

Cambridge Branch Newsletter – March-April 2016

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RECENT EVENTS

DANCING FOR PARKINSON'S

The Take a Step dance event by community dance group, Dance Ensemblé, took place on January 8 and 9, with three performances at the Junction venue in Cambridge. Organised by two of the dancers, Romina Vuono and Jeanette Simpson, co-founders of Dance Ensemblé, the show was a great success, attracting virtually sell out audiences, who gave the dancers a wonderful reception.



Dance Ensemblé, based in Cambridgeshire, uses dance to raise funds for health related charities (www.dance-ensemble.org.uk), and Take a Step was specifically for Parkinson's. A total of 10 dancers made up the Ensemblé at the Junction, and the event succeeded brilliantly, attracting more than 300 people and raising about £4000!

The performance consisted of a combination of group and solo dances, 17 in all, which were set to a wide range of music, from REM to Gary Barlow, Julian Lloyd Webber to Bob Marley.

Romina said: "There is a growing number of dance programmes offering dance classes for Parkinson's. Scientists are studying the effects of dance on Parkinson's and for many of the participants, the benefits are clear." The Take a Step shows are the product of over 12 months' work focused on increasing awareness of Parkinson's, and raising vital funds for Parkinson's. Dance Ensemblé's regular classes take place at the Frank Lee Leisure & Fitness centre, at Addenbrooke's Hospital. See the website (above) for more information.

Many people in the Take a Step audiences were Branch members, and Dance Ensemblé are very grateful for the support. "We would like to say a huge thank you to the Cambridge Parkinson's Branch for all the support they gave us; it has meant a lot to us," said Romina. Watch this space for more dance events in the future!

CURRY NIGHT

The Parkinson's Curry Night, held on Monday, February 8, was a success, attracting more than 20 people to the Zara Restaurant in Great Shelford (www.zara-cuisine.com). The restaurant put on an excellent spread, which at just £20 for three courses was also great value. A licensed bar was available, and the event raised useful funds.

VOLUNTEER FOR CAMBRIDGE EVENT



In the hope of enlisting new volunteers for the Branch, the Committee had a stall at the Volunteer for Cambridge "fair", held at the Guildhall on Saturday, January 30. Ten Branch members took a turn at managing the stall for five hours, during which time we had a constant stream of visits from those seriously in search of their ideal voluntary job, and from members of other charities wishing to share how their work might help our members. We were lucky enough to have members present who are living with PD to share first-hand experience. The following voluntary sector groups visited our stall, one or more of which may be a help to you:

- **AgeUK** – 0300 666 9860 – their Visiting Scheme might offer you a simple but valuable way to help others; or you might like to have a visit from one of their volunteers yourself.
- **The Alzheimer's Society** – 0300 222 1122 – runs activities to support those with dementia: peer support; a Dementia Café; a singing group. But above all, it aims to help and advise when dementia is diagnosed.
- **Dementia Compass** – 01223-911622 - is run by Eyde Hoffmann who would like to link services with us.

- **The Cambridge Alliance for Independent Living** – 0300 111 32301 – does what it says “on the tin”! It offers training, support for both the disabled and their carers, information and advice. Ask for Graham Lewis.
- **Dial-a-Ride** – 01223 506335 – call them and ask for one of their leaflets. If you live outside Cambridge city you may be able to use some of their services to save money on transport.
- **Healthwatch** – 01480 420628 – encourages you to share your story; attend consultations where you can have your say; volunteer, or just share your ideas with them.
- **Shopmobility** (Cambridge City Council) – Grafton 01223 461858; Grand Arcade 01223 457452 – offers scooters and wheelchairs to save you bringing yours.

SCIENCE

ANTI CHOLESTROL DRUG TRIALLED

A clinical trial using the cholesterol-lowering medication Simvastatin for people with Parkinson’s (PWP) is getting underway in centres across the country to see if it could be an effective treatment. Spearheaded by Plymouth University Peninsula Schools of Medicine and Dentistry, the double-blinded, placebo controlled study will involve 198 PWP. The trial is seeking PWP who are not already taking a statin. It will take place in 21 centres in the UK, including the Cambridge University Hospitals NHS Foundation Trust.

This trial is part of the Cure Parkinson’s Trust’s (CPT) Linked Clinical Trials programme (LCT) which is now in its fourth year. Each year the LCT international committee, comprising Parkinson’s experts from around the world, analyses a number of pre-selected compounds with the potential to slow, stop or reverse the condition. These compounds already have proven safety records and some are already used to treat other conditions. The LCT programme has seen diabetes treatments, and treatments for mitochondrial dysfunction, amongst others, move forward into Parkinson’s trials in Europe and the US. Commenting on the study, the trial’s chief investigator, Dr Camille Carroll, said it was encouraging to see compounds already approved as safe being trialled.

“There have been few innovations in the treatment of Parkinson’s for over 40 years and the results of this trial could lead to new and highly effective treatments in the armoury of medications to tackle Parkinson’s,” she said.

DEMENTIA MEDICATION HELPS WITH FALLS

A commonly prescribed dementia drug could help to prevent falls for people with PWP. Recent research has shown that PWP who took the drug rivastigmine were 45% less likely to fall and were steadier when walking, compared to controls. The results were published in the journal, Lancet Neurology.

Some 70% of PWP will fall at least once a year, with more than a third experiencing falls repeatedly, resulting in fractures, other injuries, and hospital admissions. Parkinson's UK Research Fellow, Dr Emily Henderson, from Bristol University studied 130 PWP who had fallen in the past year. Half the group was given rivastigmine capsules and the other half a placebo, for eight months.

Dr Henderson explains: “With the degeneration of dopamine producing nerve cells, PWP often have issues with unsteadiness when walking. As part of the condition, they also have lower levels of the chemical acetylcholine, which helps us to concentrate. This makes it extremely difficult to balance and walk at the same time. We already know that rivastigmine works to treat dementia by preventing the breakdown of acetylcholine, however our study shows for the first time that it can also improve walking, regularity of step, speed, and balance. This is a real breakthrough in reducing the risk of falls for PWP.”

Dr Arthur Roach, Director of Research at Parkinson's UK, said: “Preventing falls and improving balance is the biggest unmet need for people living with the condition, outside of finding a cure. These results take us a step closer to improving the quality of life and finding better treatments for PWP. But we need more information before we recommend that PWP are prescribed rivastigmine for falls.” See more at: <http://www.parkinsons.org.uk/news/12-january-2016/common-dementia-drug-could-improve-parkinsons-symptoms#sthash.bfKo5t3z.dpuf>

BRANCH MEETINGS

STEM CELLS IN RESEARCH

Lucy Collins gave a fascinating talk at the January Branch Meeting principally about the current use of stem cells in research. Lucy is completing her PhD at the Brain Repair Centre (BRC), in Cambridge. One key use of stem cells is to help model Parkinson's using induced neurons or neurons that are made in the laboratory. This process starts by taking skin cells from a patient, which are then taken one of two routes, in order to change them from a skin cell into a neuron. The first reprogrammes the skin cells, changing them into 'induced pluripotent stem' (iPS) cells. These are 'embryonic like' cells and pluripotent means they can be turned into any cell type in the body, including neurons. The second route involves direct reprogramming of the skin cell into a neuron.

"We are currently working with experts in Sweden on this direct reprogramming technique," Lucy said. "We believe it retains the age of the cell, and age is an important risk factor for Parkinson's. We hope to create better, patient-specific models of PD using these induced neuronal cells, which can then be used to screen better targeted drugs."

A current trial, Transeuro, is treating patients with a cell replacement strategy. A further cell replacement trial will be Stem PD, where the efficacy of neurons that have come from embryonic stem cells will be tested. A new research project is looking into hallucinations in Parkinson's, and the BRC is interested in finding participants both with and without hallucinations. Another area of research centres on the use of statins in Parkinson's, after a recent study showed that cholesterol may actually be protective in Parkinson's, which contradicts previous research.

AMERICAN CEMETERY

February's meeting featured an interesting talk by Arthur Brooks on the Cambridge American Cemetery on Maddingley Road, the only US WW2 cemetery in the UK. Arthur worked at the Cemetery for 14 years, before retiring last year. It is the final resting place of 3812 men and women who gave their lives in major WW2 campaigns, such as the Battle of the Atlantic. The lives of another 5127 men and women whose bodies were never recovered are commemorated on a wall of the missing.

Arthur cited some remarkable facts: each of the 3812 headstones is cleaned three days a week, and from April to October, the site is watered every night by a computer controlled irrigation system. The memorial building and chapel has a mosaic ceiling containing more than 900,000 tiles, depicting angels and ghostly aircraft. Massive teak doors are embellished with relief models of WW2 military equipment. The Cemetery is open 363 days a year. For more, see <https://www.abmc.gov/cemeteries-memorials/europe/cambridge-american-cemetery>.

NEW TREASURER

Your Branch is delighted to tell you that we are in the process of appointing a new treasurer, Jenny Wood. Jenny has wide experience as a manager and researcher, having worked for 15 years for the Office for National Statistics, and 20 years in various academic and research sectors in the UK and elsewhere. In 2011 she completed the NCVO (National Council for Voluntary Organisations) course on Working for a Charity. "I would like to get a better understanding of financial roles in the charity/voluntary sector and of accountancy work, and feel this opportunity will provide it," she says. Jenny has a personal link with Parkinson's, as her Mother was diagnosed last summer.

PRESENTATIONS

Finding interesting presentations for the David Rayner Building meetings of the Cambridge Branch is always a challenge. Can you let Caroline (carolinebent@me.com) know if you have a topic you would like to see covered, or if you know of a person whose reputation as a speaker you trust?

PARKINSON'S NURSE'S TIP

Jacqueline Young is a Parkinson's Specialist Nurse, based at Addenbrooke's Hospital, and in what we hope will be a regular item in the newsletter, she gives the following valuable tip.

If you start to experience a new problem, keep a diary of events. Ask yourself the following questions, to establish if there is a significant pattern:

- Does the problem occur at a certain time of the day?
- Does it occur when your medication kicks in or is wearing off?
- What were you doing when the problem arose?
- Does anything relieve the problem?

- Have you started on any new medication recently or done a new activity?

Keeping a record of anything unusual may be helpful for your health professional, so write notes about anything you think is important and take them with you to your next appointment. If your symptoms deteriorate, make an earlier appointment with either your GP/PD Nurse or Consultant, as early intervention may be necessary to resolve the problem. And remember, your Parkinson's does NOT suddenly change, there will be a reason for the change.

DATES FOR YOUR DIARY

JOHN LEWIS FASHION SHOW

The Parkinson's Fashion Show, supported by John Lewis, is due very soon now - Wednesday, March 9, in the Brasserie at the John Lewis department store in Cambridge. Doors open at 6pm, and the show starts around 6.30pm, lasting about half an hour. It's late opening night at the store, so you will have another hour to visit the rest of the store until 8pm. Anyone wanting to come must have bought a ticket in advance, costing £12 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; and the Personal Styling Department of John Lewis. The John Lewis store is at 10 Downing Street, Cambridge (tel 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.

GRETSCHEN AMPHLET LECTURE

The 2016 Gretschen Amphlet memorial lecture, given annually, will take place on Tuesday, April 12, in the auditorium at Fitzwilliam College, Cambridge. The speaker will be Professor Roger Barker, the head of the Barker Lab, which is sited at the Brain Repair Centre, next to Addenbrooke's Hospital in Cambridge. The lecture, now in its seventh year, is funded by John Amphlet, in memory of his late wife Gretschen, who had Parkinson's. The lecture will start at 7.30pm. To reserve a free place call 020 7963 9309 or email: rsvp@parkinsons.org.uk.

The title is: Can stem cells deliver on their promise for Parkinson's? Since the 1990s, stem cells have been seen to have huge potential for developing better therapies to slow and even reverse the progress of Parkinson's, but that potential has so far remained tantalisingly out of reach. Professor Barker, a world-leading expert in Parkinson's, is involved in clinical trials of cell and gene therapies, giving him a unique perspective into some of the most promising treatments now being developed and tested for the condition.

In his talk he will explain why cell therapies hold so much potential for Parkinson's, the work that is being undertaken internationally, and the key challenges to be tackled to make cell therapies a reality. He will talk specifically about his work leading a team of researchers from across Europe in the TRANSEURO trial, which aims to show that transplanting healthy cells into the brain can be a safe and effective treatment for Parkinson's, and how this is leading to the next generation of stem cell based trials in Parkinson's. May 2015 marked an important milestone in the research, when the first person with Parkinson's in the UK received a cell transplant.

NOMINATIONS TO BE INVITED AT AGM

The Branch's Annual General Meeting (AGM) will be held on Friday, March 18, at the David Rayner Building, starting at about 10.30am, before the normal Branch Meeting gets underway. The Committee would like to increase the number of Officers serving on the committee, and nominations are invited from members to fulfil various roles. These include a Vice Chairman, Secretary, Outings Organiser, Presentation Programme Coordinator (responsible for booking speakers at our monthly Branch Meetings), a Collections Officer, and a Publicity Officer. Plus possibly a few other, more generic officers to help with issues and events as they arise. If you are interested in helping the Branch by serving on the Committee, and would like more details of exactly what is involved in each role and how much time it requires, contact Caroline on 01223 314279, mobile 07922-479289 or email: carolinebent@me.com.

TULIP FUN RUN

To mark the conclusion of Parkinson's Awareness Week, our Tulip Fun Run happens on Sunday, April 24. The four-mile route, which can be run or walked, sets off at 10:30 from the David Rayner Building at Scotsdales Garden Centre in Shelford. Proceeds will go to the Cambridge Branch of Parkinson's UK so we invite you to take part and encourage

friends and family to sponsor you. For entry and sponsorship forms, visit www.parkinsonscambridge.org.uk or contact Charlie Nightingale at 12 Aylesford Way, Stapleford, Cambridge CB22 5DP, or 01223-844763. Entry fee is £8 per adult and £4 for 16 years and under. Everyone is welcome and if you don't want to "run", stewards will be needed along the course, as well as others to help with the start and finish, distributing posters, or making the tea!

TESCO COLLECTIONS

To all our volunteer collectors (and potential new ones), Tesco has invited us to collect at three local stores in the coming months, the dates being as follows:

Thursday, April 7 at Newmarket Road, Cambridge

Wednesday, April 27 at Fulbourn Cherry Hinton

Thursday, May 19 at Milton

We would like to see these three collections make a substantial financial contribution to our 2016 budget, so would you please look ahead in your diary and let us know on which dates/times you could collect. The aim is to cover 9-5 each day. If you know of anyone else who might be added to the list of collectors, please contact Caroline on 01223 314279, mobile 07922-479289, or email: carolinebent@me.com

HOUSE OF COMMONS TRIP

Fancy a tour of the House of Commons? Then book your place on a visit, on Wednesday, June 29. The coach will set off from Trumpington Park & Ride at 9am, and leave for home at about 3.30pm, tickets £15 each. Contact Caroline on 01223 314279, mobile 07922-479289, email: carolinebent@me.com. See next newsletter for more details!

SELF MANAGEMENT PROGRAMME

A Parkinson's self-management programme, A Path through Parkinson's, is coming to Cambridge and Bury St Edmunds in May and June, with specific dates to be announced in March. It is a free self-management programme designed to help people navigate their lives with Parkinson's. Each self-management group is led by trained volunteer facilitators with first-hand experience of Parkinson's. The aim is to share experiences and discuss the practical and emotional impact of the condition. For more details and to register your interest in taking part, go to <http://www.parkinsons.org.uk/content/self-management-programme-path-through-parkinsons>.

IN MEMORIAM

Future editions of our bi-monthly Newsletter will acknowledge the death of members; please let the editor (dboothroyd@btinternet.com) know if you hear of the passing of a local member.

Brian Kember, long-time member of the Cambridge Branch, and wife of past committee member, Helen, died on January 28, 2016.

Note: all Parkinson's related phone numbers that started with 0844 now begin with 0344, making them cheaper.

Parkinson's Local Adviser - Rhonda Waters - 0344 225 3618

Help Line 0808 800 0303 (free phone call). Specialist advisers 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.
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 – MARCH-APRIL 2016

REGULAR MEETINGS AND ACTIVITIES

Aquatherapy

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

NB: NO MEETINGS UNTIL FURTHER NOTICE

Branch Meeting

Fourth Friday of every month except December,
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
Quarterly, second Friday of the month
10:30-12:30 – see "Of Special Note"
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
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
NO MEETING 28 MARCH

OF SPECIAL NOTE

MARCH

- 9: **FASHION SHOW** at John Lewis
see article above.
11: Carers' Meeting
18: Branch meeting
NB: THE THIRD FRIDAY
10:30: Refreshments
11:00: Annual General Meeting
see article above
12:00 Lunch
Aromatherapy throughout
28: **NO YOGA** Easter Monday

APRIL

- 12: The Gretschen Amphlet Memorial Lecture
see article above
18 – 24: PARKINSON'S AWARENESS WEEK
22: Branch meeting
10:30 Refreshments
11:00 Speaker, Ripu Abrol
"Physiotherapy in PD"
12:00 Lunch
Aromatherapy throughout
24: The **TULIP FUN RUN**. *See article above*

MAY

- 27: Branch meeting
10:30 Refreshments
11:00 Speaker, David Palmer,
Auctioneer
12:00 Lunch
Aromatherapy throughout

JUNE

- 10: Carers' Meeting
24: Branch meeting
10:30 Refreshments
11:00 Speaker Samantha Cochrane,
of Scotsdales Garden Centre
12:00 Lunch
Aromatherapy throughout
29: Outing to the House of Commons.
9.00 from Trumpington Park & Ride
See article above.