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

Cambridge Branch Newsletter – July-August 2020

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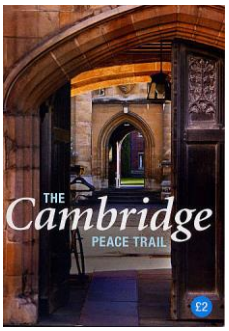
BRANCH MEETINGS

CAMBRIDGE PEACE TRAIL FOUNDER SPEAKS AT OUR FIRST VIRTUAL BRANCH MEETING

A fascinating talk about the Cambridge Peace Trail was the subject of our very first virtual Branch Meeting, on Friday, June 26, given by Arn Dekker. Arn has a passionate interest in peace and social justice, and is Treasurer for the Justice & Peace Commission. The Peace Trails connect sites in a town or city that have associations with peace and social justice, marking them with blue plaques. The UK has several such trails in places like Birmingham, Manchester, York and of course Cambridge, which was established by Arn.



"Cambridge has been a very fertile environment for Peace and Social Justice campaigners and I believe their efforts should be made more widely known," he says.

The trail starts at the corner of Station and Tenison Roads, where refugees found shelter in 1938-9 from the Spanish civil war. This is followed by Lensfield Road, celebrating the life of Thomas Hobson, who did many good works including providing Cambridge with clean drinking water, and Regent Street (Eglantyne Jebb, founder of Save the Children). Several colleges feature: Emmanuel (Alexander Wood, scientist and co-founder of the Peace Pledge Union); St John's (Thomas Clarkson, slavery abolitionist); Trinity (philosopher and pacifist Bertrand Russell, writer A. A. Milne, and scientist Arthur Eddington); Clare (poet and anti-war campaigner Siegfried Sassoon); King's (Philip Noel-Baker, Nobel Peace Prize winner); and Queens' (Erasmus, philosopher and humanist).

The guide is available for £2 from Arn (11 Goding Way, Cambridge CB24 6AH, 01223-861772, cambridgepeacetrail.weebly.com). Please add 60p postage for one copy (£1 for 2, £2 for 5, £2.50 for 10). Cheques payable to Arn Dekker. It can often also be bought in Cambridge, in places like the Fitzwilliam, Heffers, and Great St Mary's Church.

The virtual meeting, using Zoom, was well attended, attracting probably around 30 'participants'. The next Branch Meeting is scheduled for July 24 – probably another virtual. But will we be back to normal soon after? Watch this space!

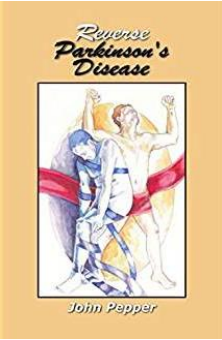
CUPPA & CAKE MEETING ZOOMS ACROSS THE CONTINENT

Our third Cuppa & Cake zoom meeting on Friday June 5, was another success, attracting at least 30 members, generating plenty of interesting discussion – and despite involving that many people, not descending into chaos!

It kicked off with an unusual element: two members chatting to us from nearly 1500 miles away. Barry and Jackie Perry have been staying at their property in southern Spain since lockdown started several weeks ago. Since then they have been unable to go anywhere outside their property, let alone get a flight or ferry back to the UK. But they said their neighbours have been wonderfully helpful, doing all essential shopping for them. And seeing them basking in the Spanish sunshine while the clouds gathered in Cambridge, you felt they were in the right place!

They had some interesting thoughts about the way the UK is being viewed from abroad. In Spain, most people seem to think it has not been handled well in the UK.

Another interesting part of the meeting concerned exercise, and in particular a controversial book written by the South African, John Pepper, Reverse Parkinson's (ISBN 98-1-4349-8353-4). It featured in our July-August 2017 issue – see our web page: 'Pepper Claims To Walk Off His Symptoms'. He says he countered his Parkinson's, and stopped taking medication, through a specialised walking technique. His website is http://www.reverse-parkinsons.net/.



He features in a fascinating book, The Brain's Way of Healing, by Norman Doidge, who also wrote a book on the same theme, The Brain that Changes Itself (ISBN 978-0-141-92368-0).

Finally, member Robert Taylor told us about his experiences with the pharmacy service **pillsorted.com**, which delivers his medication for him – see next column.

Again thanks and well done to our Membership Sec Keith for organising the Cuppa meeting.

MORE SPEAKERS FOR BRANCH MEETINGS

We have arranged two more speakers for our Branch Meetings who are prepared to deliver either in person or via Zoom, depending on how the situation develops.

On Friday, July 24, Dr Michelle Ware, Head of Courses and Conferences at CamBioScience, will give a talk entitled 'From Research to Event Organising'. She will be talking about her post-doctorate research work into Huntington's Disease with reference to sleep and circadian rhythms. She will also cover her role with CamBioScience organising training events and conferences for scientists.

Then on October 23, Kate Kirk will talk about Cicely Saunders and the founding of the Hospice Movement. Kate is Cicely's niece and is also Chair of the Arthur Rank Hospice Trust.

When we get back to 'proper' meetings at the David Rayner Building, another talk to look forward to will be from David Short, former landlord of the Queen's Head in Newton, entitled 'A Life Behind Bars'.

NEWS, EVENTS & PEOPLE

LOCKDOWN FREEZES TULIP CLUB

The last draw we were able to make for the Tulip Club was for the January prizes. The winners were No 67, Doreen and Geoff Taylor, and No 75, Gabby Farrow. The February draw was held over, as Michael (Moore) was away. Then came lockdown and we have made no draws since.

"So we have 'frozen' the Club situation as at the end of January," he says. "When we can restart the draws, we will add extra months of membership to match those lost. In that way no member will lose out. We hope everyone will agree to that. The same will hold for those of you who have kindly renewed during the lockdown period. I hope you will agree to us holding on to your cheques until we restart."

The Committee is keeping the situation under review of course, and will keep you informed of any developments.

"I hope that, despite the challenges, you are in good spirits and staying clear of the virus," Michael says. He can be contacted on michael@moores-place.eclipse.co.uk, tel 01223-244202.

PILLSORTED.COM DELIVERS FOR ROBERT

One member, Robert Taylor, spoke at the June 5 Cuppa Cake Meeting about the service he uses called PillSorted.com, which other members may find useful.

"They provide me with an excellent service, which has been invaluable in this difficult time. I do my repeat prescription online as per normal, and PillSorted deliver the medications to my door, saving me the trouble of having to go out to get them from the pharmacy."

PillSorted is a pharmacy providing NHS services, dispensing prescriptions, sorting medications and delivering them. "Our service is well suited for people with multiple repeat prescriptions," says its founder, Zeinab Larijani (pictured). "They receive a monthly package with all their medications and if required, packed in a monitored dosage system. Patients don't need to chase their repeat orders, wait in the queue or sort their pills anymore. Many communicate via email (help@pillsorted.com) or sign up using our online form (see www.pill-

sorted.com). PillSorted is based at Copley Hill Business Park in Cambridge (tel 01223-643550) and will deliver to people anywhere in the UK.

"PillSorted is born out of my passion for healthcare," Zeinab says. "I've been a pharmacist for more than 15 years and the best parts of my days are when I'm listening to my patients, helping them stay healthy and making them feel better. We're using the best technology available to get all the other tasks in the dispensary done as timely and accurately as possible so I can free up my time to serve my patients. That's what a personal pharmacist does."

She leads a small group of healthcare and technology professionals in Cambridge, and has a distinct view of how healthcare should progress in future. "I envisage traditional doctors and pharmacists evolving into a new profession, which could be called a 'compassionate caregiver,' she says. "They would combine the skills of a nurse, medical technician, social worker, and even psychologist. Trained not just in operating and understanding the diagnostic tools but also in communicating with patients, they would console them at times of trauma, and support them emotionally throughout their treatment."

CHRISTMAS LUNCH DATE SET, COVID RESTRICTIONS PERMITTING

We are hoping that the Covid-19 restrictions will have been lifted sufficiently for us to be able to hold our Christmas Lunch this year, which will be on December 11. Caterers and the David Rayner Building are already booked. But for now we are taking reservations only, and will be asking for payment and menu choices nearer the time, when we are certain it will go ahead. The cost will be £10 for members of Parkinson's UK, and £16 for non-members. This includes a three course lunch and fine wines. To place a reservation for this event please email the Vice-Chair, Mike Brown, at mikebparkinsonscambridge@gmail.com.

ALDA SUSPECTED PARKINSON'S BECAUSE HE WAS ACTING OUT HIS DREAMS

US comedian Alan Alda, best known for his role as Hawkeye in the MASH sitcom, was diagnosed with Parkinson's in 2015, and announced he had it in 2018. In a recent interview, the 84-year-old describes how one particular symptom, acting out one's dreams (REM Sleep Behaviour Disorder or RBD), made him suspect he had the condition.

"I had dreamed somebody was attacking me, and in the dream I threw a sack of potatoes at him. In reality, I threw a pillow at my wife," he says. He discovered his nocturnal activities could be an early sign of Parkinson's, and saw a neurologist, who initially doubted he had it.

"A lot of people hear they have Parkinson's and get depressed and panicky and don't do anything, just hoping it'll go away. It's not going to, but you can hold off the worst symptoms." He does this through an exercise regime featuring boxing, walking and biking, and remains positive. "It's not the end of the world when you get this diagnosis."

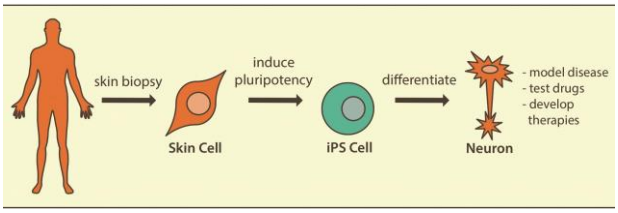
Since MASH, Alda has had roles in many Woody Allen films, and featured in the West Wing, The Aviator, and most recently the award-winning Netflix film, Marriage Story. His hit podcast, Clear+Vivid with Alan Alda, launched in 2018, focuses on the art of connection and communication.

"Laughter is good. That's one of the greatest benefits of this isolation. My wife and I are laughing more than we ever have," he says. "We can't take ourselves too seriously, even now. A friend emailed me and said, "How are you doing?" I wrote back and said, "I'm still alive. If that changes, I'll let you know." (With thanks to the online publication Parkinson's Life).

SCIENCE & RESEARCH

PATIENT'S OWN CELLS CREATE TREATMENT

We could be seeing the beginning of a major new treatment for Parkinson's. US researchers in Massachusetts have demonstrated that reprogramming a patient's skin cells to replace brain cells progressively lost in Parkinson's is technically feasible, and can lead to really significant



improvements in symptoms. Because the technique uses the patient's own cells, it means they are easily available and can be reprogrammed so that the person's immune system does not reject them.

The team say this represents a milestone in 'personalised medicine' for Parkinson's. They reprogrammed a 69-year-old male patient's skin cells so they became embryo-like stem cells, which are called induced pluripotent stem cells. Then they effectively turned them into dopaminergic neurons, the cells lost in Parkinson's, and implanted them into the patient's brain, using a new minimally invasive neurosurgical procedure.

Two years later, imaging tests indicate the transplanted cells are alive and functioning correctly as dopaminergic neurons in the brain. Because the implanted cells came from the patient, they are recognised as self by his immune system and hence not rejected. So there was no need for immunosuppressant drugs, and the cells are functioning as intended. Also, the patient has had no side-effects or unwanted growths or tumours.

Indeed, since surgery his quality of life has improved significantly. Routine tasks, from tying his shoes to walking and speaking, have all got better and activities like swimming, skiing, and biking, which he had given up years ago, are now back on the agenda.

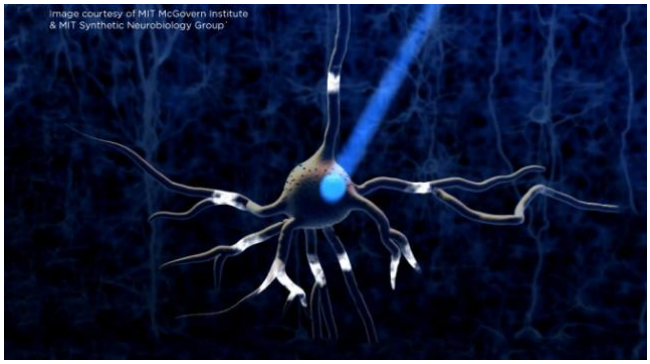
The goal now is to test the treatment in formal clinical trials. If these confirm the benefits, the result could be a major new therapeutic approach for PwP. Such trials are vital to show whether patients in general can expect similar improvements. But the researchers say the outcome is encouraging for the future prospects of the technique.

DEEP BRAIN STIMULATION SEES THE LIGHT

US engineers have used a new, innovative technique to perform deep brain stimulation (DBS) to treat an animal model of Parkinson's. It has succeeded where earlier attempts failed, and promises to provide new insights into why DBS works, and ways in which it can be improved on a patient-by-patient basis.

The new technique, called optogenetics, can target a single functional part of the brain, making it possible to see the effects of activating highly specific, different neural elements. It is virtually impossible to do this using conventional DBS as individual types of cells cannot be singled out by electrical stimulation, and the pulses obscure sensors for a crucial millisecond after firing.

In optogenetics, cells are genetically modified so their activity can be controlled with flashes of light. Previously researchers had done this with neurons in rats, in the subthalamic nucleus, flashing pulses of light at the same rate used in ordinary DBS. But the rats' symptoms were not affected, so it was concluded that stimulating the subthalamic nucleus on its own does not work.



But one man, Warren Grill, Professor of Biomedical Engineering at Duke University, was not happy. "Neurons being stimulated with optogenetics don't generally respond very quickly, and it seemed to me that researchers were flashing their lights faster than the neurons could keep up with," said Grill. "The data bore this out, as the neurons appeared to be responding randomly rather than in sync with the flashes. And previous research we conducted had shown that random DBS patterns do not relieve symptoms."

It took more than a decade for Grill to be able to test his theory. But recent developments allowed him to follow his hunch, notably a new form of optogenetics that combines better with the speeds traditionally used in DBS. They worked on rats given

VIEWPOINT

The coronavirus has been a terrible event in many ways, most of all because of the people's lives it ended, and the resulting suffering for their nearest and dearest. Beyond that is the horrendous damage it has wreaked on countries' economies around the world, probably causing millions to lose their livelihoods and face a struggle to survive over the next few months and even years.

It has also been an awful time for other organisations, for example charities, whose operations depend to a large extent on contributions from people, and their fund-raising efforts. Understandably at this time, such support is hardly top of their priorities. Some charities may suffer so much they never recover. We have to hope Parkinson's UK is not one of them. But given these difficulties, perhaps now is the time to reflect on the fundamentals of what a charity should be doing.

There are surely two things above all that a charity like Parkinson's UK – concerned with a major medical condition – should be doing. One is to raise funds for scientific research to find better treatments and ultimately a cure. The other is to directly help people with the condition, which can be done in various ways.

It is not exaggerating to say that if a charity does things that are not clearly in either of these categories, it should ask itself: why are we doing this? And there is one thing in particular all organisations often do, which is at least questionable: create bureaucracy. Every time a document is generated, a meeting held, an event staged, we should ask: is this directly relevant to finding better treatments, or is it clearly helping people with the condition? It is impossible to believe the answer is always "yes".

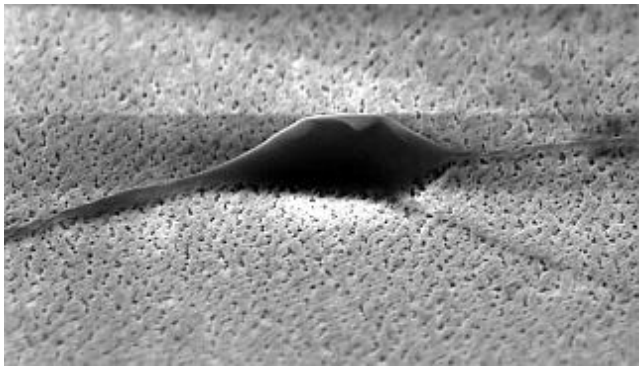
Just one example: many of us feel that too much time and effort – which charities must pay for out of their invaluable funds – is spent on producing information, and on printing and distributing it. At least two things that could be done here: don't duplicate information – just point people to it, because it very probably exists already online. And exercise a virtual ban on paper. Decades ago, there was much talk about the 'paperless office'. It has never happened. Maybe now is the time for Parkinson's UK to take the lead and pioneer the Paperless Charity!

(*from page 4)* Parkinson's-like conditions in one half of their brain, which helps determine when a treatment is successful because the resulting movement symptoms only occur on one side of the rat's body. They then delivered DBS using light at the standard 130 flashes per second. And Grill had been right nearly 15 years ago: the technique worked, and the rats' symptoms were substantially alleviated.

Grill says their result has several important implications. One is that we must take into account the operating speed of optogenetics when designing experiments. Another was the fact that in other neurons outside the subthalamic nucleus, there was a dramatic shift in their firing pattern, giving clues as to how DBS works. But perhaps the most important result is simply that the technique worked at all. Besides offering a much clearer look at neural activity by removing electrical artefacts, the ability to deliver DBS to precise subsets of neurons should allow researchers to begin probing exactly which parts of the brain need to be stimulated, and how therapies might be tailored to treat different motor control symptoms on a case-by-case basis.

NANOSTRUCTURE STIMULATES GROWTH OF STEM CELLS

Researchers in Hong Kong have invented a nanostructure that can stimulate neural stem cells to turn into nerve cells. Transplanting these into rats with Parkinson's improved their symptoms, with new cells replacing damaged ones around the transplantation site. The invention provides potential insights into stem cell therapies and hope of a new treatment.



Part of the nanostructure (magnification x 10,000).

Conventional stem cell culturing techniques have various drawbacks. They involve the use of growth factors, increasing the risk of cancerous tumours developing. Also, the brain-like structures they produce usually only poorly resemble their

counterparts in the brain. And the techniques take more than a month, resulting in a risk of contamination.

The nanostructure developed at the HK Baptist University is a silica plate coated with a microscopic layer billionths of a metre thick. It features trillions of zigzag structures that induce neural stem cells to develop into miniature, substantia nigra-like structures, with no need for chemical growth factors. When the neural stem cells come into physical contact with the nanozigzag matrix, the 'physical massage' induces the cells to turn into dopaminergic neurons, the researchers say. A self-organised, mini brain-like structure can be developed in only two weeks, with the risk of cancer substantially reduced.

Rats given the transplantation all showed improvements in their Parkinson's symptoms, and by the 18th week, dopaminergic neurons were seen, widely spread around the transplantation site. No tumour-like characteristics were detected. A control group without transplantation showed no signs of improvement.

“The mini brain-like structures exhibited excellent survival and functionality in rats and resulted in early and progressive improvement,” they say. “It lays the foundation for stem cell therapies that may ultimately cure Parkinson's.”

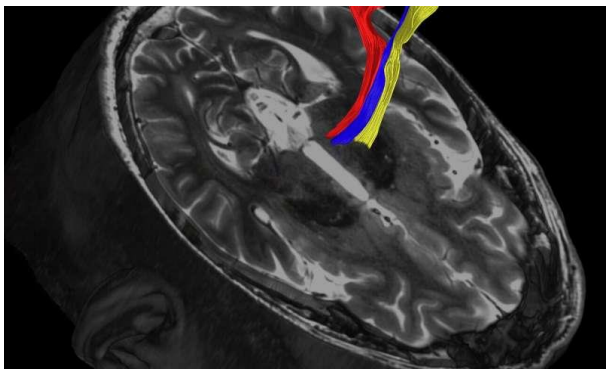
By varying the stiffness, density and arrangement of the nanozigzags, or the shape of the matrix layer, the neural stem cells can be differentiated into different functional cells. The invention has shown great potential for the treatment of other conditions such as Alzheimer's and certain cancers.

NEW MRI TECHNIQUES IMPROVE PRECISION

New MRI techniques that can more precisely target a small area in the brain linked with tremor may lead to better outcomes without surgery and less risk of negative effects. A paper in the journal Brain describes how neuroradiologists can now zero in on a pea-sized region in the brain's thalamus, which is involved in movement. Then high-intensity focused ultrasound (HIFU) is used to ablate, or burn away, the problem tissue.

The University of Texas Southwestern Medical Center in Dallas plans to start using the technique when it opens a new Neuro HIFU programme this autumn. Adverse effects from imprecise targeting include problems with walking, or slurring words. These are usually temporary, but can be permanent in 15-20% of cases. Locating the precise area to treat inside the thalamus is a challenge for both conventional DBS and HIFU. Doctors have relied on either landmarks or maps of the brain to do this, but every brain is different, and tiny errors can damage surrounding tissue, or cause portions of the target to be missed.

Three newly refined MRI imaging techniques are improving targeting precision, the article says. The most widely studied and perhaps most promising is diffusion tractography (pictured), which uses the movement of water molecules in brain tissue to identify tracts connecting different parts of the brain. A clinical trial will soon test this in patients.



The other two methods have positively daunting names: ‘quantitative susceptibility mapping’, which creates contrast in the image by detecting distortions in the magnetic field caused by substances such as iron or blood; and ‘fast grey matter acquisition TI inversion recovery’. Working like a photo negative, this turns the brain's white matter dark and its grey matter white, to provide greater detail in the grey matter.

PROFESSOR BARKER LEADS REVIEW OF GDNF

A leading figure in the Parkinson's research world who is well known to us, Professor Roger Barker, is the lead author of a major review of glial cell line-derived neurotrophic factor (GDNF).

The review appears in the Journal of Parkinson’s Disease, the leading academic journal associated with the condition, and considers the current state of play with regard to GDNF. It follows the clinical trial that ended in 2017, based in Bristol (see Newsletter issue May-June 2019), which was featured in a BBC documentary. The results were

somewhat disappointing for what had been seen as an exciting new treatment with great potential.

Professor Barker (pictured), of the Cambridge Centre for Brain Repair, headed a panel of prominent leaders in the field, who last August discussed whether GDNF has a future, growth factors in general, and the nature of any further trials.

“There is clear evidence that GDNF and related growth factors can restore the dopaminergic nigrostriatal pathway in animal models of Parkinson's,” Professor Barker says. “However, this has yet to translate into a clinically meaningful and robust response in patients.”

Growth factors support the growth and survival of cells. Ever since GDNF was discovered in 1993, the hope has been that we could use it (and other growth factors) to repair the damage caused to the brain by neurodegenerative disease, especially Parkinson’s. The experts discussed the history and current status of therapy based on GDNF and a related growth factor, neurturin (NRTN), comprehensively reviewing the studies that have been done.

It was generally agreed that GDNF and NRTN have worked relatively well in animal models but failed to show a major impact in humans, highlighting the predictive limitations of toxin animal models when searching for disease-modifying therapies. There are several reasons for these limitations. One, GDNF is relatively ineffective in the face of severe lesions – when more than 80% of dopamine-producing neurons have been lost – which more closely mimics the human condition.

Another is that the animal models used did not replicate the late stages of Parkinson’s, in particular the progressive, alpha-synuclein related pathophysiology that is characteristic of the human condition. And so far, when models are used that more accurately replicate the alpha-synuclein situation, GDNF seems to lose much of its effect.

The panel agreed it was still unclear if GDNF has a future for treating Parkinson's. But they made recommendations as to what future trials should consider, and how they might be designed. Specifically, compared to the complex neurosurgery needed to implant an infusion delivery system as used in the recent trial, they felt a viral delivery system involving less complex surgery would be advantageous. Another key point is the type of patient enrolled in a trial, and the panel said early-stage Parkinson's patients would be most likely to benefit from the treatment. That is because they have more neurons and fibres left to rescue, with fibre loss restricted to the dorsal striatum, where the therapeutic agent could be targeted. Other important points were the form of growth factor given, the dose and volume, the mode of delivery, and length of the follow-up.

However, one positive that emerged from the trial was that many participants felt their clinical scores did not reflect their experiences. So researchers worked with the Cure Parkinson's Trust (CPT), whose founder Tom Isaacs was a participant, on a more in-depth analysis. The aim was to see if different combinations of clinical measures could create a more insightful way of showing therapeutic effects.

This resulted in a new, composite measurement scale called PDCORE. CPT’s Dr Richard Wyse, R&D Director, said: “Using a most original approach, the authors re-analysed patients’ data to create a new way of evaluating their clinical progress.” The researchers stress this is not intended to claim that GDNF worked, but to find a better way to evaluate Parkinson’s patients, potentially useful for evaluating therapies like GDNF in future trials. The study was published in the journal Brain.

Now a study of another neurotrophic factor, cerebral dopamine neurotrophic factor (CDNF) is underway at the University of Helsinki. They have found that a tiny fragment of CDNF, which they call C-CDNF, can pass through the blood-brain barrier and retain the positive properties of normal CDNF. They will now test this in laboratory models of Parkinson’s to assess its potential as a neuroprotective therapy. It is hoped that C-CDNF will allow for a more straightforward oral or peripheral administration of a future neurotrophic factor-based therapy for Parkinson’s.

Also, a new clinical trial testing a GDNF-based gene therapy for Parkinson’s is starting, and the biotech company Herantis will announce results of a CDNF clinical trial later this year. It is already planning to progress to the next stage of clinical development.

COT QUILTS FROM CAROLINE

"My excuse for watching TV for the last three months," is how Caroline, our former Branch Secretary, describes these brilliant cot quilts that she has made. "The two cot quilts were made using left-over cloth from my grandsons' cot and twin quilts," she explains. "They measure 35in by 44in, and have been sewn entirely by hand – approximately 80,000 stitches each! I rather hope that any member with a new grandchild born or conceived during lock-down might buy one for a minimum of £50, to go to the Cambridge Branch." Is there someone out there interested in these quilts? Not only are they beautiful, but given the extraordinary period during which they were made, they will surely always be particularly memorable.

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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
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