

Cambridge Branch Newsletter – November/December 2014

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FUND RAISING

Collections at three Tesco stores in September and October brought in a total of £1,047.24. Thanks to all who came along and collected.

Pam and Chris Holt gave to the branch a generous £350 from the money raised at the Dovecote cream tea. Jenny Brew and Christine Corbyn continue with their fundraising on our behalf.

Congratulations to all fundraisers. We have reached our target for 2014, in fact exceeded it, so nothing else is planned for this year. We start from zero again on 1st January with plans laid for the Tulip Fun Run on 26th April and for a fashion show at the Cambridge John Lewis store for which the date is not yet settled.

TULIP CLUB –The winners were: - in Sept Adrian Izzard and Glynis Brookman and in October Pam Cressey and Caroline Bent



CHRISTMAS LUNCH

Christmas is coming – which means our special lunch is imminent! If you have not already got tickets, now is the time! It takes place on Friday, December 5, at the David Rayner Building (DRB), 12 for 12.30. Tickets are £16 each, and can be obtained from Margaret Steane by post (109 Waterbeach Road, Landbeach, Cambridge CB25 9FA), with a cheque made payable to Parkinson's UK Cambridge Branch and a stamped addressed envelope. Alternatively, you can book by phone by calling Margaret (01223-860128) and pay on the day, but please note: any cancellation in the week running up to the lunch will have to be paid for.

JOAN SUCCEEDS! Joan Hallifax, who told us at branch meeting in August about her plans to raise money for Parkinson's by climbing Mount Kilimanjaro, has done it! In the process, she and her group have raised more than £80,000, with more donations still to come.

The climb took place in the first half of October, and Joan reached the summit – at 5895m (19,336 feet), Africa's highest point – after five days of climbing.

"It was a privilege to spend time with such an amazing group of people. The challenge was gruelling, much harder than I imagined, but it is something that will stay with me forever. I do not think I have ever seen as many sick people on a mountain at one time!"

Joan's fellow climbers included Parkinson's sufferers, some of them also reaching the top. "I am in awe of their achievements in so many different ways and their determination was just amazing," she says.

"A big thank you to all of you who have supported the cause and sponsored me. Before we set off we had raised £80,000, enough for two Parkinson's nurses plus money towards research, so it will make a real difference. And we all still have a bit more to raise."

Joan has promised to come to our branch Christmas lunch on December 5 to make it a great start to the festive season!

BRANCH MONTHLY MEETINGS

The main speaker at September's branch meeting was the **Mayor of Cambridge**, Councillor Gerri Bird. Gerri is well known as a campaigner for the rights of disabled people, having worked for Disability Cambridgeshire, and is now involved with organisations giving support and advice to disabled people.

She gave us a brief summary of her remarkable life, having been born in Cork, Ireland, in a Magdelene Home where at the age of just 10 months she contracted polio. She stayed in hospital until she was 7, when she was sent to Cambridge, where her mother had moved. At 12 she was adopted by another family, and went to school, but only for three years, leaving at 15. After marrying and having two children, she worked at Addenbrooke's Hospital for a time, then joined a disability charity. For 25 years she has been confined to a wheelchair, but that hasn't stopped her becoming a councillor, and now Mayor of Cambridge.

Over the years, Gerri has certainly never let her disability hold her back, having jumped out of an aeroplane, swum competitively, even won trophies for banger-racing. Two years ago she almost died from legionnaire's disease and double pneumonia. Now she says she works seven days a week, and frequently attends up to eight events in a day.

Members at the meeting then made several suggestions for disabled-related improvements, such as removing the three hour limit at the Beehive car park, for those with blue badges. Gerri suggested getting a petition going to put to the council.

The lead Parkinson's nurse for the whole of Cambridgeshire, Carolyn Noble, gave a brief talk at the September branch meeting. She told us the last few months had been a difficult time in terms of staffing, but that now a new, full team of nurses was virtually in place and would be operating by November. She said she would bring the whole team with her to a meeting in the New Year.

She was aware people had experienced difficulties getting hold of a nurse, and had had to wait a long time after leaving messages before they were contacted. Making responses much more timely is a top priority, she said.

Parkinson's patients with queries or concerns about their medication should contact a nurse, but if they have an infection, they should go to their GP, Carolyn told members.

The other nurses making up the team are Hazel White, Liz Terry, Amanda Eady and Lorna Woor. Carolyn's contact details are: Tel: 01733-776145, email carolyn.noble@ccs.nhs.uk.

A presentation was given at a recent branch meeting about the reorganisation of the NHS, involving the creation of a new body, the **Clinical Commissioning Group (CCG)** for Cambridgeshire and Peterborough. This has replaced the previous body responsible for health services in our area, the Primary Care Trust.

Dr Arnold Fertig, a GP in the Cambridgeshire area for over 30 years, is the CCG clinical lead for older people, and gave the meeting an overview of the CCG's Older People's Programme. One of his key points was that there has been too much focus on activity levels for their own sake, and not enough on actual positive outcomes for patients.

This will change, he promised, thanks in part to new contracts that will link the payments made to companies supplying healthcare specifically to clinical outcome and patient experience. The most recent development is the CCG's selection of the UnitingCare Partnership as the Preferred Bidder to improve older people's healthcare and adult community services. It will start delivering services from April 2015.

For Parkinson's, particular targets include ensuring the provision of comprehensive nursing assessment, counselling, and support and symptom management through all stages, as well as avoiding admission to hospital whenever possible. For more information call 01223-725304, email capccg.engagement@nhs.net, or visit the website www.cambridgeshireandpeterboroughccg.nhs.uk

We also heard from Elizabeth Locke who described the work of **Healthwatch, Cambridgeshire**,. She encouraged members to be in touch if they had suggestions for improving health and social care in the area, or to report positive or negative experiences of health care: enquiries@healthwatchcambridgeshire.co.uk or 01480 420628."



AROMATHERAPY

Some members may not be aware that at every branch meeting, Alix Allan is providing an aromatherapy service. It runs throughout the whole meeting, and is very easy to reserve a spot – just write down your name on the list that is available at the reception table.

For those new to it, aromatherapy is a branch of alternative medicine using oils derived from plants for massage. This can help with physical problems, aches and pains, anxiety, constipation etc. Alix has been treating Parkinson's patients and their carers for the last 10 years. Most people feel the benefits and feel more relaxed after a treatment. Aromatherapy has become more popular since the 1970s but has been used for centuries for therapeutic purposes.



The SCIENCE COLUMN

The Barker Lab Open Day on Parkinson's took place on Saturday, October 18, at the Brain Repair Centre at Addenbrooke's Hospital. It was extremely well attended and featured a series of interesting presentations, followed at the end with a question and answer session chaired by Professor Roger Barker himself.

He also opened the meeting, with an overview of Parkinson's as it is today – saying how we are increasing both our knowledge about the variable nature of the disease, and how to treat it. Parkinson's is not just about movement difficulties, he said, as in about 50% of cases it is associated with depression and anxiety as well. And it seems there are at least two versions of Parkinson's, a more benign form, often found in younger people under about 70, and a more aggressive type that affects many areas of the brain apart from just dopamine producing cells.

Cambridge is one of the first places to see trials of cell transplants for Parkinson's, with the first patient having treatment in November, to be followed by several others, as part of the Transeuro project. Another area where the UK is a world leader is gene therapy, with a Bedfordshire patient, Sheila Roy, having undergone pioneering therapy as part of the ProSavin trial, and progress in the use of GDNF, a trial based in Bristol (see other article in this issue).

Several other speakers at the Open Day covered a range of topics. Dr Isabelle St-Amour had come from Quebec, Canada, to talk about the analysis of blood, and the search for Parkinson's biomarkers. Dr Romina Vuono's talk centred on sleep and how Parkinson's affects it by reducing melatonin concentrations. Dr Heike Laman, from Cambridge University's pathology department, discussed her work on the genetics of Parkinson's, especially a particular gene, known as PARK15. The Barker Lab's Lucy Collins described her work on creating nerve cells from skin cells, and finally Simon Stott, organiser of the event, showed how only some cells are affected by Parkinson's – like a storm affecting only some houses.

A lively question and answer session after lunch closed a fascinating day, one that the Lab plans to repeat twice a year from 2015 onwards.

Parkinson's UK has had a major boost for the biggest clinical trial it has conducted, which relates to GDNF, standing for Glial cell line-Derived Neurotrophic Factor.

"We believe GDNF may hold the key to stop Parkinson's getting worse, something which no existing treatment can do," it says.

The boost comes from leading pharmaceutical company Pfizer, which has committed to investigating the possibility of a larger study into the potential treatment when the Parkinson's UK project ends in 2016.

“Our project is investigating whether infusing GDNF directly into the brain using a specially designed delivery system could help to improve symptoms like stiffness, slow movement and tremor – and slow down the development of the condition. This announcement means that if the results of our trial are promising, a larger clinical trial could take place – providing the vital support we need to ensure the treatment could be made available to people with Parkinson's.”

Steve Ford, Parkinson's UK Chief Executive, said: “We're delighted Pfizer has recognised the potential of GDNF, and are backing what could be a serious game-changer in the treatment of Parkinson's.”

See more at: <http://www.parkinsons.org.uk/news/16-september-2014/gdnf-parkinsons-trial-given-major-boost-pfizer#sthash.d2Rzy6zl.dpuf>

CARERS FOR DEMENTIA

The growing success of its telephone peer support service has prompted Parkinson's UK to look to recruit more volunteers to help people with Parkinson's dementia or dementia with Lewy bodies. The aim is to put patients in touch with carers or partners of dementia sufferers to offer short term support (as opposed to longer term befriending).

Volunteers will have the opportunity to attend a one day training event, which will form part of the recruitment and selection process, to be held in Central London on Wednesday, December 3. Expenses will be reimbursed. For more information contact Lesley Shah on 0808-800-0303 or at peersupport@parkinsons.org.uk.

DATES FOR YOUR DIARY

Parkinson's UK Research Support Network is staging a visit for anyone interested in seeing researchers at work in the lab. It takes place on November 27, from 2-4pm, at University College, London, when Professor Sandip Patel will explain his work. Professor Patel is investigating an idea about the causes of Parkinson's, which could open up a new avenue of research. Findings from this could help develop novel treatments for both Parkinson's and Gaucher's disease. All places are free but must be booked in advance. Find out more and book at <http://bit.ly/1sBiW7t> or call Parkinson's UK on 020 7963 9313.

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

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 – NOVEMBER 2014

REGULAR MEETINGS AND ACTIVITIES

Aquatherapy

Thursdays weekly, 14:30-15:30
Chesterton Sports Centre, Gilbert Rd, CB4 3NY
Contact: Derek 01223 262248
NOT 18/12, 25/12 OR 1/1/2015

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: Julia 01223 365020

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
check especially over the holiday period

Nightingale Singers (ex. Sing Loud)

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: Michele 01223 563774
NOT 22/12, 29/12

OF SPECIAL NOTE

NOVEMBER

- 28:** Branch meeting
10:30 – Tea & Coffee
11:00 Christmas party -- Raffle, quiz, music, and more with our supportive John Lewis friends
12:00 Lunch
Aromatherapy throughout

DECEMBER

- 2:** Christmas Party at Bring and Share lunch in Milton
5: Branch Christmas Lunch at the David Rayner Building, Scotsdales Garden Centre, Gt Shelford, CB22 5JT
12 noon for 12:30
See article above for details

JANUARY 2015

- 23:** Branch meeting
10:30 – Tea & Coffee
11:00 Heidi Allen, Conservative Parliamentary Candidate for South Cambs.
12:00 Lunch
Aromatherapy throughout

FEBRUARY

- 27:** Branch meeting
10:30 – Tea & Coffee
11:00 Jenny Grant, Photographic Artist, will share her experience of living with Parkinson's.
12:00 Lunch
Aromatherapy throughout

MARCH

- 27:** Branch meeting
10:30 – Tea & Coffee
11:00 **AGM**
11:30 Mr Rob Morris -- Deep Brain Stimulation surgeon.

APRIL

- 26:** **SAVE THE DATE – TULIP FUN RUN**

