

Cambridge Branch Newsletter – January/February 2015

Editor
David Boothroyd 01353 664618
d.boothroyd@btinternet.com

FUND RAISING

TREASURER'S COLUMN Once again there are many people and organisations to acknowledge and thank for much hard work resulting in generous donations. Firstly, two events from the summer where the branch has recently been given a share of the funds raised: the Shelford Feast - £500; and the Covent Garden Street Party - £525. Pam Arnott and the residents of Haig Court raised an incredible £220 at a coffee morning. Special thanks to Jenny Brew for making the beautiful nativity scene which was the star prize and all the other donors of prizes at the raffle held after the Christmas Lunch which raised £129. This all just goes to show that when fund raising is fun it is also profitable.

Many thanks go to my fellow sandwich and soup providers and to all the members who generously put 'something in the pot' for lunch at the David Rayner Building. In 2014 we raised £520. Sadly, we must also thank the families and friends of the late Leslie Alfred Day and Ulla Anne Cronin for donations made in their memory. Also, thanks to the Fulbourn Ladies Group for their generous gift of £300 raised at a coffee morning in October.

As a result of everyone's hard work and the financial rules under which branches operate as part of the parent charity, we have an excess of income over expenditure and will be sending funds to national office in 2015. I am working on the end of year report for Parkinson's UK national office and will report on the figures at the AGM in March.

THE JOHN LEWIS FASHION SHOW



A fund-raising fashion show will take place in the Brasserie of the John Lewis department store in Cambridge at **6pm on Wednesday, 25 March 2015**. Since it is a late-opening night, audience members will have the option of staying on until 8pm to shop following the Show.

Some of the models will be Parkinson's Cambridge members and friends, others will be John Lewis Partners. The clothing and accessories displayed this year will focus on smart practicality, adaptability, and comfort!

Your £10 ticket 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.

COME ALONG, it should be a fun night!

Tickets will be 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 fashion department; or Scotsdales Garden Centre at Great Shelford.

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.

TRANSPORT PROJECT Enclosed with this issue of the printed newsletter (and as an attachment to the email version) is a flyer about a new pilot project on transport for Parkinson's members. Your Cambridge Branch is taking part in a Parkinson's UK Pilot Scheme that aims to make transport available to members and carers, for the purpose of attending Branch activities. We are trying to find out how many people would find such a service useful, so there is a form to complete, with just a few details required.

BRANCH MONTHLY MEETINGS

A short but interesting talk was given at the November meeting by **Andrew Curran**, who has recently come from Ireland to live in Cambridge. Andrew was diagnosed with Parkinson's at the age of just 29, and is now 36. He said the first few years after his diagnosis were a difficult time but that since then, he has worked out a strategy to help him deal with the situation, based on three key factors.

The first is exercise – Andrew is a keen cyclist and tries to travel this way as much as possible. Cambridge is therefore an ideal location for him! The second is diet – not in the sense of any foods with supposedly anti-Parkinson's effects, but just ensuring he eats as healthily as possible. And the third is mindfulness, a meditation technique that is frequently linked with beneficial effects on people's state of mind.

Andrew feels strongly that this combination has been a major help in dealing with his Parkinson's, and spoke at the meeting to encourage others struggling with the condition to know about his optimistic message.

He is an Ambassador for the World Parkinson Congress, which has been organising major Parkinson's conferences every few years since 2006. These have attracted thousands of participants from more than 60 countries worldwide. Visitors include neuroscientists and Parkinson's specialists, nurses, people with Parkinson's, care partners, pharmaceutical industry leaders and government representatives. Steve Ford, Chief Executive of Parkinson's UK, is a member of the WPC leadership team.

The next WPC takes place in the USA from September 20-23, 2016, at Portland, Oregon. For more information, see www.wpc2016.org, or call 001-923-4700.

Everybody with Parkinson's is told how important exercise is, especially for helping with mobility and mental well being. Here, **Cath Butler**, who was diagnosed in 2013, describes how much she enjoys Nordic walking – that is, walking with a pair of poles that involves applying force to the poles with each stride. The result is, Nordic walking has been estimated to exercise more of the whole body and increase energy consumption by over 40% compared with normal walking.



“I first became interested in Nordic walking when I was trying to lose weight and I learnt you could burn 400-600 calories an hour. That seemed preferable to the treadmill in the gym! Being outside on a lovely sunny day watching the buzzards circle over the Gogs - what could be more pleasant? Of course a coffee at the Gogs farm cafe afterwards didn't really help with the calories but hey a cappuccino is only 200, right?!”

“So I joined a group learning how to Nordic walk - really not hard. Then I got my Parkinson's diagnosis and as it progressed had to give up the walks as I felt I was holding the others up. However, I then discovered Oliver Gynn's restricted mobility group at Wandlebury, which meets in the car park at 1pm on Wednesdays. Apart from the car park fee of £3 there is a £5 instruction fee but the loan of poles if you don't have any is free.

“Oliver has lots of experience of people with Parkinson's and also welcomes those who have had strokes, hip replacements or whatever may affect mobility. I was concerned how far I could walk but Oliver goes at a gentle pace with stops whenever needed and the hour passed very quickly chatting to others, trying to make out Ely cathedral in the distance and saying hi to the dog walkers.

“Those of us with Parkinson's and other mobility problems know we are meant to keep as active as we can. I enjoy Nordic walking - it gives me the 'feel good' factor, and I feel more secure walking with two poles than if I were walking unaided. Being with others and knowing I'm not holding them back is a big factor for me and it's great to be out among the trees of Wandlebury even if that stiff east wind does catch you out round the odd corner! Roll on the summer!”

If you would like to have a go, join Oliver and his band of Nordic walkers! See his website or phone him for the date. info@nordicwellbeing.co.uk 07947 835522

Last year the November 29 issue of the Cambridge Evening News featured someone well known to many amongst us: **Diana Brodie, poet, Cambridge resident** – and former editor of this very newsletter!

Diana has recently had her first volume of poems published by Poetry Salzburg, entitled Giotto's Circle. The title refers to an incident in the 14th century, when the then Pope, looking to commission a major work of art, asked for a sample of work from the artist Giotto. Instead of something elaborate and complex, he drew a perfect circle, without a compass. He got the job. "Simplicity can be very beautiful," Diana says.

She has been writing poetry for many years, and her first work was published in an anthology in 2004, at virtually the same she was diagnosed with Parkinson's. Now she says she makes a lot of typing mistakes, loses papers, and sends unintentional emails!

"But it's the arrival, not the journey, that matters most, and I can focus well," she says.

In 2014, Diana was runner-up in the Mervyn Peake awards, 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. Her poem is published in the Parkinson's calendar for 2015. Her poetry has led to connection with people round the world: from a retired university lecturer in Sydney, to the Poet Laureate of Louisiana. But she very rarely addresses the subject of Parkinson's in her poetry.

"Illness is self-important enough already and keeps butting in to my life," she says. "I don't want to flatter it with my attention."

SCIENCE COLUMN



Results published in the journal 'Cell Stem Cell' from researchers at Lund University in Sweden have taken a key step forward in using **stem cells to replace the nerve cells lost in Parkinson's**. Stem cells are 'unspecialised' cells which can develop into almost any cell in the body. They are found in early embryos, fetuses, umbilical cords and also in some adult tissues.

The research team converted human embryonic stem cells into the dopamine producing nerve cells that are lost in Parkinson's. They injected these new cells into the brains of a rat model of Parkinson's in which the dopamine producing nerve cells had been damaged on one side. Results showed that the nerve cells produced from human embryonic stem cells successfully repaired this damage. The new nerve cells were able to produce dopamine and form connections within the brain.

Arthur Roach, Director of Research for Parkinson's UK, says the research is a key step forward in understanding how stem cells might shape future Parkinson's treatments.

"There are important potential advantages of these cells over cells taken from fetuses, which were used in past cell transplantation work. This study could be a stride towards clinical trials in people with Parkinson's but there are still many questions that need to be answered before this development can be tested on people with the condition."

See more at: <http://www.parkinsons.org.uk/news/7-november-2014/parkinsons-stem-cell-breakthrough-brings-new-hope#sthash.X4StDGcE.dpuf>

Also in the same article is a report on research showing that **mitochondria, the energy producing batteries of cells, could play a key role in Parkinson's**. Results published in 'Nature Communications' by Dr Kim Tieu from Plymouth University have shown that blocking a particular protein associated with mitochondria could be a promising avenue for developing new treatments for Parkinson's. This study is a promising step towards slowing down or stopping the progression of Parkinson's, according to Claire Bale, Parkinson's UK research communications manager.

"We've known for decades that problems with mitochondria play a key role in the death of nerve cells in Parkinson's, but the research in this area hasn't yet led to new treatments. This study, which reveals a potential new drug target to protect mitochondria, is a promising step towards slowing down or stopping the progression of Parkinson's."

A new funding project for research into Parkinson's was started in November called Parkure. Neuroscientists from Edinburgh University are inviting people to help find a cure for Parkinson's by buying 'shares' through crowd-funding. Research associate Dr Lysimachos Zografos says the team hope to raise £100,000 to kick start the search. Ultimately, the aim is to test up to 10,000 drug compounds every year.

"We've already developed a fast and efficient way of testing compounds by using genetically modified fruit flies. With funding in place, we can begin examining existing drugs, developed for other conditions, to see if they could be useful in the treatment of Parkinson's, a process known as repurposing."

With this type of drug development, safety tests are already established and drugs can move quickly from lab to patient. The scientists hope the data collected will attract companies that can pay for large-scale clinical trials. The group has already received grant support from the university, plus legal and accounting assistance.

Steve Ford, CEO of Parkinson's UK, says: "We're supportive of any efforts to increase the amount of research for a cure. Parkure's approach – to crowdfund support for drug testing in fruit flies – is novel, and just one of the many avenues that will bring us closer to a cure."

Edinburgh is a natural home for medical innovation. Malcolm Bateman, of the Edinburgh Science Triangle, a partnership which includes four universities and six research institutes, says the city's track record includes "insulin (1922), penicillin (1928), the hepatitis B vaccine (1978) and the MRI scanner (1980), so we are hugely hopeful that Parkure might follow in this legacy."

Anyone who takes up a share in the crowdfunding could benefit financially if the venture is commercially successful. The test could also be used to look for drugs for other conditions like Alzheimer's. For more details, see www.parkure.co.uk

DATES FOR YOUR DIARY

2015 TULIP FUN RUN

This year's Tulip Fun Run is set for **Sunday, 26 April 2015**, which is the culmination of Parkinson's Awareness Week 2015 (20-26 April). As before, the aim is to raise public awareness, build better understanding of the condition and raise funds to support the services provided by the Branch.

Our Cambridge Tulip Fun Run will start **at 10.30am**, using the same course as 2014, beginning and ending at the David Rayner Building at Scotsdales Garden Centre, and taking in part of the Addenbrooke's site. It follows the success of the 2014 event, which raised well over £2000. Everyone is welcome and if you don't want to run – or walk! – help will be needed in various capacities at the David Rayner Building and stewards are required to guide participants on the route.

Entry forms may be downloaded from the Branch website: www.parkinsonscambridge.org.uk, or requested from Charlie Nightingale: 01223 844763; 12 Aylesford Way, Stapleford, CB22 5DP; cllnightingale@btconnect.com.

And if you cannot be there, you could sponsor someone who can!

GRETSCHEN AMPHLET MEMORIAL LECTURE

This annual lecture relating to Parkinson's is set for 7.30pm on April 14, at Fitzwilliam College, Cambridge. The two speakers will be Dr Arthur Roach, Director of Research for Parkinson's UK, and Dr Dilan Athauda, Clinical Research Fellow for the National Hospital for Neurology and Neurosurgery, London, whose lecture will be about drug repositioning. For tickets, contact Katy Payne of Parkinson's UK on 020-7963-9309.

ANNUAL GENERAL MEETING

The AGM of the Branch will take place on Friday 27th March 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 is standing for election as a full member.

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 – CAMBRIDGE BRANCH CALENDAR – JANUARY 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
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

OF SPECIAL NOTE

JANUARY

- 23: Branch meeting NB 23rd IS 4TH FRI!**
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 art and her
experience of living with PD.
12:00 Lunch
Aromatherapy throughout

MARCH

- 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 -- Deep Brain
Stimulation surgeon.
12:15 Lunch
Aromatherapy throughout

APRIL

- 14: 7:30 Gretschen Amphlet Memorial Lecture,**
Fitzwilliam College, Cambridge (*see above*)

- 24: Branch meeting**
10:30 – Tea & Coffee
Speaker to be confirmed.
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!**