BRANCH MEETINGS

AGM REPORTS SUCCESSFUL YEAR
The March Branch Meeting opened with the Annual General Meeting, which heard the Chairman’s and Treasurer’s Reports, before the election of the new committee.

Chairman Charlie Nightingale – now in the post for nine years – said it had been another busy period. Events included the Tulip Fun-Run and Boxcam cycle ride, as well as two excellent Branch outings, to Bletchley Park and the Thursford Christmas Spectacular.

This was on top of all the regular events members run, such as the Milton lunches – thanks to Gabby – and the aromatherapy managed by Alix. Charlie also gave special thanks to John Lewis, for their wonderful support throughout the year.

In her annual report, Treasurer Jenny Wood said that despite her fears, the budgeted income target was exceeded by more than £9000, with income achieved being £24,595. A well done to all!

Strong fundraising efforts came from many sources, including in no particular order John Lewis, the Tulip Fun-Run, collections by volunteers, and notably Bourne Golf Club, which raised £4500, and the Four Cohorts team in the Boxcam ride, who raised a remarkable £7750 (both to be shared equally between the Branch and Parkinson’s UK).

One advance in 2017 was the transfer of the Branch’s banking to the Coop Bank, providing online banking. This reduces the administration tasks, and is popular with suppliers, and hopefully donors and fundraisers too, Jenny said.

The new committee was then elected, with three vacancies noted, in particular a co-treasurer (for which an advert is now featured on the Parkinson’s UK and Charity Jobs websites, (see https://www.parkinsons.org.uk/get-involved/volunteering-roles/branch-treasurer-cambridge). Two other unoccupied positions are Membership Secretary, (following Henry Bland’s resignation), and a Meeting Programmer. Applications welcome!

NURSES COME TOGETHER TO MEET MEMBERS
A six-strong group involved in Parkinson’s specialist nursing attended the March Branch Meeting. This gave members an excellent opportunity to meet the nurses and discuss their situations face-to-face.

They are, from the left: presenter Danielle Duffill and Becky Slimmon, Parkinson’s Specialists; Louise Geal, Administrator; Claire Snee, Parkinson’s Nurse; Nicola McQueen, Parkinson’s Specialist (Addenbrooke’s Hospital); and Amanda Eady, Parkinson’s Specialist.

After introducing everyone, Danielle gave an interesting talk, centred on the five most common questions the nurses are asked, namely: “How do I know if a symptom is Parkinson’s or not?” Answer: it can be difficult to be sure but things that are never Parkinson’s include infections, and anything that happens suddenly. “When will I get a tremor?” Estimates vary from 40 to 70% of People with Parkinson’s (PwP) having a tremor, despite the public’s assumption that this is always the case. But in
many cases, other symptoms have more impact on the quality of life than a tremor.

**When will L-dopa stop working?**

L-dopa can work for decades. But it is most effective if the tablets are taken on time. If you get the timing wrong, the effectiveness of the next dose may be affected.

**“Will my children get Parkinson’s?”**

This is unlikely. Your genes may influence the probability, but it is rarely a case of genetic inheritance.

**“What about the future?”**

We have over 1800 patients, and it is very variable, no two are the same. Exercise is particularly valuable – regular exercise has been shown to slow down the progression of Parkinson’s, by helping to stimulate the brain’s dopamine-producing cells.

Another follow-up question was, **“How do I reach a Parkinson’s nurse?”** The number is 0330-726-0077 (8am-5pm), when you select your region, then talk to the call handler, who ensures your message reaches one of the nurses. Nurses are rarely in the office, Danielle explained, as they have to travel throughout the region. But as a call is put into the system, they are made aware of it as quickly as possible.

**INFORMATION STALL**

Our HQ produces so much information, it is difficult to display it all on our stall. As well as the booklets displayed we have three large folders entitled: Symptoms; Families and Carers; and Treatments-Therapies-Research, all packed with information. For example, the Symptoms folder includes Eyes and Parkinson’s; Feet and Parkinson’s; Freezing; Restless Legs Syndrome; Falls; and International Travel. In the Families are Daily Living Aids, and Wills Attorneys and Advance Decisions. And Treatments covers topics like Physiotherapy, Speech Therapy and Research Opportunities. Feel free to browse any at your leisure, but please don’t take them out of the DBR, and return them by the end of the Branch Meeting.

**WORKING Wii IS AVAILABLE**

We finally have a working Nintendo Wii, to be shared with branch members, thanks to our Secretary, Trish, who repaired it. There will be a sign-out form and members can borrow the Wii after the May meeting. “I have found it useful for balance and flexibility training,” she says. The Wii needs to be connected to a TV but comes with its instruction book.

**NEWS AND EVENTS**

**GRETSCHEN AMPHLET LECTURERS LOOK TO FUTURE TAILORED THERAPIES**

If the two lecturers who gave this year’s Gretchen Amphlet Memorial (GAM) lecture in Cambridge are proved right, treatment for Parkinson’s will be very different in the relatively near future.

Within the next decade or less, following diagnosis, a patient will go straight to a clinic and have a battery of diagnostic tests done, lasting a week or more. This will show what kind of Parkinson’s they have, allowing them to receive treatment that is tailored to their specific case.

Making this prediction were Dr Simon Stott, a Research Associate at the Barker Lab in Cambridge, and Professor Oliver Bandmann, a Consultant Neurologist at Sheffield University.

The title of their joint talk was: ‘From simple tests to tailored treatments’, and their basic starting point is that Parkinson’s is not a single disease, but a range of conditions that vary widely in symptoms, severity, and speed of progression.

Better diagnostic tools will be needed, and Dr Stott has been participating in a project using breath samples. Accuracy levels of 80% and more have already been achieved, he said. In another project, Prof Bandmann has worked on distinguishing different varieties of Parkinson’s using skin samples.

There are at least four mechanisms that can lead to Parkinson’s, he said: brain inflammation, mitochondrial or lisosome malfunctioning, and protein aggregation. “We just don’t know why people differ so much,” he said. “The way we treat people today is still very much from the 19th century. It is vital that we stop the disease getting worse.” Therapies tailored to each individual condition could do that.

The two scientists were giving the ninth GAM lecture, at Fitzwilliam College, on the evening of April 17. As ever, the talk attracted a packed house, and also
featured Steve Ford, CEO of Parkinson’s UK, who led the Q&A session that followed the lectures (see above, at podium). Two others taking part were Dr Ruth Herman, a retired academic diagnosed with Parkinson’s four years ago, and Dr Arthur Roach, Director of Research for Parkinson’s UK. The lecture was shown live and is now available on YouTube: https://www.youtube.com/watch?v=KxoKOWvCwDU&feature=youtu.be.

**TULIP FUN-RUN THE BEST EVER!**
Talk about a success! This year’s Tulip Fun-Run has to go down as the best we have ever staged. As the photos show, it attracted a great turnout – nearly 80 runners and walkers took part – and was a fantastic way to start the week featuring World Parkinson’s Day (April 11). A massive well done to all those who helped organise it!

Getting ready to go. The Fun-Run was started by Cllr David McCraith, Chairman of South Cambs District Council, next to Chairman Charlie Nightingale.

And they're off – nearly 80 in all, a record turnout.

**MUSIC THERAPY A RESOUNDING SUCCESS**
The Music Therapy Course that we have helped organise, working with Anglia Ruskin University (ARU) and the Multiple Sclerosis Society, has been a great success. A survey of the results based on questionnaires shows this clearly (red bars on left are from the first week, purple from the last):

![Graph showing survey results]

One participant said: “I was dubious about coming in the first place, but it’s been really great fun, and nice people. It has encouraged me to use my voice more.” Another added: “It has been a good mix of theory and fun. The friendships, and supporting each other, has been so important. We have gelled as a group.”

Sessions were run by an experienced music therapist, with a focus on vocal exercises that work on projection, breath control, posture and articulation. This was followed by singing. Therapists say that vocal and singing exercises, with an emphasis on phonatory (= vocalisation) and respiratory efforts, have great potential to provide PwP with stronger vocal projection, enhancing speech intelligibility.

The sessions culminated in a special showcase event in March, which was recorded. Now, we have started similar classes to be continued on a regular basis, at the same venue, the Ross Street Community Centre, CB1 3UZ. Cost is £30, payable in advance, for 10 weekly sessions, running from 14.00-16.00. On-street parking is available. Details are on our Facebook page.

The Branch is also planning further research with ARU, which will include the running of similar sessions in Ely and Peterborough.
VIEWPOINT: RED FACED PFIZER

Research Associate Dr Simon Stott, one of this year’s Gretchen Amphlet lecturers (page 2), discusses a controversial event in the pharmaceutical industry.

On Saturday, January 7, Pfizer – one of the world’s largest pharmaceutical companies – announced that it was abandoning its Alzheimer’s and Parkinson’s research efforts. Naturally, the affected communities reacted with disappointment to the news, and there were concerns that other pharmaceutical companies would follow suit in the wake of this decision.

Pfizer did provide an explanation about why it made this move: “This decision was driven by science, not cost,” it said. “As the world’s fourth largest investor in pharmaceutical research and development (R&D), we expect limited impact…to our overall investment in R&D because of this decision. Our reallocation of funding will allow us to place greater focus on areas where we have the strongest possibility of bringing therapies and vaccines to patients in the near term.”

This explanation is both reasonable, and nonsensical. It is reasonable because, yes, it is clearly in the interests of the company to focus on what it believes it does best (‘neuro’ has never been its priority). However, if the decision is not going to have any material impact on the “overall investment in R&D” then why make it at all? If neurological conditions make up such a miniscule portion of R&D, why not simply continue research on them? Or at the very least, close them down quietly? Why alienate a community of potential customers and create the huge PR disaster that the announcement became? Particularly if the company is still going to be investing indirectly in neurodegenerative research? (In its announcement, Pfizer also explained that in lieu of research, it would set up a dedicated neuroscience venture fund to support efforts to help advance progress).

In truth, Pfizer, like all of the pharmaceutical companies, simply cannot afford to walk away from neurodegenerative conditions. It represents a major growth opportunity for the pharmaceutical companies, as expansion in other areas of healthcare slows. To ignore this is only going to be detrimental to a company’s long term prospects. Thus, Pfizer can step away from neurodegeneration and have a breather for a while. But they will most definitely be back.

INTERESTED IN FORMING A CYCLING CLUB?

A new member, John Blackburn, is trying to find out if others might be interested in forming a cycling club. “One of my favourite leisure activities for many years has been cycling, not competitive, just sight-seeing and touring,” he says. “Two years ago I was diagnosed with Parkinson’s but continued riding with Peterborough CTC and U3A. But the situation deteriorated and my wife and I decided to move nearer to our daughter in Histon, where we now live.” John (left, in red) hopes there are other members who used to enjoy a weekly ride may have the strongest possibility of returning to riding. Perhaps we could form a club now that Parkinson’s has been diagnosed? If you are interested in riding as a group contact John Blackburn at johnandelaine.blackburn@gmail.com 01223-236076 mobile 07817-457638.

MOBILITY SCOOTER AVAILABLE

Member Ian Jennings has a mobility scooter for anyone who needs one. It is an Invacare Leo, about three years old and in good condition. But please do not contact Ian before May 10: ian.jennings13@btinternet.com, 01223-302017, 19 Brandon Court, CB1 1DZ.

JOHN LEWIS RAFFLE

Many thanks to John Lewis, who staged a raffle in March. Prizes were all Easter-related and included a lot of chocolate! The sum raised will go towards the traditionally enormous John Lewis annual contribution to the Branch.
SIGN THE PRESCRIPTION CHARGES PETITION!
We need only 4000 more signatures on the Parkinson's UK petition to scrap prescription charges. With 10,000 signatures you get a response from the government. With 100,000, a petition will be considered for a debate in Parliament. So get signing! https://www.parkinsons.org.uk/get-involved/prescription-charges.

In March, a group of PwP hand delivered a petition to 10 Downing Street. Signed by 33,875 people, it asks the government to protect PwP from stressful, unnecessary reassessments of their Personal Independence Payments (PIPs). PIPs are intended to help people with extra costs imposed by their medical condition. But a quarter of PwP reassessed have lost some or all of their support. And Government figures show almost 70% of people who appeal against the decision get it changed back.

SCIENCE AND RESEARCH

WEARABLE BRAIN SCANNER LETS YOU MOVE
Nottingham University scientists have invented a radically new type of brain scanner that can be worn on the head, allowing patients to move while being scanned. It could revolutionise brain imaging, and could be of great value for studying Parkinson's.

The scanning technique used is called magnetoencephalography (MEG), which records tiny magnetic fields generated by the brain. It has been around for decades, but conventional scanners are large, weighing half a ton, and patients have to keep completely still.

The new wearable MEG uses special lightweight quantum sensors mounted in a 3D printed helmet. The sensors work at room temperature, whereas previously they had to be kept incredibly cold. Also, they can be placed directly on the scalp, greatly increasing the signal they can pick up. It means that babies, children and people with movement disorders can have their brain activity measured. The researchers describe it as a step change for mapping brain activity.

Using the scanner, they have made electrophysiological measurements while subjects make natural movements, including head nodding, stretching, drinking and even playing ping pong. The results compare well to those of the current state-of-the-art, even when subjects make large movements.

The team plan to show their scanner at the Royal Society’s summer science exhibition in July with their ‘Quantam Sensing the Brain’ exhibit. The MEG helmet will be available for people to see and try. They will also be demonstrating live brain imaging to visitors in their ‘Brain Room’, where people can control computer games by thinking.

STUDYING WHY EXERCISE SLOWS PROGRESSION
Vigorous exercise on a treadmill has been shown to slow the progression of Parkinson’s, but the exact molecular reasons behind it have remained a mystery. Now scientists at Colorado University have shown that exercise on a running wheel can stop the accumulation in mice brain cells of the protein alpha-synuclein.

Clumps of alpha-synuclein are believed to play a central role in the brain cell death associated with Parkinson's. The mice started to get Parkinson’s symptoms in mid-life, and at 12 months old, they were given running wheels. After three months, the running animals showed much better movement and cognitive function, compared to control animals whose running wheels were locked.

They found that exercise increased brain and muscle expression of a key protective gene called DJ-1. People with a mutation in DJ-1 get severe Parkinson’s at a relatively young age. The researchers tested mice that were missing DJ-1 and found their ability to run had severely declined, suggesting DJ-1 is required for normal movement.

"Our results indicate that exercise may slow the progression of Parkinson’s by turning on DJ-1, thereby preventing abnormal protein accumulation in brain,” said Curt Freed, Professor of Medicine at Colorado. The experiments had major implications for humans. “Our experiments show exercise can get to the heart
of the problem in Parkinson’s,” Freed said. “Patients who exercise are likely able to keep their brain cells from dying.”

In other work, back in 1988, Freed and a colleague performed the first transplant of human foetal dopamine cells into a Parkinson’s patient in the US. His lab is currently working to convert human embryonic stem cells to dopamine neurons. These techniques should make it possible to produce unlimited quantities of dopamine cells for transplant.

TREMOR SUPPRESSION GLOVES
A research team from the University of Western Ontario in Canada has developed a new glove that gives PwP improved motor control while reducing involuntary muscle contractions. The team says that most suppression devices targeting elbows or wrists often produce exaggerated tremors in the fingers, causing even more difficulty controlling movement.

Instead of simply suppressing all tremors, the new gloves track voluntary movement, so if a person is trying to accomplish a particular task, the gloves allow the action to happen while minimising the tremor. Sensors on the fingers and hand track the full frequency spectrum of the user’s movement. Voluntary motion and tremor motion have different frequencies, so by applying appropriate filters, the glove is able to distinguish between the two types of motion.

The University will start patient trials over the next couple of months, and plans to refine the control system and the hardware to make the glove lighter and less obtrusive. Then the aim is that a company will commercialise the technology to bring the gloves to patients.

CLINICAL TRIAL FOR FOCUSED ULTRASOUND
A New York medical centre is to start a clinical trial of focused ultrasound (FUS) for treating Parkinson’s. Specifically, it will evaluate the safety and efficacy of using FUS to perform a pallidotomy, which destroys a tiny brain region that malfunctions in Parkinson’s.

The FUS system to be used in the trial has already been approved by the FDA for treating essential tremor (ET). Leading the trial is Dr. Michael Kaplitt, of the Weill Cornell Medicine Centre, who in 2016 was the first doctor in New York to use FUS on patients. He has successfully treated dozens of ET patients since.

The new clinical trial, sponsored by the device’s manufacturer, Insightec, will evaluate more than 100 participants. It will assess the effectiveness of FUS at managing their dyskinesia, and if successful, will make conventional DBS unnecessary for them.

Dr. Kaplitt will be working with other investigators and participants at centres worldwide. The trial could open the way to a new, non-invasive treatment for PwP that may greatly enhance the quality of life.

DATES FOR YOUR DIARY

WHITTLESFORD BARN SHOW
An exhibition of drawings, painting and photographs takes place on the weekend of May 19-20. Staged by Jenny Wilson, it runs from 10am-5pm at The Barn, Rayners Farm, Whittlestone, CB22 4NZ.

Admission is free, there is ample parking, and a share of the money raised goes to Parkinson’s UK.

HANAH STEPS IN FOR STEVE
Unfortunately, our planned speaker for the Branch Meeting on May 25, Parkinson’s UK’s CEO Steve Ford, is unable to make the date. Instead, we are delighted to have Hanah Burgess, Director of Finance and Performance, who is going to talk to us about the overall functioning of Parkinson’s UK.

One potential topic is how available funds are used: what proportion goes on salaries? Or research? Publicity and publications? Buildings’ maintenance? What else requires major funding?

In fact, May 25 is a notable day for thousands of organisations throughout the UK, both companies and charities, as it is the actual day the European Union’s new General Data Protection Regulation rules come into force. Hanah is currently leading the work that Parkinson’s UK is doing to comply with GDPR, making her the ideal person to tell us all about it!
**BOXCAM ENDING AT DAVID RAYNER BUILDING**
The Boxcam Cycle Ride is due to happen again later this year, on **September 22 and 23**. And this year it will finish at our very own David Rayner Building! Last year’s event saw great fundraising for our Branch by the Four Cohorts, who raised well over £3500.

**SHELFORD FEAST**
The Shelford Feast, always a popular annual event, takes place this year on **Sunday, July 15**. We need new ways to attract visitors to the Parkinson’s stall. Suggestions would be welcome, as would volunteers on the day. Contact Branch Secretary, Trish (below).

**JULY VISIT TO SANDRINGHAM FLOWER SHOW**
Tickets are still available for our trip to Sandringham, the Queen’s Norfolk house, on **Wednesday, July 25**, the day of the Royal Flower Show. This is one of the most prestigious horticultural events in the East of England. Now in its 137th year, it is set in the magnificent surroundings of Sandringham Park with the House and Sandringham Church as a backdrop. A one-day show, it attracts 20,000 visitors every year. Our coach will leave Trumpington Park & Ride at 09.30, arriving at 11.15. The return journey will leave Sandringham at 15.30, arriving back at Trumpington Park & Ride around 17.30. The coach will be bigger than usual, a 79-seat double decker, which can take one fixed wheelchair, and three more that can transfer to coach seating. Around 30 tickets are still available, costing £27 each for members, £30 for guests. Contact Margaret (below).

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Assistant Secretary: Caroline Bent  carolinebent@me.com  01223-314279  07922-479289
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Gabby Farrow (Honorary Member)  01223-356433

**USEFUL CONTACTS**
Parkinson’s Local Adviser – Candy Stokes  0344 225 3618  cstokes@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 advice and information contact the Parkinson’s Nurse Team on 0330-726-0077.
Branch Website:  www.parkinsonsukcambridge.org.uk
Parkinson’s UK  215 Vauxhall Bridge Road, London SW1V 1EJ.
T 020 7931 8080  F 020 7931 8080  E enquiries@parkinsons.org.uk  www.parkinsons.org.uk
REGULAR MEETINGS AND ACTIVITIES

*NEW*

Aquatherapy
Thursdays weekly, 14:30-15:30
Chesterton Sports Centre, Gilbert Rd, CB4 3NY
Contact: Laurie 01223 295711

Branch Meeting
Fourth Friday of every month except December
10:30-13:30,
David Rayner Building, Scotsdale's Garden Centre,
Gt Shelford, CB22 5JT
Includes soup and sandwich lunch.
Details in “OF SPECIAL NOTE”, but be aware that
the programme may change, and consult website
or phone to check if necessary.
Contact: Caroline 01223-314279

Bring and Share lunch
First Tuesday of each month, 12:15-15:00
Barnabas Court, Milton, CB24 6WR [To reach
Barnabas Court leave A14 at Milton (A10) exit, head
to Tesco, take Cambridge Rd off Tesco roundabout
and Barnabas Ct is second on right. All are welcome
to all or part of meeting]
Contact: Gabby 01223-356433

*Music Therapy* NEW
Fridays weekly, 14:00 to 16:00
The Ross Street Community Centre
Cambridge CB1 3UZ
Contact: Alison Shaw 07936 191655

*Yoga*
Mondays weekly, 10:30-11:30
NO YOGA ON BANK HOLIDAY MONDAYS
The Meadows Community Centre, Room 2, St
Catharine's Road (corner of Arbury Rd & Kings
Hedges Rd) CB4 3XJ
Contact: Michèle 01223-563774

OF SPECIAL NOTE

MAY
11: Collection at Tesco Milton
25: Branch Meeting
   11:00 Speaker: see article above
   Hanah Burgess, Manager of Finance
   and Programme for Parkinson’s UK.
   + 3 members of CU Engineering
   Dept. working on reduction of hand
tremors
   12:00-12:15 Lunch
   Aromatherapy throughout

JUNE
22: Branch Meeting
   11:00 Speakers:
   Ray Hackett and Diane Cornwell:
   “Wildflowers and Walking at Wandlebury”
   Aromatherapy throughout

JULY
25: Branch Outing to Sandringham — see article above

27 JULY, 24 AUGUST, AND 28 SEPTEMBER
Branch Meeting speakers may include:
   Councillor Nigel Gawthrope –
   by then Mayor (probably Sept)
   Ian Cumming
   Travel Photographer
   Peter Jackson
   Scotsdale’s
   Horry Parsons
   Project Manager building Bury’s
   Millennium Tower

OCTOBER
26: Branch Meeting
   11:00 Speakers: Heidi Allen, MP and
   Natasha Burgess (P-UK liaison with the
government)
   Aromatherapy throughout