

Cambridge Branch Newsletter – May-June 2016

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BRANCH MEETINGS

AGM 2016 AND TREASURER'S REPORT

The AGM 2016 took place at the March 18 Branch Meeting, at the David Rayner Building (below). Highlights included the election of four new committee members, including a new Treasurer, Jenny Wood, a Publicity Officer, Annabel Bradford, and two more, Steven Andrews and Helen Kember. Current committee members were re-elected.



In his Chair's Report, Charlie Nightingale invited people to come forward with money they had raised. Jean Delbridge said her department at John Lewis had raised more than £800. Two people who ran the Cambridge half marathon, Angela Butcher and Annabel Bradford (see below), raised £620 and over £2000 respectively. Helen Kember also presented donations given to her in memory of her husband, Brian, who died recently.

Charlie also made special mention of Gabby Farrow, whom the committee invited to become an Honorary Committee Member in recognition of all the hard work she has done for the Branch over many years. Our new treasurer, Jenny Wood, then presented her first report on the state of the Branch's finances. She thanked the previous treasurer, Julia Ewans, for her work as treasurer over recent years, and said that despite Julia's somewhat gloomy predictions at the beginning of 2015, we exceeded our budgeted income target by £4,882, achieving £18,732. Well done everyone.

Much of the Branch's income is unpredictable, Jenny said. "In 2014, general donations fell, but 'in memoriam' donations picked up some of the slack. Fortunately in 2015 this was reversed: general donations were higher, so that the combined figure, although lower than 2014, was only marginally lower than 2013.

"In 2015 we had strong fundraising efforts from the ever-wonderful John Lewis team, collections at Asda and Tesco and, of course, the Fashion Show, Tulip Fun-Run and Tulip Club," she said. "As always, our members and volunteers are the Branch's greatest asset and we all thank you for your support."

"Last year's expenditure was again a little below the forecast budget (£19,360) at £16,320, but with a lower overall income there is a small deficit. Fees from activities were lower than in the previous two years. The committee has budgeted funds for 2016 to establish more exercise opportunities and to subsidise transport, including an outing."

PHYSIO FOR PARKINSON'S: KEEP MOVING!

The latest Branch Meeting, held on Friday, April 22, featured as guest speaker Ripu Abrol, a physiotherapist specialising in Parkinson's, who works at Brookfields Hospital in Cambridge. He told members that some newly diagnosed Parkinson's patients often have fears about activities involving some kinds of movement, such as gardening, and stop doing them, which can worsen potential problems like stiffness and poor posture.

He then described exercises that help, including ones involving stretching and muscle strengthening, and postural improvement - the latter being something as simple as standing against a wall, with shoulders and lower back touching the wall. Three of the best forms of exercise, Ripu said, are cycling, dancing, and walking on a treadmill, ideally done 3-4 times a week for 30-40 minutes at a time. "Even after only 4-6 weeks, intensive treadmill walking leads to good changes. Researchers are reporting very positive results." Overall, his message was loud and clear: keep moving!

RECENT EVENTS

CAMBRIDGE HALF MARATHON

Annabel Bradford, daughter of Tony Bradford, a member of our branch, chose Parkinson's UK as the charity to support when she ran the Cambridge Half Marathon recently, in a Personal Best time of 1 hour 45 minutes. Annabel set up a www.justgiving.com donation webpage with a fundraising goal of £1,000, calling on friends, colleagues and family to help her reach her goal. She says everyone was very generous and supportive, and her employer Redgate Software donated £500. Annabel's final total was £2,454.75, putting her in the top 3% of fundraisers on JustGiving.com in February, and the highest individual fundraiser for Parkinson's UK nationally in February and March. This donation will be shared equally between the Parkinson's UK Cambridge Branch, and Parkinson's UK Find a Cure. Annabel also joined the Committee at this year's AGM as Publicity Officer (see AGM Report above).

PIP ROW AND OUR MP TO VISIT MAY BRANCH MEETING

A huge political controversy was aroused in March by the inclusion in the Budget of proposed cuts to the Personal Independence Payments (PIPs) benefit. This was going to affect many Parkinson's patients, potentially cutting their benefit by as much as a third, and forcing them to live on as little as £73 per week.

The plan faced extremely fierce opposition from many of the Government's own MPs, prominent among them being the South Cambridgeshire MP, Heidi Allen (left). Parkinson's UK campaigned strongly against it and the row also played a part in the resignation of the Cabinet minister, Iain Duncan Smith, who was Secretary of State for Work and Pensions. In the face of such fury, the government was forced into a major climb-down, and has effectively pushed the cuts in the benefit "into the long grass".



Several areas of the media, notably TV and the national press, featured profiles of people with Parkinson's (PWP), showing how badly affected they would be by the proposed cuts. Our MP appeared on Andrew Neil's Sunday Politics programme broadcast on March 20, saying that she thought Duncan Smith was right to resign. "He had had enough," she said. She also confirmed she would have voted against the government if it had proceeded with the cuts. Last October Heidi Allen used her maiden speech in the Commons to attack the tax credit cuts, claiming it was going too hard and too fast, and "too many people will be adversely affected". For more, see <http://www.telegraph.co.uk/news/politics/conservative/12199949/Six-things-we-learned-from-Iain-Duncan-Smiths-resignation.html>.

- **To hear more from Heidi, make sure you attend the Branch Meeting on Friday, May 27, when she will be coming to talk to us. Also coming is Natasha Burgess, parliamentary adviser from Parkinson's UK.**

PARKINSON'S AWARENESS WEEK AND TULIP FUN-RUN

Parkinson's Awareness week (April 18-24) ended with our Tulip Fun-Run, which took place on the Sunday. It covered the same route as in previous years, namely beginning and ending at the David Rayner Building, Scotsdales Garden Centre, and taking in part of the Addenbrooke's Hospital site. Some 30 people took part, both runners and walkers. The amount raised was more than £500, with sponsors' money still to come.

Other notable events included extensive coverage in the media, such as: an item about Parkinson's on the BBC 1 news on Monday, April 18; the screening of a documentary called Parkinson's: The Funny Side, by Paul-Mayhew Archer on Wednesday, April 20, (which was also put on to BBC iPlayer after it was broadcast – check the iPlayer website to see if it is still available); and a series of items on Radio 5 Live. As ever, Parkinson's UK organised a whole series of events across the country, and also made extensive use of social media including Facebook, Twitter, Instagram, YouTube and Google+.

GRETSCHEN AMPHLET LECTURE

The use of stem cell techniques holds out huge potential for major advances in the treatment of Parkinson's. But it is still best to be cautious, as previous stem cell trials going back decades were significantly flawed in their approaches, and caused the attention of many researchers worldwide to shift to other potential treatments.

This was a key underlying theme of this year's Gretschen Amphlet Memorial Lecture, which was given at Fitzwilliam College on the evening of April 12 by Professor Roger Barker. He is Professor of Clinical Neuroscience at Cambridge University, as well as Honorary Consultant in Neurology at Addenbrooke's Hospital.

The fundamental approach of stem cell treatments is to implant dopamine producing cells into a patient's brain, with the aim of getting them to survive and grow, helping to restore the dopamine that is lost in Parkinson's, ideally to virtually normal levels.

"Stem cell-based therapies for Parkinson's are rapidly moving towards clinical trials in a number of centres," Barker said. One such is TRANSEURO, led by Barker, as reported in previous issues of this newsletter (using fetal cells, similar in effect to stem cells). One of the first people to undergo the TRANSEURO procedure, last autumn, is Richard Windle, who was a member of the panel that fielded the Q&A session after the lecture. The question he was most often asked, he said, is "Has it had any effect yet?" "Too early to say", he told the audience.

Coincidentally, another trial was announced less than two weeks before Barker's lecture, on March 31 from the International Stem Cell Corporation (ISCO), based in California. ISCO claims this is "the first clinical trials of a stem cell treatment for Parkinson's", which will take place in Melbourne, Australia, lasting 12 months and featuring 12 patients. A key aim will be to look at the safety of this therapeutic approach. If successful, it will be followed by much larger studies.

"As with many such exciting news items, one should react with caution," Barker said, "especially since the outcome of this trial can affect the development of other stem cell programmes moving towards clinical trials." In the ISCO trial, the follow up will only be for one year. This "almost certainly will not be long enough to detect clinical improvement, if there is any," he said.

"Acting prematurely has the potential to tarnish many years of scientific work, and can also threaten to derail and damage this exciting field of regenerative medicine. Hopefully, in 2016, we are ready to take a more careful approach as we strive to repair the Parkinson's brain with stem cell-based therapies, avoiding many of the mistakes that have dogged this field over the last three decades."

An edited version of the lecture will be available from around the beginning of June, on the news and events section at the Parkinson's UK website (www.parkinsons.org.uk).

ANOTHER SUCCESSFUL FASHION SHOW

This year's John Lewis supported Fashion Show in aid of Parkinson's UK was another great success, attracting a full house at the John Lewis store in Cambridge, on the evening of Wednesday, March 9. It was opened by the Mayor of Cambridge, Councillor Robert Dryden, and compered by John Lewis's Iain Playa.

Special thanks to everyone who helped to make the show such a success: all the models (including several Branch members and their children), as well as Ellie Buckle for her guitar playing, Dolly Bamrah and her team from Personal Styling, Christine Shaw, and Jean Delbridge for running the raffle, which featured what must be a record number of prizes! And finally to the John Lewis Partnership, for offering the space and assistance in mounting the event.

SCIENCE

GENETIC LINK TO ALPHA-SYNUCLEIN



Scientists at the Parkinson's UK-funded Oxford Parkinson's Disease Centre have discovered new clues as to how Parkinson's spreads from cell to cell. It concerns alpha-synuclein, a naturally occurring protein that is believed to play a central role in the spread of Parkinson's. The research, published recently in Stem Cell Reports, is the first to link the release of this protein with the most common genetic risk factor in Parkinson's – GBA1.

The team, led by Professor Richard Wade-Martins, head of the Oxford Centre, studied stem cells and brain cells created from the skin of participants. They compared cells from two groups, one with Parkinson's carrying the GBA1 genetic mutation and a control group without the condition. The researchers found

that when someone has a GBA1 mutation, protein recycling does not work properly in the cell. This creates a build-up of alpha-synuclein, which is then released into the brain, contributing to the spread of Parkinson's.

Professor Wade-Martins, explains: "Our brain cells work like a complex manufacturing unit, building new proteins to carry out activities and recycling proteins that get damaged. We already know that Parkinson's may spread when alpha-synuclein escapes from affected cells into the brain, where it can then get taken up by other cells. Thanks to this study, for the first time we know how the protein is released, giving us new clues on how this spread happens. Most importantly, these findings open up new avenues into investigating potential new therapies or treatments that could stop the spread of alpha-synuclein and slow the condition's progression."

Dr Arthur Roach, Director of Research at Parkinson's UK, which funded the study, said: "This is a good example of how studying a genetic form of the condition can provide important insights into what is thought to be a fundamental feature of all forms of Parkinson's. These findings offer new ideas on how we could stop the condition in its tracks." See more at: <http://www.parkinsons.org.uk/researchnews18feb2016#sthash.qiWWSn4w.dpuf>

MINDFULNESS

An unusual research study, led by City University, London, is looking to study mindfulness, which the researchers describe as "a talking therapy designed to help people adjust to living with long term conditions and cope with challenging symptoms and emotional states." The study, funded by Parkinson's UK, is looking at whether a remotely delivered mindfulness course could be used to treat anxiety and depression in people with Parkinson's (PWP). The course will last eight weeks and be delivered via video conferences using Skype.

To take part, PWP must have a computer and internet access at home, be able to communicate fluently in English, and have been on a stable dose of Parkinson's medication, antidepressants or anxiolytics for a minimum of 1 month. Participants will take part in a 30 minute session at home, once a week for eight weeks. During the study, they will also be asked to complete questionnaires and regularly practice mindfulness meditation. Those taking the course will be randomly assigned to either the mindfulness or a wait-list group. The mindfulness group will begin the course immediately and those assigned to the wait-list group will start the course after 5-8 months. The closing date for taking part in the study is June 2016. For further information please contact the research team directly: Dr Debora Sa on 07399-094791 or debora.v.sa@city.ac.uk. Participants will receive a summary of the main research findings.

RESPIRATORY DRUG

Trial of a drug that could potentially slow down or stop the progression of Parkinson's is soon to start at the Royal Free Hospital in London. It focuses on ambroxol, which is typically used to treat respiratory conditions. Earlier work conducted by the trial's principal investigator, Dr Anthony Schapira, has demonstrated that ambroxol improves the function of a protein that plays a key role in cellular "trash removal" processes. Recent evidence suggests that impairment of these processes is linked to neurodegenerative disease onset and progression. Additionally, mutations in the gene that encode this protein are seen as the greatest risk factor for developing Parkinson's.

The trial is the latest to be launched as part of the [Linked Clinical Trials \(LCT\)](#) initiative, a programme spearheaded by the Cure Parkinson's Trust (CPT). By focusing on existing medications that have already passed the rigorous drug approval process and shown promise in preclinical laboratory studies for treating Parkinson's, LCT aims to significantly reduce the time and cost required to bring new therapies to people with Parkinson's.

"With this trial, we're moving beyond treating Parkinson's symptoms," said Patrik Brundin, head of LCT's international scientific committee. "We want to actually slow or stop disease progression."

DATES FOR YOUR DIARY

HOUSES OF PARLIAMENT TRIP DATE CHANGE



Unfortunately, we have had to change the date for our trip to the Houses of Parliament, to Monday, August 8. The coach will set off from Trumpington Park & Ride at 9am, arriving back soon after 4.30pm. Tickets are £15 each. Contact Caroline on 01223 314279, email: carolinebent@me.com.

BARKER LAB OPEN DAY

The next Barker Lab Open Day will be held on Saturday, July 9, from 10am-2pm, at the John van Geest Centre for Brain Repair, Forvie Site, Robinson Way, CB2 0PY, Cambridge. To book a place, contact Dr Romina Vuono on barkerlab.registration@yahoo.co.uk, or Shannon Tinley-Brown on 01223 331160, no later than Friday, June 24.

DANCE CLASSES TO START IN JUNE

The two women who co-founded Dance Ensemblé, Romina Vuono and Jeanette Simpson, are planning to offer regular dance classes in Cambridgeshire for people with Parkinson's (PWP). For more, see <http://www.dance-ensemble.org.uk>, or contact Romina at rvuono@dance-ensemble.org.uk. Dance Ensemblé staged a highly successful dance event, Take a Step, in January, held at the Junction venue in Cambridge (see the March-April newsletter). This raised £4515, and a cheque presentation will be held on Saturday, May 21, at 3.45pm in the Hexagon Room at the Frank Lee Centre on the Addenbrooke's Hospital site in Cambridge. All welcome – book a place at info@dance-ensemble.org.uk, no later than May 14.

To raise funds for setting up the dance classes, a quiz night run by Parkinson's UK will be held in the Hexagon Room on Thursday, June 2, at 7.15pm. Entry fee per person is only £3, for teams of four or more. Tickets can be bought on the night.

MEMBERS VOLUNTEER FOR SELF MANAGEMENT GROUPS

Three of our Branch members have volunteered as facilitators for the Parkinson's Self Management groups being set up in our area: Martin Forbes, David Johnston and Valerie Varty. One group is in Cambridge, the other two in Bury St Edmunds and Bishops Stortford.

The key role of a Facilitator is to help a discussion to take place within a Parkinson's Self Management Group. The aim of the Groups is to bring together people with Parkinson's, partners and carers, to share experiences and discuss the practical and emotional impact of Parkinson's. Self management is suitable for people at all stages of the condition, from newly diagnosed to the later stages. We will report in more detail once the Groups are underway. For more about Self Management, see <http://www.parkinsons.org.uk/content/self-management-programme-path-through-parkinsons>.

YOGA TIME

Please note that the time slot for Michele's Yoga Class has been changed, and as from now takes place in Room 2, at the same place (Meadows Community Centre) but one hour earlier than before, that is 10.30-11.30.

IN MEMORIAM

Future editions of our bi-monthly Newsletter will acknowledge the death of members; please let the editor (dboothroyd@btinternet.com) know if you hear of the passing of a local member.

Note: all Parkinson's related phone numbers that started with 0844 now begin with 0344, making them cheaper.

Parkinson's Local Adviser - Rhonda Waters - 0344 225 3618

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. If you would like advice about your Parkinson's or information about groups they run please contact the Parkinson's Nurse Team on **01223 723018**.

Branch Website – www.parkinsonscambridge.org.uk

Parkinson's UK 215 Vauxhall Bridge Road, London SW1V 1EJ

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Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom.
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PARKINSON'S UK – CAMBRIDGE BRANCH CALENDAR – MAY-JUNE 2016

REGULAR MEETINGS AND ACTIVITIES

Aquatherapy

Thursdays weekly, 14:30-15:30
Chesterton Sports Centre, Gilbert Rd, CB4 3NY
Contact: Caroline 01223 314279

NB: MEETINGS WILL RESUME IN MAY

Branch Meeting

Fourth Friday of every month except December,
10:30-14:00,
David Rayner Building, Scotsdales
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 month, 12:15-15:00
Barnabas Court, Milton, CB24 6WR
NB: no lunch on May 3
[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

Carers' Meeting

Programme of support, chat, information and friendship
Quarterly, second Friday of the month
10:30-12:30 – see "Of Special Note"
Davison House, Brookfields Hospital, CB1 3DF
Aromatherapy 10:30-12:00
Contact: Lorna 01223 723018 or 07770 533948
Numbers limited: PHONE to indicate interest

Nightingale Singers

Speech Therapy through Song
First Saturday of month, 14:00-16:00
David Rayner Building, Scotsdales Garden Centre,
Gt Shelford, CB22 5JT
Contact: Charles Nightingale 01223 844763

Yoga

Mondays weekly, **10:30-11:30**
NB: CHANGE OF TIME
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

- 2: NO YOGA
3: NO BRING AND SHARE
19: Collection at Milton Tesco, help needed, please contact Caroline (01223-314279)
21: at 15.45, Presentation of Ensemble cheque, see article above
27: Branch meeting:
A BUSY MEETING, SO PLEASE BE AS PROMPT AS POSSIBLE TO AVOID MISSING ANY PART OF IT!
10:30 Refreshments.
11:00 Speaker, David Palmer, Auctioneer
Also present: **Heidi Allen, MP for South Cambridgeshire, and Natasha Burgess, Parliamentary Advisor at Parkinson's UK .**
See article above.
12:00 Lunch.
Aromatherapy throughout.
30: NO YOGA

JUNE

- 2: Quiz Night, raising funds for the Dance Classes, see article above
10: Carers' Meeting: Speaker, Valerie Freestone, Dementia Specialist Nurse at Addenbrooke's.
NB – see "REGULAR MEETINGS"
24: Branch meeting:
10:30 Refreshments.
11:00 Speaker Samantha Cochrane, of Scotsdales Garden Centre.
12:00 Lunch.
Aromatherapy throughout.

We have invited **Steve Ford, Chief Executive of Parkinson's UK**, to be our speaker at the David Rayner Building meeting in July, August, September or October. Other speakers will be fixed following his decision.

JULY

- 9: Barker Lab Open Day – see article above.

AUGUST

- 8: Outing to the Houses of Parliament.**

NB: CHANGE OF DATE

9.00 from Trumpington Park & Ride
See article above.