

Cambridge Branch Newsletter – March-April 2015

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FUND RAISING

FASHION SHOW



The Parkinson's Fashion Show taking place in the Brasserie at the Cambridge John Lewis department store is nearly upon us! Book the date in your diary - **Wednesday, March 25**. Doors open at 6pm, with the show starting at around 6.30pm and lasting about half an hour. It's late opening night at the store, so everyone will have another hour to visit the clothing department (or others) until 8pm.

Some of the models for the show will be Parkinson's Cambridge members, others will be supplied by John Lewis. Anyone wanting to come must have bought a ticket, costing £10 each, which will double as a raffle ticket and include a glass of wine or a soft drink and finger food on arrival. **DON'T FORGET TO BRING IT WITH YOU!** Admission will be limited to those carrying tickets.

Tickets are still available from Caroline Bent (01223 314279), 21-23 Covent Garden, Cambridge CB1 2HS carolinebent@me.com; at branch meetings at the David Rayner Building; the John Lewis Personal Styling department; or the information desk at Scotsdales Garden Centre at Great Shelford.

The John Lewis store is at 10 Downing Street, Cambridge (01223-361292), and parking is available in the Grand Arcade car park, where there is plenty of blue badge parking on the ground floor. The Brasserie is on the third floor of the store.



TULIP FUN RUN It's now less than eight weeks before this year's Cambridge Tulip Fun Run, which takes place on Sunday, April 26. If you haven't done so already, now is the time to get your entry form – and start training! The run marks the end of Parkinson's Awareness Week 2015, which aims to increase public awareness and understanding of the condition.

Our Tulip Fun Run will start at 10.30am, opened by David Bard, Chair of the South Cambs District Council. It will use the same four mile course as 2014, beginning and ending at the David Rayner Building, Scotsdale's Garden Centre, and taking in part of the Addenbrooke's Hospital site. Last year's event was a great success, raising well over £2000. All are welcome and you can either run or walk the course – in fancy dress or not! Stewards are also needed to help with the start and finish, distribute posters, or make the tea.

For more information and an entry form see <http://www.parkinsonscambridge.org.uk/index.html>, or write to C. Nightingale, 12 Aylesford Way, Stapleford, Cambridge CB22 5DP, (01223-844763). Entries must be received by April 18.

SYDNEY HARBOUR BRIDGE



Gaye Hubbard is pictured with her daughter Amanda at the top of Sydney Harbour Bridge, which they climbed last November to raise money for Parkinson's Cambridge, as well as other charities. Gaye, who lives near Sandy in Bedfordshire, was visiting her daughter who is in Australia for two years. Her link with Parkinson's is through Amanda's father-in-law, who has Parkinson's. Gaye raised a total of £1280 – but had to steel herself to do the climb as she doesn't like heights. A great example of combining an adventure with fund raising!

BRANCH MONTHLY MEETINGS

SURGERY FOR PARKINSON'S

The March branch meeting, set for Friday the 27th, will feature Rob Morris, who has been a consultant neurosurgeon at Addenbrooke's for the last year. The theme of his talk will be 'Surgery for Parkinson's disease - why, when and how?'

One surgical treatment for Parkinson's that can help to control movement and tremor problems is deep brain stimulation (DBS). This involves an operation to insert wires into the parts of the brain that control movement. DBS sends electrical impulses to the brain interrupting the abnormal signals that are causing the symptoms. Another specialised project taking place at Addenbrooke's is the Transeuro study, which involves brain cell transplantation for Parkinson's.

Rob has an unusual background for a neurosurgeon, having originally studied English Literature at Cambridge. But while working as a hospital porter during the summer holidays he saw an operation on a patient with Parkinson's.

"I was amazed to witness the disappearance of tremor during surgery," he says. "I changed career plans and 15 years later was learning how to do such operations myself. I trained in neurosurgery in north London at Queen Square and then undertook 18 months of specialist training in epilepsy surgery and movement disorder surgery at Kings College Hospital. I am now working to expand the functional neurosurgery service in Cambridge to provide care for patients both at a local and national level."

Should be a fascinating talk!



KILIMANJARO CLIMB

A team that climbed Mount Kilimanjaro in Africa to raise money for Parkinson's has done just that – to the tune of more than £110,000! One of the climbers was Joan Hallifax (left, at the summit), who spoke to us at a branch meeting before the climb, and then came to the Christmas lunch. She says the sum raised was much more than expected. Well done to all!

PARKINSON'S IN THE PRESS

Parkinson's has had quite a bit of coverage in the national press recently. One article in the Daily Telegraph reported that scientists believe they have found the tipping point in the brain which triggers Parkinson's.



Cambridge University researchers discovered the level at which a protein in the brain, alpha-synuclein, becomes toxic. Normally, it plays an important role in the smooth flow of chemical signals in the brain, and the level can increase without damage. But when it reaches ten times normal levels it begins to clump into dangerous structures, which are the first step in the chain of events that leads to the development of Parkinson's.

The findings represent an important step towards understanding how and why people develop Parkinson's and how the disease could be spotted earlier. Lead author of the study Dr Celine Galvagnion, a Research Associate at St John's College, Cambridge, said finding a cure for Parkinson's depends on our ability to understand it.

"For the first time, we have been able to provide a mechanistic description of the initial molecular events that can ultimately result in the development of the disease. This provides us with a likely explanation of how the initial steps leading to Parkinson's occur."

Previous research has suggested that overexpression of alpha-synuclein in the brain is somehow linked to the onset of Parkinson's. Together, the results provide for the first time a mechanistic description of the key role that membrane interactions can play in the initiation of neurodegenerative diseases, including Parkinson's.

The development was welcomed by Dr Arthur Roach, Director of Research at Parkinson's UK. "The formation of deposits of the protein alpha-synuclein in the brain is characteristic of Parkinson's and some related brain diseases. The precise role this plays in the disease is not completely understood but it is believed to contribute to the damage to brain cells. In the disease process this aggregation takes place inside cells with a highly complex collection of lipid membranes, so any conclusions can only be used as a guide to what might happen in Parkinson's."

Another story featured in the Daily Mail and Daily Mirror suggested **drinking beer could have benefits for people with Parkinson's**. The research, published in the Journal of Agricultural and Food Chemistry, showed that a chemical in hops, xanthohumol, could slow or even prevent neurodegenerative conditions by protecting brain cells from oxidative stress, a type of damage known to affect cells in Parkinson's.

"Many drugs have their origins in natural products," says Dr Arthur Roach, Parkinson's UK director of research and development. "Xanthohumol, the molecule in beer this study focuses on, appears to have protective effects on cells grown in the lab similar to those lost in Parkinson's."

Unfortunately, Roach added: "It certainly does not suggest drinking a pint a day could stave off the condition. This is a very early step, and only further work will indicate whether this could lead to new drugs for Parkinson's and other neurodegenerative diseases." See more at: <http://www.parkinsons.org.uk/news/30-january-2015/can-beer-have-benefits-people-parkinsons#sthash.Ptj5NTMx.dpuf>

SCIENCE COLUMN



LIQUID LEVODOPA A recent clinical study, by pharmaceutical company Neuroderm, has highlighted the development of a new liquid form of the key Parkinson's drug, levodopa. This holds promise as a potential future treatment for advanced Parkinson's.

The study involved 16 people with advanced Parkinson's who were given a continuous infusion of the drug under their skin from a pump worn on a belt. The liquid levodopa was able to maintain stable, high levels of levodopa in the blood.

Levodopa is normally taken as a tablet, which is absorbed in the intestines. In advanced Parkinson's, changes in digestion can affect how quickly levodopa is absorbed, leading to on-off fluctuations. A continuous supply of levodopa can provide better control of symptoms and reduce 'off periods'.

There is already a gel form of levodopa available, called duodopa, which is pumped continuously into the intestine. But duodopa therapy requires surgery and is expensive, so access to this treatment is currently quite limited. The new liquid form could reduce 'off periods' and help people with Parkinson's stay in control.

See more at: <http://www.parkinsons.org.uk/news/8-january-2015/promising-results-new-liquid-form-levodopa#sthash.iBoebha3.dpuf>

NEW DRUG APPROVED The EU has approved a new Parkinson's drug, safinamide, which is the first completely new drug to be approved for treating Parkinson's in the last 10 years.

The drug was tested in a two-year study in people with mid to advanced Parkinson's who were already taking levodopa. This showed safinamide helped reduce 'off' periods, when medications stop working, and improved quality of life and mood. It may also help reduce levodopa-induced involuntary movements (dyskinesia).

Safinamide works like other MAO-B inhibitors already used to treat Parkinson's, which prevent the breakdown of dopamine in the brain by blocking an enzyme called monoamine oxidase type B. Safinamide does this in a slightly different way, which may make it more effective.

"We welcome this study, which led to the recent approval of safinamide by the European Medicines Agency," says Dr Arthur Roach, Parkinson's UK director of research. "The drug has been shown to have benefits for patients, but it

is important to note its effects are similar to other MAO-B inhibiting drugs. We now have one more tool for managing the symptoms of Parkinson's. As more clinical experience is obtained, safinamide may emerge as a favoured choice in some situations."

It is not known yet when safinamide will be available to people in the UK. See more at:
<http://www.parkinsons.org.uk/news/13-january-2015/new-parkinsons-drug-safinamide-wins-eu-approval#sthash.Wte3jD6e.dpuf>

BRING AND SHARE The Bring and Share lunch, held at Barnabas Court, Milton, is a small friendly group that meets on the first Tuesday of every month. A small contribution of food is welcomed but not obligatory. People with Parkinson's and their carers are welcome, as is anyone else interested in joining. For more information contact Gabby Farrow on 01223-356433.

DATES FOR YOUR DIARY

SESSIONS FOR CARERS Cambridgeshire County Council's Carers Support Team is staging Carers Health and Well-being sessions on Thursday, March 12, from 10 to 12 noon. The location is the Ark Blue Room at Cambourne Church, on Jeavons Lane, Great Cambourne CB23 6AF. Basic First Aid Awareness will be given by the British Red Cross. Places are limited so booking is required, by calling the Carers Support Team on 01480-377616. Tea and coffee will be available and a light lunch will run from 12 to 2pm.

ANNUAL GENERAL MEETING The AGM of the Branch will take place on Friday, March 27, at the David Rayner Building starting at 11am. This is part of the usual monthly meeting. The formalities of Chair and Treasurer Reports and election of the committee should not take very long. There will be an opportunity for an open discussion at the end of the meeting. Nominations for election to the committee and resolutions should be sent to Caroline Bent (carolinebent@me.com) as soon as possible. At present all the full members of the committee (Charles Nightingale, Caroline Bent, Margaret Steane, Henry Bland, Myra Moore and Julia Ewans) are willing to stand for re-election and the co-opted member David Boothroyd (your editor) is standing for election as a full member.

MEMORIAL LECTURE

The Gretsch Amphet Memorial Lecture about Parkinson's is due to take place in Cambridge next month, on Tuesday, April 14, in the Auditorium at Fitzwilliam College. The lecture will start at 7.30pm and end at 9.00pm.

The theme of the annual lecture will be Old Drugs, New Tricks, and will focus on how Parkinson's UK plans to fast-track new treatments. The new Director of Research for Parkinson's UK, Dr Arthur Roach, will outline the charity's vision for research with particular reference to drug repositioning.

He will be followed by Dr Dilan Athauda, Clinical Research Fellow at the National Hospital for Neurology and Neurosurgery, London. Dr Athauda will discuss Exenatide, a drug developed for diabetes that could have the potential to slow the progression of Parkinson's. It is currently under trial.

At the end of the lecture, people will be able to question the panel. See more at:
<http://www.parkinsons.org.uk/content/gretsch-amphet-memorial-lecture-2015#sthash.zKQsz3Ax.dpuf>.

Places are free but must be booked in advance. Please visit www.parkinsons.org.uk/amphetlecture to book your tickets. For more general information, contact the Parkinson's UK Events team on 020 7963 9309 or events@parkinsons.org.uk

The memorial lecture is now in its sixth year and is funded by John Amphet, in memory of his wife Gretsch, who lived with Parkinson's for seven years.

“Gretchen and I were married for 42 years and lived in Cambridge for over 20 years. We were active members of the local Parkinson’s branch where we received help and support. When Gretchen passed away I wanted to do something to commemorate her life, so I spoke to the chair of the branch, who suggested holding a Parkinson’s related lecture in her memory. I thought it was a fantastic idea and the annual event has been running ever since.”

The lecture aims to bring together people with Parkinson’s and their families, researchers and maybe even major donors to help fund research into the condition.

BARKER LAB OPEN DAY

The Parkinson’s Open Day at the Barker Laboratory, Addenbrooke’s Hospital, takes place next month, on Saturday, April 18. Now is a good time to register as the previous two open days in 2014 were very popular.

The morning session will focus on lab-based science and the afternoon will look at clinical work currently being planned or conducted. Speakers will discuss the progress being made in modelling Parkinson’s in cell cultures; the search for novel therapeutic pathways by disrupting genes; and alpha-synuclein aggregation in Parkinson’s. Other topics will be the ongoing Transeuro transplantation project, new drug trials being proposed, and a diagnostic breath testing study beginning in September. The event will end with a Q&A session with Prof Barker.

The Open Day starts at 10am at the Brain Repair Centre, behind Addenbrooke’s, on the Forvie Site, Robinson Way, Cambridge CB2 0PY. It will finish after lunch. Anyone interested should contact Simon Stott on 01223-331160 or email barkerlab.registration@yahoo.co.uk. For more information, see the Barker lab website:

<https://sites.google.com/site/thebarkerlab/>

BAR HILL TESCO Parkinson’s UK will be staging an awareness day on April 21, at the Tesco supermarket at Bar Hill, thanks to the store giving free use of its community room. The morning will be devoted to talking to shoppers visiting the store, to tell them about Parkinson’s in general.

Then in the afternoon, Parkinson’s will run three awareness sessions for the Tesco staff. The sessions will describe the condition, tell them how it feels to be a shopper with Parkinson’s, the potential problems they face, and what staff can do to help make their customers’ experience as good as it can be. Volunteers may be needed, and anyone interested should contact Julie Wilson, Information and Support Manager for Parkinson’s UK, tel 0844-225-3612.

NIGHTINGALE SINGERS Dates for the Nightingale Singers meetings have now been decided for 2015, being the first Saturday of the month, from 1400-1600. The dates are: March 7, April 4, May 2, June 6, no meetings in July or August, September 5, October 10, and November 7. All meetings are at the David Rayner Building, Scotsdales Garden Centre, Gt Shelford, CB22 5JT. If you are interested, contact Charles Nightingale on 01223 844763.

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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A charity registered in England and Wales (258197) and in Scotland (SC037554).

PARKINSON'S UK – CAMBRIDGE BRANCH CALENDAR – MARCH-APRIL 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: 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 07770 533948

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. See article above.
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

OF SPECIAL NOTE

MARCH

12: Carers Health and Well-being Awareness –
Cambourne (details 01480 377616)
19: 10:00–14:00 NRS Safe & Well Open Day
Huntingdon (details 01530 232372)

25: FASHION SHOW

6pm in the Brasserie at John Lewis
See article above

27: Branch meeting

10:30 – Tea & Coffee
10:45 -- **BRANCH AGM**
11:30 Mr Rob Morris, consultant
neurosurgeon. See article above.
12:15 Lunch
Aromatherapy throughout

APRIL

12: Tesco Bar Hill Parkinson's Awareness Day
am: for customers

14: GRETSCHEN AMPHLET MEMORIAL LECTURE

7:30 Fitzwilliam College, Cambridge. See article above. Reserve your place: 020 7963 9309

18: BARKER LAB OPEN DAY

10:00 Forvie Site, Robinson Way,
Cambridge. See article above.

24: Branch meeting

10:30 – Tea & Coffee
10:45 Denise Sibley-Moore: "Yoga for Parkinson's"
11:00 Dennis McKenzie, clairvoyant and
psychic
12:00 Lunch
Aromatherapy throughout

26: TULIP FUN-RUN

10:30 at the David Rayner Building
see article above

MAY

22: Branch meeting NB 22nd IS 4TH FRI!

Future speakers may include Dame Mary Archer.
Other suggestions always welcome.