesting pieces of research news in plain English. He joined the research charity Cure Parkinson's as their deputy director of research in 2018 and became its director of research in 2022.

SCIENCE & RESEARCH

DOES TIME IN NATURE SLOW PROGRESSION?

Living in an area with easy access to parks and rivers appears to slow the progression of neurological diseases. That's the conclusion of a new study based on more than a decade and a half tracking disease risk among over 60m Americans aged 65 years old and up.

Previous research has shown that natural environments like forests and parks can reduce stress. They also provide settings for physical activity and social interactions, and cut exposure to air pollution, extreme heat and traffic noise.



The study looked at hospital admissions for Parkinson's and other neurological illnesses. The researchers focused on hospital admissions, so they were not assessing initial risk of developing the condition. Instead, they wanted to know specifically if increased exposure to nature lowered the odds that diseases would progress quickly.

Researchers observed significant protective links: the greener an older individual's surrounding environment, the lower their risk of hospitalisation.

The study covered 16 years, during which more than 1m were hospitalised for Parkinson's. Throughout, researchers stacked each patient's ZIP code against several types of geological survey data that indicated a region's overall 'greenness'. That data included the amount of vegetation present, as well as the percentage of land devoted to parks and waterways.

Results were more positive for Parkinson's than other conditions like Alzheimer's. By all measures studied, living in a greener environment meant a lower risk of hospitalisation. Also, people living in greener spaces tend to be more physically active, which is known to play a part in long-term preservation of motor function.

VIBRATING GLOVE LOOKS PROMISING

A vibrating glove is causing considerable excitement in the US. Developed at the world-renowned Stanford University by researcher, Peter Tass, it is showing the potential to alleviate a range of symptoms – even more than expected.

Admittedly, only a small group of patients have so far taken part in trials. But they found that wearing the glove for two hours, twice a day, reduces tremor, stiffness, abnormal walking, slow body movement and balance problems.



Some patients reported the glove also alleviated mood swings, behavioural changes, depression and the loss of smell and taste.

The suggested mechanism for these effects is that the fingertip stimulation given by the gloves could alter abnormally synchronous activity in the central nervous system.

Convincing the research community that the vibrating glove really has significant therapeutic effects will require further testing.

The idea of using vibrations to treat Parkinson's is not new, Tass says. In the 19th century, the neurologist Jean-Martin Charcot (pictured) created a vibrating chair after learning that his patients' symptoms briefly improved after long, jostling carriage and horseback rides. Charcot was the man who insisted James Parkinson's surname should name the condition that the English doctor was first to scientifically describe and analyse.



Charcot's vibrating chair, and the vibrating platforms and therapies developed by researchers who followed, alleviated some symptoms of Parkinson's, but the results were temporary.

When Tass was a medical student, he became intrigued with self-organisation – the seemingly spontaneous assembly of patterns and structures, such as clouds and snowflakes.

“My goal is to create treatments that are more effective and less brutal on the body by utilizing the self-organisation power within the body,” he said.

The symptoms of Parkinson's arise when large groups of neurons abnormally fire in unison. Using computer simulations, Tass and his team discovered that specific stimulus patterns can desynchronise neuron-firing and reduce abnormal synaptic connections between neurons. They called this ‘coordinated reset stimulation’.

In the 2014 study in humans, coordinated reset stimulation was applied for three consecutive days in two daily sessions of up to two hours. The researchers found the stimulation reduced the neural synchrony associated with Parkinson's and this correlated with improvement of motor function.

Next, the team set out to deliver the stimulation without implanting electrodes in the brain. This was done by coordinated delivery of vibration bursts delivered through mechanical stimulators to the fingertips. Our fingertips have many sensory neurons, so a large portion of the cortex of the brain is dedicated to receiving signals from them. This is important because a non-invasive therapy must act on a sufficiently large portion of the brain to have similar benefits as Deep Brain Stimulation (DBS).

The result is a glove that looks like something from a sci-fi film. But it can be worn while performing regular daily activities, and is attached to a device that delivers bursts of 250 hertz through pin-sized openings on plastic pads strapped to the fingertips. Each glove collectively stimulates a patch of skin smaller than a coin.

Pilot studies revealed that the vibrations were well-tolerated, produced no side effects, improved the patient's motor performance and reduced Parkinson-related neuronal synchrony in the brain.



Peter Tass with a patient wearing the gloves.

For now, the glove treatment is available only to Parkinson's patients participating in several clinical trials of the

device addressing different sub-populations of Parkinson's patients as well as motor and non-motor symptoms. Tass is also working with an industry partner to gain US Food and Drug Administration clearance for the treatment, which he hopes to have by mid-2024. For more information, contact the Tass Lab (<https://med.stanford.edu/tass-lab.html>) at parkinsonsvcr@stanford.edu.

VIEWPOINT

Consciousness: a mystery that might help us.

In his excellent book, *The Brain's Way of Healing*, science writer Norman Doidge devotes a chapter to a South African man called John Pepper (see the newsletter of July-August 2017). The gist of the chapter is Pepper's claim that he has virtually stopped the progression of his Parkinson's through fast walking. And crucially, to do this walking he devotes far more conscious attention to his actions than people usually need to do in order to walk.

Making walking a consciously controlled activity contrasts with the way most of us do it, in a virtually subconscious, automated way. It is as though we are reverting to our infancy, when we had to learn to walk. This was done with the searchlight of consciousness focused on the activity. Then gradually it becomes more and more automated – which means using far less fully conscious control.

The supposed reason this technique has enabled Pepper to stop his Parkinson's progressing is that the areas of the brain handling conscious attention are not those that have been damaged by Parkinson's. Bringing these undamaged areas into play has enabled Pepper to avoid – even overcome – Parkinson's symptoms.

This is a consistent theme of Doidge's whole book, and it is a fascinating suggestion. But there is a problem: consciousness is still largely an unsolved mystery for neurology. For example, no one knows the answers to questions such as: Where is consciousness 'located' in the brain? Does consciousness require synchronous activity across several different areas? Or is one particular element in the brain crucial to consciousness occurring?

Until we have some sort of answers to these questions, we are just assuming that putting an activity into the spotlight of conscious attention is using brain areas undamaged by Parkinson's.

And when it comes to consciousness, things get even more complicated. Even when, or if, we answer the questions above, another one will remain: why do we have consciousness at all? What is it about particular brain states that result in them being conscious – by which we mean 'something it is like to undergo them?'

This has been entitled the Hard Problem of consciousness by the philosopher David Chalmers. He is doubtful that we will ever solve it. But if we can make use of consciousness to overcome neurological conditions like Parkinson's, perhaps in the end that doesn't matter.

PARKINSONS UK INVESTS IN COUGH MEDICINE

Parkinson's Virtual Biotech is investing £1.1m to co-fund a trial of a cough medicine, ambroxol, to see if it can slow progression. It is joining forces with Cure Parkinson's, and its strategic partners. The trial is called ASPro-PD, and is the world's first Phase 3 trial of ambroxol. Total cost is £5.5m.

As far back as 2009, researchers discovered that a medicine used to treat coughs and sore throats, ambroxol, could also be used to treat Parkinson's. Ambroxol boosts levels of an enzyme called GCase, which is known to help clear away waste products

which have gathered in brain cells. For Parkinson's, it is hoped that ambroxol could help clear away the clumps of the protein alpha-



synuclein that develop, and damage brain cells.

Results from a trial in 2020 showed that ambroxol was safe for PwP, and also showed that it could reach the area of the brain needed to boost GCase. The new trial will test the drug in a larger group of PwP, and compare it to a dummy drug to see if it can slow the progression.

There is some evidence to show that people who have a change in one gene associated with Parkinson's might benefit from treatment with ambroxol. The team are inviting anyone interested in joining the trial to register now for the PD Frontline study and use their online genetic testing service. (<https://cureparkinsons.org.uk/2021/11/pd-frontline/>). PD Frontline is a remote study offering online genetic testing for PwP, so they can be referred to appropriate clinical trials.

ASPro-PD is led by Professor Anthony Schapira at London's UCL and preparations for recruitment of trial participants have already started. Everyone taking part in the ambroxol trial will be genetically screened, via PD Frontline, as part of the trial selection criteria.

SLEEP BENEFIT MAY BE EXPLAINED

Sleep Benefit (SB) is a poorly understood phenomenon where some – but not all – PwP have fewer symptoms when they wake up. A study has now shown it could be associated with higher levels of dopamine transporter (DAT) proteins in a region of the brain called the putamen.

These findings are significant as they provide the first direct neurochemical evidence that might explain the SB effect. SB was first reported over 40 years ago and has since puzzled researchers, as patients generally don't have medication in their system after a full night's sleep. SB can even occur after daytime naps for some patients.



The putamen may be involved in sleep benefit.

To this day, the cause of SB remains

mysterious, but previous studies have suggested that PwP with longer disease duration, poor sleep efficiency, and greater motor impairment were more likely to experience SB. Sleep efficiency is the percentage of time spent asleep while in bed.

Now, researchers at Zhengzhou University Hospital in China have evaluated brain levels of DAT, which is a protein that helps control the release and re-uptake of dopamine by nerve cells, to reveal whether it is involved in SB.

Several findings emerged from the trial. One was that of those patients who experienced SB, significantly more were 'tremor dominant' compared with those who did not exhibit SB. Also, the 'SB patients' were taking significantly less L-dopa, and brain scans revealed their DAT levels were higher in several regions of the brain, especially the putamen, a brain region affected in Parkinson's.

If SB is linked to DAT levels in the putamen, researchers speculate that brain cells with higher amounts of the protein might be better able to regulate dopamine signalling after sleep, leading to an easing of symptoms.

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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 call) Specialist advisers answer questions on any aspect of Parkinson's

Parkinson's Nurses locally: for help and info contact the Parkinson's Nurse Team on 0330-726-0077

Addenbrooke's Hospital Parkinson's Nurses 01223-349814

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

Parkinson's UK 020-7931-8080 enquiries@parkinsons.org.uk www.parkinsons.org.uk

STOP PRESS! STOP PRESS! STOP PRESS! STOP PRESS! STOP PRESS!

Announcing the Cambridge Branch of Parkinson's UK's Annual General Meeting

March 24th 2023, at 10:45, at the David Rayner Building

Scotsdales Garden Centre, Cambridge Road, Gt Shelford, CB22 5JT

This brief meeting is open to all those living with or supporting others with Parkinson's Disease, residing in the greater Cambridge area. Members of Team Parkinson's will approve an annual financial report and confirm the appointment of existing and/or new officers and members of the management Committee to serve for one year.

Nominations for membership of that Committee are cordially invited at

carolinebent@me.com or 01223 314279.

Support the Branch to continue its success.

As mentioned, above we need new members on the Committee. We need urgently,

A Vice Chair

A Shadow with good PC skills to shadow the Secretary and Membership

A shadow with good PC and financial knowledge

Parkinson's Cafe hosts (not necessarily a committee role)

Training will be provided for all the roles. The ideal candidate will be an active retired person with or without Parkinson's who enjoys getting involved. Family members will be most welcome. The success of the Branch in supporting local PwP and their family/carers is the driver for our volunteers. We are a friendly bunch of enthusiasts, and your involvement will not be onerous.