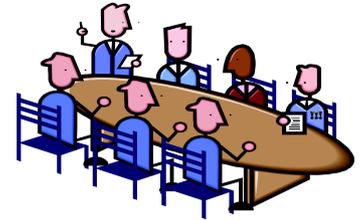


Cambridge Branch Newsletter – September/October 2014

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COMMITTEE NEWS It is with regret that we have to announce the departure from the Cambridge Branch committee of Geoff Gardiner, who feels unable to continue in his role on the committee. Geoff has been a stalwart of Parkinson's Cambridge, and has done sterling work. He will be much missed. And many thanks!



NEW INITIATIVES? Some members have wondered if the Cambridge Branch could widen the range of activities we organise. Well, we are always open to suggestions! Anyone is welcome to contact us with ideas, and we could have a good discussion about this at September's Branch meeting, set for Friday, September 26, at the David Rayner Building, as usual. Come along and have your say!

AQUATHERAPY The Cambridge aquatherapy group meets every Thursday, at Chesterton pool, on Gilbert Road, and the class lasts an hour from 2.30 to 3.30. It has been running successfully for many years, but recently fewer people have been attending. We need more people to come or it could come to an end!

"People get fantastic benefits from it," says the group's organiser Derek Reeds. "It keeps them moving and for those with balance problems, or movement difficulties, once you are in the water everything becomes so much easier and you don't have to worry. It makes it the perfect form of exercise for people with Parkinson's, and people always say they feel better for doing it."



The group has a professional physio, Laurie, who takes the class, which is divided into two halves. In the first, people do what they want, which gives Laurie time to see everyone and give them individual advice. Then in the second half, everybody does exercises together. When the class is over, everyone pops upstairs for a cup of tea and a chat.

There is a growing awareness among Parkinson's experts that exercise is really important and beneficial, potentially having a major impact on people's overall condition. So if you feel like some safe, rewarding exercise – and a great afternoon out – come along!

FUND RAISING

We have finally been granted Tesco collection dates. We badly need more volunteers for this important fundraising effort – if you can possibly spare the time, it would be greatly appreciated!

Please tell Caroline (01223-314279 or carolinebent@me.com) if you can do one or more of the following dates – being midweek dates we will need every available person! We may well have to go for a shorter collection spell, say 10-4 rather than the usual 9-5. But let's see what you all say.

The dates are: Thursday 4th September at Bar Hill Tesco
Thursday 11th September at Milton Tesco
Friday 10th October at Fulbourn /Cherry Hinton Tesco



It would be a great help to have confirmation of your contact details: landline, mobile, street address.

TULIP CLUB –The winners were: - in July Derek Reeds and Charlie Nightingale and in August Margaret Steane and Barbara Vining.

The main speaker at the **July Branch meeting** was Joan Hallifax, who described how she is planning to raise money for Parkinson's UK by climbing Mount Kilimanjaro, the highest mountain in Africa.

Joan now lives in Sussex but has close ties with Cambridge, where her parents lived. Her mother had Parkinson's, and her father raised funds for the Cambridge Parkinson's branch, including setting up a swimming group in Bottisham.

Joan is doing the climb with a group of 15 others, some of them with Parkinson's, others being carers, and they aim to raise £90,000. They have so far practised in the Peak District, but Kilimanjaro is over 19,000 feet high, and Joan said her main worry is altitude sickness. To minimise the risk, the climb is spread over four days and the whole trip lasts 10 days, from October 10 to 19.

The retail chain Mountain Warehouse is offering a £2000 prize to the climber that attracts the most votes, see <http://www.mountainwarehouse.com/charity/> to vote for Joan. And to donate, go to <http://uk.virginmoneygiving.com/JoanHallifax>. Fund raising will continue until the end of the year, and hopefully Joan will be at our Christmas party to tell us how she did!



SCIENCE COLUMN

AMANTADINE SUPPLY PROBLEMS - Some members have been having problems with the supply of the Parkinson's drug Amantadine (or Symmetrel), in pill form, with pharmacies saying they are unable to get supplies.

The shortage has continued since May despite assurances from the manufacturer Alliance Pharmaceuticals that it is tackling the issue. Supplies of the alternative syrup version are also running low, and this has caused problems for some people, not working as well as the pill.

"The manufacturing site was inadvertently closed as part of a routine maintenance protocol before the Symmetrel capsules order was packed," Alliance says. "Extra staff is being brought in at the manufacturing site to minimise this disruption. Please be assured that we understand how important Symmetrel capsules are for many patients across the UK and we are committed to restoring supply of this vital medicine as soon as possible."

See more at: <http://www.parkinsons.org.uk/news/5-august-2014/supply-problems-parkinsons-drug-amantadine>

DUODOPA - NHS England has said the Parkinson's drug Duodopa will not be routinely available on the NHS, which means doctors in England must make lengthy, bureaucratic applications for funding every time they want to prescribe it. Parkinson's patients will face long waits with no guarantee that they will receive the potentially life-altering drug. However, the NHS will continue to honour existing prescriptions for it.

Duodopa, a form of levodopa, is a gel that is continually administered into the small intestine from a special pump carried by the patient. It's only prescribed to people with Parkinson's after all other treatment options have been exhausted. For some patients, it's the last chance they have to be able to control their symptoms and improve their quality of life.

Steve Ford, Parkinson's UK chief executive, says: "We are hugely disappointed that NHS England's Directly Commissioned Services Committee has not taken this opportunity to routinely commission Duodopa. Even when specialists believe Duodopa is the best or only option, people are facing long delays or being denied the potentially life-altering treatment altogether. We call on NHS England to urgently reconsider this decision."

Professor Ray Chaudhuri, Consultant Neurologist and member of the Parkinson's UK Clinical Advisory Panel, adds: "This is a dreadful decision which ignores the voices of people with Parkinson's. Duodopa can have a dramatic effect on the quality of life of not just those with the condition but also their caregiver. It has the potential to give relative independence to those who don't have any other treatment options."

See more at: <http://www.parkinsons.org.uk/news/30-june-2014/nhs-england-says-no-routine-duodopa-commissioning#sthash.LCpe2gd3.dpuf>

The Neurological Alliance has launched its inaugural **neurological patient survey**. Developed to gather information about the experiences of care received by people affected by neurological conditions, the survey is the first of its kind for the neurological community. The findings will be crucial in understanding what progress is being made in improving neurological services, and what still needs to happen.

The survey is open to anyone with a neurological condition living in England and will close on Monday 15 September 2014. The findings will also be used to feed into the Alliance's first annual variations report later in the year.

See <http://www.neural.org.uk/updates/239-Patient-experience-survey-launched---take-part-today> for details.

DATES FOR YOUR DIARY

Tea at the Dovecote: Pam and Chris Holt plan good weather and delicious scones at their lovely home at Haslingfield on Sunday 7th September 2-5pm.

BRANCH MEETING – 26th September

The **Lead Parkinson's Nurse Specialist for the Cambridgeshire PD Nurse team, Carolyn Noble**, will be at the September branch meeting, which takes place on Friday, September 26.

"We will have more news about our new nurses, their names and contact details included," she says. "I understand it has been a very difficult period of uncertainty for everyone and that includes us as a team. However, I am confident you will soon be getting to know us all and we look forward to working with you to the best of our ability."

Another speaker at what looks set to be a busy meeting will be **the Mayor of Cambridge, Councillor Gerri Bird**. She 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.

An important date for your diaries: our **Christmas lunch** will be held on Friday, December 5, at the David Rayner Building (DRB), 12 for 12.30. Tickets are £16 each, and can be obtained at the Branch meetings at the DRB or 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 by Monday 17 November 2014. Numbers are limited so apply early!



The **Parkinson's Open Day at the Barker Laboratory**, at Addenbrooke's Hospital, is coming up soon - Saturday, October 18 – so now is the time to enrol if you haven't already. The first Open Day, in March, proved very popular.

Dr Heike Laman, from the Pathology Department at Cambridge University will speak about genetics and Parkinson's. Other topics will include sleep disturbances in Parkinson's, and how skin cells are being turned into dopamine neurons. There will also be a question and answer session.

The Open Day starts at 10am at the Brain Repair Centre, behind Addenbrooke's, on the Forvie Site, Robinson Way, Cambridge CB2 0PY. Anyone interested should contact Simon Stott on 01223-331160 or email barkerlab.registration@yahoo.co.uk.

Parkinson's Awareness Week 2015 will take place from April 20 to 26 next year, Parkinson's UK has announced. As before, the aim will be to raise public awareness and build understanding of the condition.

One event taking place during Awareness Week is our **Tulip Fun Run**. Time and date have already been set – 10.30am, Sunday, April 26. The Fun Run will use the same course as this year, beginning and ending at Scotsdales and taking in part of the Addenbrooke's site. It follows the success of this year's event, which raised over £2000. Everyone is welcome and if you don't want to run – or walk! – stewards will be needed to help with the start and finish, distribute posters, or make the tea.



South Cambridgeshire District Council is holding a **Disability Open Day** at its offices in Cambourne, on Friday, October 31, from 10 to 4. The Cambridge Branch will be represented.



The **English National Ballet** is coming to Ipswich on October 15, and again on December 10, to stage dance sessions as part of its Dance for Parkinson's programme, which has been running since 2010. For more information, see the website <http://www.ballet.org.uk/learning/dance-parkinsons/> or call Danielle Jones on 020-7590-2929.

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 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. 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 – SEPTEMBER 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 27/10, 22/12, 29/12

OF SPECIAL NOTE

SEPTEMBER

4: Collection at Tesco, Bar Hill
7: Tea at Dovecote
11: Collection at Tesco, Milton
26: Branch meeting
Art throughout the day with introduction from Vicky Hunt
11:15 Meet the Worshipful Mayor of Cambridge, Gerri Bird, who will explain her "Disability Campaign"
12:00 Lunch
12.00 John Lewis team will hold a nearly new sale
NO AROMATHERAPY

OCTOBER

10: Collection at Tesco Fulbourn
18: The Barker Lab (Brain Repair Centre)
Open Day – *see article above*
24: Branch meeting
11:00: Fundamental First Aid
Presented by Harvey Levinson, of the St John's Ambulance (retired)
12:00 Lunch
Aromatherapy throughout
31: South Cambs DC Disability Open Day
Cambourne, 10:00 – 16:00

NOVEMBER

28: Branch meeting
11:00 TBC Dr Arnold Fertig will introduce the new Lead Provider of NHS care
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
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

2015

MAY include talks by Richard Tyner, the User Involvement Advisor for Parkinson's UK, and Mary Archer about Grantchester - WILL include Rob Morris, Deep Brain Stimulation surgeon, on 27/3 after the AGM.
IF YOU HAVE SUGGESTIONS FOR SPEAKERS OR PRESENTATIONS, CONTACT CAROLINE

