

Cambridge Branch Newsletter – July-August 2015

Editor
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BUCKINGHAM PALACE VISIT



A special day out to Buckingham Palace is being planned for the Cambridge Branch, taking place on Thursday, August 27. The cost will be only £19 each. The coach that will take us there will leave the Trumpington Park and Ride car park at 10am, with the aim of arriving in London at 12 noon. There will be time for a coffee at the Cardinal Shopping Centre, a short walk from the coach drop off point near the Royal Mews. We suggest you bring a packed lunch with you.

Our entry time to the Palace is 13.00, preceded by a security check at 12.45. The coach will set off back to Cambridge at 15.00, and is due to get back to Trumpington at 17.00. For more information or to book your place on the trip, contact Charles Nightingale 01223 844763 cllnightingale@btconnect.com. Tickets will also be available at the next branch meeting, at the DRB on June 26. The price includes an audio tour of the Palace's State Rooms and a guided tour of the garden. The itinerary allows time for a group to take in the panoramic view of the lawn from the Garden Café and to visit the Garden Shop.

RESEARCH SUPPORTERS' CONFERENCE

Following the success of the event last year, Parkinson's UK has announced it will be hosting another Research Supporters' Conference on Saturday, November 14, at the Crown Plaza Hotel in Birmingham. The conference will run from 11am until 4pm. It will cover key areas of research into Parkinson's, and more details will be available when registration opens in July. If you want to be sent the registration link as soon as that happens, contact researchevents@parkinsons.org.uk.

Meanwhile, a new research study is being conducted by the Institute of Neurology and the National Hospital for Neurology & Neurosurgery in London. This will investigate ways of tackling difficulties associated with Parkinson's, especially mobility, reaction times and memory. People with Parkinson's who have mobility problems, as well as those without the condition to act as controls, are invited to apply. Participants will take part in a test session at the Institute of Neurology at University College, London, involving questionnaires and simple reaction time tasks, lasting around 1.5 hours. The closing date for taking part is November this year. Travel expenses will be reimbursed. To apply, contact Dr Ana Guinote at University College, 07868-309319 or a.guinote@ucl.ac.uk.

TESCO COLLECTION

Tesco Supermarket at Milton has offered us the opportunity to collect for the Cambridge Branch at the store on Friday, August 7. Because this is the ONLY collection date for this year, so far, we would like to have collectors for a full day – say 9am to 5pm, that is 16 people in all. We have a number of people on a list as past collectors, who have already been contacted. But we would really like to have some new faces showing up for this important publicity and fundraising event. Please contact Caroline Bent (01223 314279; carolinebent@me.com) if you can possibly help out

CREAM TEA

Chris and Pam Holt have traditionally held a fund-raising cream tea in the garden of their home in Haslingfield. It is a very special occasion, well supported by their friends and neighbours. You are cordially invited to come along at 2:30 on Sunday, September 13. The address is 29 High Street, Haslingfield, CB23 1JW, and the suggested donation being £5.

DONATION

We would like to make it clear that the donation of £808 in memory of the late Miss Dora Emily Hoehns-Henschel, which was noted in the last newsletter's Treasurer's Report, was intended for Parkinson's UK nationally, not the Cambridge Branch. Accordingly, a cheque has been sent to the headquarters in London.

BRANCH MONTHLY MEETINGS

PATIENT AND PUBLIC INVOLVEMENT IN PARKINSON'S

The headline describes the subject of a presentation by Dr Simon Stott of the Barker Laboratory, which is set for the Branch meeting on Friday, July 24. The key theme of his talk will be that People with Parkinson's (PwP) and their families are often able to provide some unique insights into the research that should be conducted into their condition.

That is why the Barker Lab is keen to initiate 'Patient and Public Involvement' (PPI) in its research. This initiative, being encouraged by Parkinson's UK, would see PwP and carers becoming more involved in the planning of research projects. The goals would be for a more PwP-focused research, and new ideas based on PwP perspectives. At the Barker Lab, this will be applied to both ongoing projects as well as planned/proposed projects.

Dr Stott will explain how the Barker Lab think this process of PwP consultation may work, outlining some ideas that are currently being discussed. He will also provide some updates about on-going research projects, like the Transeuro trial, which had its first transplantation in May (see separate article), and the planning of the breath testing study, which will start in September. The Barker Lab is situated at the John van Geest Centre for Brain Repair, University of Cambridge, Forvie Site, Robinson Way, Cambridge CB2 0PY, tel: 01223 331160 email: ss2060@cam.ac.uk.

BRAIN-STORMING

AT THE MEMBERS' MEETING in May, people were asked for both positive and negative comments about the services offered by the Branch. Happily the negative comments were few. They included: more should be done to ensure those diagnosed with Parkinson's and their carers know about the Branch, its services and meetings. Both consultants and GP surgeries should impart this information.

The branch website address (www.parkinsonscambridge.org.uk) should be more prominently featured on every Newsletter. Every effort should be made to welcome new arrivals at Branch meetings, and to make sure they understand the normal pattern of the meetings. The issue of transport to Branch events continues to be a challenge.

On the positive side: there seemed to be general agreement that therapies, fund-raising opportunities, the David Rayner Building as a venue, the Newsletter, and the plan to arrange outings in the future, were all good features of the Branch's work. Presentations which feature members who have risen to the challenge of living with Parkinson's are welcomed.

There were many suggestions about speakers and activities at DRB, such as: an activities/skills day during which members could display their interests and talents; speakers like a Parkinson's consultant; topics to be covered include drug side-effects, dementia, mobility and sleep problems; someone directing their skills and knowledge towards the carers; members who have special interests they might share. Finally, a 'conversation' between the Branch and the Neurology department at Addenbrooke's would be of huge benefit to both participants.

The opportunity was taken to thank our John Lewis friends for the wonderful contribution to our funds, in excess of £800 this year.

HELP AT HAND SCHEME

The Help at Hand scheme provides financial help when an emergency or short term problem arises. This could include: a carer suddenly being taken ill so more help at home is needed; an urgent domestic problem arises; help is needed with transport costs such as to hospital, a Parkinson's-related appointment or Branch functions; and if a few sessions of an approved alternative therapy would alleviate symptoms or stress. Other needs will be considered, so please ask. Funds are only provided for Branch members and their carers, with payments limited to £150 per annum per household. Payment can cover all or part of costs, but the branch does not organise the help – that is up to the applicant. Receipts for expenditure are required in all cases, and prior approval is normally needed. However, retrospective applications will be considered for costs incurred in an emergency. Applications are considered by two branch committee members who form the 'approval panel', which deals with all applications in strict confidence – no names appear in the Branch accounts. There is no means testing. For an application form, see the Cambridge Branch website (www.parkinsonscambridge.org.uk) or contact Ian McKee on 0844-225-3614.

SCIENCE COLUMN

FETAL CELLS TRANSPLANT

A Parkinson's patient in Cambridge has had fetal cells transplanted into his brain, the first time this has been done for two decades. The treatment, which took place on May 18, is the aim of Transeuro, an international project led by Cambridge University's Professor Roger Barker. He heads the Barker Lab, at the Barker Lab, on the Forvie Site, Robinson Way, Cambridge CB2 0PY, which holds Open Days that we have reported on regularly.



Fetal cell treatment was first carried out in Sweden more than 20 years ago, but further trials in the US showed no improvement after two years, and the research stopped, in favour of deep brain stimulation. But this is now seen as a mistake, because it can take longer for cells to 'bed in' properly. Many patients improved dramatically around three years after the treatment, and this improvement lasted for a decade and longer, even enabling many of them to stop taking Parkinson's medication. In the best cases, patients who had the treatment pretty much went back to normal, Barker says.

However, a drawback to using fetal cells is that obtaining them depends on donations from women terminating their pregnancies, which severely limits the supply. Limited supply meant the Cambridge patient had only one side of his brain treated. Barker hopes he will have the other half done soon, and a further 19 people will have the treatment, in Cambridge and Sweden.

But a much greater supply would be available if stem cells could be used, and this is the aim, with trials planned for 2017. Barker hopes lessons learned from the fetal transplants will help. In Japan, researchers are creating dopamine-producing cells from induced pluripotent stem cells, which means they can be created from an adult's ordinary body tissues.

The whole process is generating real optimism in the Parkinson's community. When Barker announced the Cambridge man had been treated at a meeting of the Parkinson's Disease Global Force in New York, he was greeted with spontaneous applause from the audience. The story received major coverage in the press, including The Independent on May 27, and the May 30 issue of New Scientist.

TECHNOLOGY FOR TREMORS

Two potential items of technology are being developed for people with tremors. First, Parkinson's UK has recently been contacted by medical students at Imperial College, London University, who are developing a product to tackle hand tremors in Parkinson's called the GyroGlove. This is a wearable, mechanical stabilisation system for individuals with hand tremors, which mechanically stabilises the hand. The device is currently at the development stage and the team is keen to work with people affected by a tremor who would be willing to share their thoughts and views on this wearable technology.

This will be discussed at small focus groups led by the research team at Charing Cross Hospital, London. There will be a prototype of the device at the discussion but it is not yet ready to be tested. Travel expenses will be reimbursed. Anyone with Parkinson's who is over 18 and has a hand tremor can take part. The closing date for participating is Thursday, December 31, 2015. Contact the research team directly: Paul de Panisse, Imperial College, London, 07801 755446 or notremor@imperial.ac.uk. Once the study is completed, researchers will produce a summary of the main research findings.

The second piece of technology being developed for tremors is underway at Cambridge University, where Connie Liu, an engineering student, is working on a tremor-cancelling pen to help patients with tremors write independently. "It is non-invasive, and works by counteracting the tremors solely inside of the pen," she explains.

If anyone in the Cambridge Parkinson's Branch who has writing tremors and might be willing to work with them, Connie would be very interested in talking to them. "We are passionate about designing this device to be as helpful as possible for tremor patients, and we can only do that with valuable user feedback. We are excited to demonstrate our device and would be happy to stop by at a Branch meeting," Connie said.

Contact Connie in the Department of Engineering on 07958 619900 or email at ckl37@cam.ac.uk.

ANXIETY A COMMON SYMPTOM

Many people mistakenly believe Parkinson's is a condition that only affects movement, whether in the form of tremors, or stiffness and problems with balance. But this is far from the case. In many instances, People with Parkinson's (PwP) suffer from excessive anxiety and stress.

This is confirmed by a survey conducted by Parkinson's UK, which asked PwP, as well as carers, and health and social care professionals, what they thought were the top 10 priority areas for improving everyday life with Parkinson's. Anxiety and stress was rated number two in the list. (Not surprisingly, balance and falls was number one.)

The findings were published in the British Medical Journal (<http://bmjopen.bmj.com/content/4/12/e006434.full>). See also the Parkinson's website (<http://www.parkinsons.org.uk/content/our-top-10-research-areas-improving-everyday-life>).

The problem of anxiety was also discussed at the recent Parkinson's Research Open Day held in London in May (see separate article in this newsletter). Professor Richard Brown, of King's College, London, who gave a talk on his psychological research, said anxiety was a common problem, more so than depression, which also affects PwP. This was one result of a four year study by a team from King's College led by Professor Brown and funded by Parkinson's UK.

Professor Brown said there was now an active search underway to find an effective new treatment for anxiety. One possibility is an approach called cognitive bias modification, which tries to move a person's attention system away from the negative thoughts and feelings that cause anxiety.

DATES FOR YOUR DIARY

SHELFORD FEAST

The Shelford Feast takes place on Sunday, July 12, always a popular event, and Lorna and Kevin Walker (89 Macaulay Avenue, Great Shelford, CB22 5AF, 01223 844723) will have a Parkinson's stall at the Feast. They will be assisted by Rosie Meikle, under the direction of Helen and Brian Kember, who have been in charge for many years.

They will distribute information about Parkinson's and the local branch, and hope to raise some funds by having a tombola. If you have an hour to help on the day that would be much appreciated – please let Lorna know – and you would enjoy all the fun of the Feast too.

But if you can't make it, could you instead bring a tombola prize to the Members' Branch meeting on June 26, or drop it in to Lorna at the above address? Any funds raised go into the Feast's 'pot' and if we are lucky we will be chosen as one of the charities supported by the 2015 Feast.

UK TOGETHER EVENT

The Parkinson's UK Together Event will take place from 11am to 4pm on June 29, at the Meadows Community Centre in Cambridge. It is an important meeting to attend to see what the future will look like for the Local Group Network and also the new staff structure. The focus will be on three points: building on the last five years – what have we achieved together? The new strategy and what difference it will make. And local networks – what does the future look like? For more information, contact Julie Wilson on 0844 225 3612 or jmwilson@parkinsons.org.uk.

DANCE CLASSES RAISE MONEY



Dance Ensemblé, a dance group based in Cambridgeshire, are raising funds for Parkinson's in their classes for adults, held at Frank Lee Leisure and Fitness over the past year. Dance Ensemblé includes people of all abilities who love to dance, many with a personal connection to Parkinson's. They are organising more classes for 2016 as well as a dance performance next January to increase awareness of the condition and raise more funds. Please **save the date** for a dance event on January 8 and 9, 2016; for more details go to the website <http://www.junction.co.uk/take-a-step>. On May 16 the first cheque was presented to Julie Wilson of Parkinson's UK. To find out more: info@dance-ensemble.org.uk, or visit their website (www.dance-ensemble.org.uk).

RESEARCH OPEN DAY

Researchers based at the Wolfson Centre for Age-Related Diseases (CARD), part of King's College, London University, recently staged their second annual Open Day for people with Parkinson's, together with carers and family members.



The Open Day featured presentations by several researchers at CARD, who covered a wide range of topics including: glutamate as a potential drug target; dyskinesia in a rodent model; research using fruit flies; investigating non-motor symptoms; and psychological research (see separate article on anxiety).

After lunch, the 50 or so people attending were split into several groups and given tours of the Wolfson centre, when researchers explained the areas they were working on and showed practical examples of what they do on a daily basis. There were also visits to see some of the animals used in their Parkinson's research, such as marmosets.

More presentations followed, including one discussing the current hot topic of drug repositioning. An interesting day closed with a question and answer session.

Information and Support Worker - Rhonda Waters—0844 225 3618

Help Line - 0808 800 0303 (free phone call). Helpline specialist advisors can answer your 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.
A company limited by guarantee. Registered in England and Wales (948776).
Registered office: 215 Vauxhall Bridge Road, London SW1V 1EJ.
A charity registered in England and Wales (258197) and in Scotland (SC037554).

PARKINSON'S UK – CAMBRIDGE BRANCH CALENDAR – JULY-AUGUST 2015

REGULAR MEETINGS AND ACTIVITIES

Aquatherapy

Thursdays weekly, 14:30-15:30
Chesterton Sports Centre, Gilbert Rd, CB4 3NY
Contact: Derek 01223 262248

Branch Meeting

Fourth Friday of month, 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
[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: Caroline 01223 314279

Carers' Meeting

Programme of support, chat, information and friendship
Second Friday of month, 10:30-12:30
Davison House, Brookfields Hospital, CB1 3DF
Aromatherapy 10:30-12:00
Contact: Lorna 01223 723018 or 07770533948

Nightingale Singers

Speech Therapy through Song
First Saturday of month, 14:00-16:00
NOT July or August 2015
David Rayner Building, Scotsdales Garden Centre,
Gt Shelford, CB22 5JT
Contact: Charles Nightingale 01223 844763
NOT JULY OR AUGUST

Yoga

Mondays weekly, 11:30-12:30
The Meadows Community Centre
St Catharine's Road (corner of Arbury Rd & Kings Hedges Rd) CB4 3XJ
Contact: Michèle 01223 563774
NOT BANK HOLIDAY MONDAYS

OF SPECIAL NOTE

JUNE

- 26: Branch meeting
10:30 Tea/Coffee, snacks courtesy of our John Lewis friends
11:00 "Rupert Brooke and Grantchester"
Speaker: Dame Mary Archer
12:00 Soup and sandwich lunch
Reflexology and massage throughout by Philip Atkin, substituting for Alix

JULY

- 4: **NO NIGHTINGALE SINGERS**
12: Shelford Feast. (*see article above*)
24: Branch meeting
10:30 Tea/Coffee, snacks
10:45 "Patient and Public Involvement in Parkinson's" (*see article above*)
Speaker: Simon Stott of the Barker Lab, Brain Repair Centre
12:00 Soup and sandwich lunch
Aromatherapy by Alix throughout

AUGUST

- 1: **NO NIGHTINGALE SINGERS**
7: Collection at Tesco Milton (*see article above*)
27: **LONDON OUTING** (*see article above*)
28: Branch meeting
10:30 Tea/Coffee, snacks
11:00 Rhonda Waters, ISW, and Rosie Mickle, information volunteer, will lead a discussion about "Information Resources"
12:00 Soup and sandwich lunch
Aromatherapy by Alix throughout
31: **NO YOGA**

SEPTEMBER

- 13: Cream Tea in Haslingfield courtesy of Chris and Pam Holt
25: Branch meeting
11:00 "The History of the John Lewis Partnership": Sarah Ingram.
Reflexology and massage throughout

JANUARY 2016

- 8 and 9: DANCE SHOW for Parkinson's at the Junction – save the date!