

Cambridge Branch Newsletter – September-October 2015

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VISIT TO BUCKINGHAM PALACE

Below are some of the branch members who went on the day trip to Buckingham Palace on Thursday, August 27, which proved to be a fascinating day out. At the start of the tour, each person was given an individual hand-held multimedia device (like a large mobile phone) and headphones, so everyone could go at their own pace. The tour started with a short video by Prince Charles, who said the iconic building is one of the world's last working palaces. Our tour concentrated on the State Rooms, and we also got to see many of the extraordinary works of art from the Royal Collection, with special insights from experts who work in the Palace. For many of us, the highlight was the Palace dining room, with the huge table set immaculately with crystal and gold plate, ready for a state banquet.



We ended up in the Palace gardens, where the Queen hosts her famous garden parties. There was also time for a welcome cuppa and of course, a visit to the Palace gift shop!

POETRY WINNER

Congratulations to Cambridge branch member Diana Brodie, whose entry has won the poetry category in the 2015 Mervyn Peake awards, for her poem 'A Shadow of Myself'. The Mervyn Peake awards is run by Parkinson's UK to celebrate the talents of people with Parkinson's. Established in 2002, the awards are in memory of the artist and writer, who had Parkinson's. Peake is best known for his trilogy, Gormenghast.

Winning this year's award follows other recent successes for Diana – the publication of her first volume of poems (see the January 2015 issue of the newsletter), and being a runner up in the Mervyn Peake awards last year. She has a poem in the current issue of the poetry magazine Agenda, and also one in an anthology, Furies, published by forBooksSake. Diana's first volume of poems, entitled Giotto's Circle, was published by Poetry Salzburg. She has been writing poetry for many years, and her first work was published in 2004, when she was diagnosed with Parkinson's. For more, see <http://www.parkinsons.org.uk/content/mervyn-peake-awards-2015-winners>.

BRANCH MONTHLY MEETINGS

DAME MARY GIVES TALK ON RUPERT BROOKE



Poetry was also the theme of a talk by Dame Mary Archer at the June Branch Meeting, in which she spoke about the life of the poet, Rupert Brooke. Dame Mary has a special personal link with Brooke as she and her husband, the writer Jeffrey Archer, have since 1979 lived in the Old Vicarage, Grantchester. This is also the title of one of Brooke's most famous poems, written while he was living there between 1911 and 1912. The poem ends with two of the best known lines in British poetry: "Stands the Church clock at ten to three? And is there honey still for tea?"

Dame Mary told the meeting that Brooke studied classics at King's College, Cambridge, and was staying at the Old Vicarage in order to write a dissertation. He had to do this because he wanted to become a fellow, and had not achieved a first class degree as an undergraduate. Well known and highly regarded for his World War 1 poems, Brooke fought in the war but not for long – he was bitten on the lip by a mosquito, the wound became septic, and he died aged just 27, in April 1915.

Dame Mary, who is a patron of the Rupert Brooke Society, was chairwoman of the Cambridge University Hospital NHS Foundation Trust for 20 years until November 2012, and is now Chair of the Science Museum Group. She told members she has seen the challenges that Parkinson's presents, and has for years been a friend of our Branch's present chairman, Charles Nightingale.

BRAIN REPAIR CENTRE RESEARCH SCIENTIST

The speaker at the July branch meeting was Dr Simon Stott, a research scientist working in the Barker Lab, part of the Brain Repair Centre (BRC) in Cambridge.



Simon started his talk by describing the Transeuro project, involving the transplantation of fetal cells into the brain of a Parkinson's patient in Cambridge (see the article in the last newsletter, "Fetal Cells Transplant"). A second patient has now had a transplant, Simon told members. A major difference between Transeuro and previous transplant trials is that patients will take immunosuppressant drugs for at least 12 months, and the follow up will last three years, as it is now recognised that it can take this long for cells to 'bed in' properly. In previous trials, many patients improved dramatically around three years after treatment, but by then the research had stopped because it was assumed the transplants had not worked.

The second part of Simon's talk was about a breath analysis study he is involved in, which is set to start later this year. This will feature a breath analyser that has been developed at the Technion Israel Institute of Technology. This looks for traces of volatile organic compounds (VOCs) in the air we exhale. In a small trial in Israel involving 57 people, some with Parkinson's and some without, the test could identify the individuals with Parkinson's by looking for distinctive patterns of VOCs. Parkinson's UK and the BRC researchers were intrigued by these early findings and together with the British Council (BIRAX) are now funding a bigger study involving 200 volunteers.

"We would like to find biomarkers that can separate different types of Parkinson's and maybe even identify patients earlier," Simon said. "A breath test would be really appealing because it's non-invasive, not painful, and can be done in seconds."

Another hope is that there may be molecules in the breath of people with Parkinson's which throw up new options for drug targets. Finally, Simon outlined the Patient and Public Involvement initiative, which aims to get people with Parkinson's and their carers more involved in the design and running of trials. At the Barker Lab, this will be applied to both ongoing and future projects.

SCIENCE COLUMN

NHS FUNDS DUODOPA

The NHS in England has announced it will fund Duodopa, a life-changing drug for people with advanced Parkinson's. This means that if a Parkinson's specialist prescribes Duodopa, patients will be able to receive it without delay. This decision follows a campaign by Parkinson's UK, which got nearly 100 MPs to sign a petition calling on NHS England to urgently address the situation.

Duodopa is a gel that is continually administered into the small intestine from a special pump carried by the patient. It can help to control the symptoms of advanced Parkinson's when all other treatments have stopped working. It can have a dramatic effect on people – and can mean the difference between someone being in a wheelchair, barely able to lift their head, and being able to walk around independently. It is estimated that around 75–100 people with Parkinson's could now benefit from Duodopa each year. Laura Cockram, Policy and Campaigns Manager at Parkinson's UK, said she was elated that the NHS has finally arrived at this decision.

"We know this treatment has had transformative effects on many people who have been treated with it, and how vital it is that those who need Duodopa receive it without delay. I would like to thank all of our supporters, including those in the professional community and our campaigners, who have worked tirelessly to show the NHS and government why funding Duodopa is so crucial. This is an important day for Parkinson's care."

SUPPORT FOR GUT THEORY

New research provides some of the strongest evidence to date that Parkinson's may start in the gut and spread upwards through the nervous system to the brain. This theory was put forward in 2003 by the German researcher Heiko Braak, but was initially shrugged off by many other scientists.

The new study was carried out by researchers from Aarhus University in Denmark and published in the *Annals of Neurology* journal. The Danish research team studied the medical records of 15,000 patients who had a procedure to

sever the vagus nerve in their stomach. The vagus nerve is the main pathway of communication between the gut and the brain, and until the mid-1990s the procedure was used to treat ulcers. The team was keen to see how many people who had the procedure went on to develop Parkinson's. The team found that in the group that had their entire vagus nerve severed, fewer people reported developing Parkinson's. But interestingly, people who only had a small part of the vagus nerve severed did not have lower Parkinson's rates.

Many people with Parkinson's experience problems in their digestion – such as constipation – and these changes can occur many years before the movement symptoms of Parkinson's emerge. As Parkinson's UK reports, we are still in the early stages of understanding how Parkinson's may spread throughout the body. These findings add an important piece of the puzzle that could help us understand risk factors for Parkinson's and one day lead to treatments that can prevent Parkinson's altogether.

OLD DRUGS, NEW TRICKS

Over the years, tens of thousands of drugs have been developed and are now sitting on the shelves of chemists on our high streets. Although many of these drugs were designed to treat a particular condition, most have many other unintended effects. Parkinson's UK wants to find out if there are drugs that are already in everyday use for other illnesses that could be beneficial to people with Parkinson's. If there are, these treatments would be available much more quickly than a new treatment that has to be developed from scratch. So Parkinson's UK is asking its members if they have ever noticed a time when taking a non-Parkinson's drug has affected their Parkinson's symptoms.

“We're interested to hear about all kinds of drugs – they could be prescription or non-prescription,” it says. “And we're interested in any effects you have noticed, positive or negative, on any aspect of your Parkinson's symptoms, both movement and non-movement.”

Parkinson's UK emphasises it must be something you yourself have experienced or witnessed and not something that you have read about. If you have anything at all to report please email Parkinson's UK at rsn@parkinsons.org.uk.

DATES FOR YOUR DIARY

JOHN LEWIS FASHION SHOW 2016

Like this year, the fashion show will take place in the Brasserie, on Wednesday, March 9. Watch this space!

BARKER LAB OPEN DAY

The next **Barker Lab Parkinson's Open Day** will take place on November 7, from 10am until 2pm, at the Brain Repair Centre. To register, email barkerlab.registration@yahoo.co.uk, or call 01223-331160. Registration is required as attendance is limited to 60 people and the deadline for registering is October 16. Details about speakers will be available soon.

RESEARCH SUPPORTERS' CONFERENCE

Registration has opened for this year's Parkinson's Research Supporters' Conference, which takes place on Saturday, November 14, from 11 to 4pm, at the Crowne Plaza Hotel, Birmingham. The audience will hear first-hand about some outstanding Parkinson's research. Book your place at the conference here: <http://bit.ly/RSNconference>.

BRANCH AGM 2016

Next year's Annual General Meeting will take place around 11am on Friday, March 18, at the David Rayner Building, before that day's Branch Meeting. **NOTE: THIS IS NOT THE FOURTH FRIDAY SINCE THAT IS GOOD FRIDAY.**

CARERS GROUP

Amanda Eady, one of our Parkinson's nurses, describes the Carers Group, which meets on the second Friday of the month in Davison House, Brookfields Hospital. **BUT PLEASE NOTE: THE SEPTEMBER MEETING HAS BEEN CANCELLED DUE TO ILLNESS.**

In one room a speaker gives an informal talk on a subject requested by our carers. For accompanying patients Parkinson's nurse Lorna Woor runs an activity, such as word games, sweet making or baking. Recent talks have included advice about how to encourage someone to get up from the floor after a fall, how new legislation affects

carers, and a personal view of some of the difficult decisions carers sometimes need to make. In the coming months we are hoping to have speakers advising about first aid, using walking poles and coping with dementia. We will try to find future speakers on any subject you might find useful.

We always have time for an informal chat helped along with a drink and biscuits. This gives everyone the chance to swap ideas and sometimes relieve some tension. The only request we make is that you call us on 01223 723014 prior to the meeting to let us know if you want to attend and whether you will be on your own or accompanied. If the phone is not answered then please leave a message with the names of those who wish to attend. Our aim is to help our carers to support our patients, so we want you to make the meeting your own. Meetings run from 10.30-12.30. To attend, take the lift to the first floor; turn right out of the lift to the two rooms at the end of the corridor.

DANCE AT THE JUNCTION



Dance Ensemblé is a community dance group based in Cambridgeshire that uses dance to raise funds for health related charities (www.dance-ensemble.org.uk). "Take A Step" is the product of over 12 months work focused on raising awareness of Parkinson's, and to raise funds for Parkinson's UK. All proceeds from the show, on January 8 (7.30pm) and 9 (2pm and 7.30pm), go to Parkinson's UK. Tickets are available at the Cambridge Junction: <http://www.junction.co.uk/take-a-step>. Book before Sunday 1st November to take advantage of the early bird discount.

NEW ROLE FOR JULIE

Julie Wilson has recently been appointed by Parkinson's UK as Area Development Manager for Cambridgeshire (and several other neighbouring counties). Here she explains what that involves.

Some of you may know me as I have been around for a long time in another role at Parkinson's UK – mostly line managing the Information & Support Workers in the Eastern Region. My role of Area Development Manager for your area is to help develop and improve services and activities. This involves working with our supporters, volunteers, external agencies, health and social care professionals and other relevant bodies. Another element to my role is to make sure people affected by Parkinson's have access to high quality services, and ensuring that the voice of people affected by Parkinson's is the key to our work.

My first priority is to look at the current services being provided and see where there are any gaps. I want to look at each county's priorities and with help put together a plan for how this can be achieved in each. Please feel free to get in touch with me (0300 123 3695, jimwilson@parkinsons.org.uk) if you would like to ask me anything or have anything you think I need to know. A regional meeting is set for October 16 at the Meadows Community Centre to further discussion of the 'Core Offer'. Anyone interested should contact Caroline Bent (01223-314279).

ROLLATER AVAILABLE

A branch member, Cath Butler, has a rollater available, as she no longer requires it. A rollater is like a zimmer frame on wheels with a seat so you can have a sit down. It has hardly been used, and Cath is happy to give it away if someone can collect it. It fits in the back of the car, folding fairly flat and the seat acts as a basket with lid. If you are interested, contact Cath on cbutler533@btinternet.com or 01223-842762, address 116 Abberley Wood, Great Shelford (off Granhams Rd), CB22 5EZ.

PEER SUPPORT SERVICE

Parkinson's UK is recruiting volunteers for its Peer Support Service, which offers support to anyone affected by Parkinson's. This is a free and confidential service, provided by trained volunteers ready to listen, offer emotional support and share their experiences and understanding. Sharing experiences with others or just listening can really help make a difference to people affected by Parkinson's. Recent users of the service have commented: "Not knowing anyone with Parkinson's, and being able to talk to someone who has it, was invaluable and helped me develop the strength to talk to family and friends about the future."

Parkinson's UK says it welcomes applications from anyone with Parkinson's and especially from people who are carers, have had a diagnosis at a young age, or were diagnosed in the last three years, and women who have experienced deep brain stimulation. The role is home-based, but applicants will be required to attend training at

National Office, 215 Vauxhall Bridge Road, London, SW1V 1EJ. The next training happens on September 18 and there are still places available. See <https://www.parkinsons.org.uk/jobs/19-may-2015/telephone-peer-support-service-volunteer> or contact Elizabeth Rickarby on 020-7963-9343.

HEALTHY VOLUNTEERS NEEDED

The Brain Repair Centre (BRC), of Cambridge University, is currently looking for healthy control participants to help with its research. It wants to compare patients' results on different movement and thinking assessments against the results of controls to see whether there are any differences. This is vitally important because without data on the performance of controls, the BRC's research cannot progress, and it will not be able to see what changes are taking place in patients that are different to the rest of the population.

If you would be interested in taking part, volunteers have to go to the BRC and do a series of assessments looking at different thinking processes, and complete some short questionnaires. The whole visit will take about 1.5 hours and the BRC will reimburse travel expenses. To take part, you must not have been diagnosed with Parkinson's, Huntington's disease or any other neurodegenerative disorder. For more information contact Natalie Valle Guzman on nv259@cam.ac.uk or call 01223-331160.

REVIEWERS WANTED

The National Institute of Health Research (NIHR) is part of the NHS that aims to improve health through research. Parkinson's UK have recently been contacted by the NIHR as they are looking for people with Parkinson's, or their carers, to review applications they have received from researchers. The NIHR is continually looking for new lay reviewers for other programmes. Reviewers must not have a professional background in health or social care research or be working as a researcher, medic or nurse. It is also helpful for reviewers to have relatively good computer skills as they must review the applications online. The NIHR pays £125 to reviewers for the time and effort involved. To express your interest in being a lay grant reviewer for the NIHR, contact Haydee Garcia on 020-8843-8041 or haydee.garcia@nihr.ac.uk.

TULIP CLUB

The Tulip Club is a draw that raises funds for the Cambridge branch of Parkinson's UK. Membership costs £12 per year, and every month members' numbers are entered into the draw. Two prizes of £10 are won each month, with a bonus at Christmas, the two prizes then being £30 each. The monthly draw takes place at the Branch Meeting in the David Rayner Building. People can join the club at any time, and membership will run for 12 months from that date. Anyone can take more than one subscription. To join, you need to fill out a simple membership form and send it with a cheque for £12 made out to Parkinson's UK (Cambridge Branch). Forms are available from Michael Moore of 103 Queen Edith's Way, Cambridge CB1 8PL, tel 01223-244202, email michael@mooresplace.eclipse.co.uk.

FUND RAISING

Two branch members, Surendra Jebasunderam and Merryn Grimley, held a joint birthday/summer party, and asked all guests to make donations to the Branch instead of bringing presents. They raised more than £250. And another member, David Johnston, is cycling from John o' Groats to Land's End, aiming to finish in late September. See www.justgiving.com/teams/get-David-to-Lands-End Congratulations to all!

Note: all Parkinson's related phone numbers that started with 0844 now begin with 0344, making them cheaper. Information and Support Worker - Rhonda Waters—0344 225 3618

Help Line 0808 800 0303 (free phone call). Specialist advisors 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

T 020 7931 8080 **F** 020 7931 8080 **E** enquiries@parkinsons.org.uk **W** parkinsons.org.uk

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 – SEPT-OCT 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

NO MEETING IN SEPTEMBER

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, 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

OF SPECIAL NOTE

SEPTEMBER

- 11: **NO CARERS' MEETING**
12: Parkinson's UK AGM in London
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.
12:00 Lunch
Reflexology and massage throughout

OCTOBER

- 16: Forum to discuss the "Core Offer" at the Meadows C C (ask Caroline)
23: Branch meeting: (NB NOT 30th)
11:00 – 12:00 The **Parkinson's nurses** will be present both to explain their role and routine.
12:00 Romina Vuono will talk about the DANCE SHOW (see January)
12:15 Lunch
Reflexology and massage throughout

NOVEMBER

- 7: 10am: Open Day at the Brain Repair Centre
27: Branch meeting: CHRISTMAS PARTY

DECEMBER

- 4: CHRISTMAS LUNCH
No additional Branch meeting

JANUARY 2016

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

FEBRUARY

- Date to be fixed: A Curry Night in Shelford

APRIL

- 24: The Tulip Fun-Run

MARCH

- 9: Fashion Show at John Lewis
18: **MAKE A NOTE NOW: THE BRANCH MEETING AND AGM 2016 WILL BE ON FRIDAY 18 MARCH (because the fourth Friday is Good Friday**