

Cambridge Branch Newsletter – July-August 2016

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

SPECIAL NOTICE – MEMBERSHIP LIST

Following a recent up-date of our membership list, the Cambridge Branch Membership Secretary would be grateful to know the following:

- (a) Do you have any objection to remaining on our mailing list?
- (b) If you currently receive the Newsletter by post, could you instead do so by email (saving valuable funds)?
- (c) Are there are errors in your name or address?

To ensure accuracy, please contact the Membership Secretary at hbland4n6@sky.com and 17 Caxton Lane, Foxton, CB22 6SR; or the Secretary on 01223 314279 and carolinebent@me.com.

BRANCH MEETINGS

HEIDI ALLEN MP

Our MP for South Cambridgeshire, Heidi Allen, gave a brief talk at the May 27 Branch Meeting. This was her second visit, the previous one being just before the election. She spoke of her own particular area of interest, namely work pensions and benefits. She said she had met the new Secretary of State, Stephen Crabb, a few times, and was enthusiastic about working with him.

She moved on to discuss her ambition to get more affordable housing built in the area. She said property prices in the region were now so high that even the wealthy were struggling to buy a home. She welcomed the building of new 'starter' homes for first-time buyers at Northstowe, the new town off the A14.

Heidi made waves at Westminster last year by using her maiden speech to attack George Osborne's proposed tax credit cuts. She voted against her own party, and the cuts were subsequently dropped.

"Voting against your party is a bit of a lonely experience – a very quiet and eerie feeling and quite uncomfortable," she said. "Maiden speeches are supposed to be non-controversial but I'm not a fan of saying things that don't mean much," she said. "I used mine to tell the Chancellor he was wrong. I'm so glad I did it because he did a U-turn. When you have a weak opposition, sometimes you just have to speak out. I became an MP to be the voice for people who don't have one, and I would do it again."

Heidi added that traditionally, after their maiden speech, all Tory MPs get a letter from the Prime Minister – she is still waiting for hers!

AUCTIONEER'S TALES

At the same Branch meeting, we had another speaker, the well known auctioneer David Palmer. He has been working as an auctioneer for decades and has appeared frequently on TV, in programmes such as Bargain Hunt. He lives locally, in Ely.



David told the audience a series of amusing anecdotes about his work, including potentially embarrassing coincidences, such as the time when he auctioned Lot 49, a slipper bed pan, to be followed by Lot 50: a pair of brown stools!

Then there was the occasion in the Maltings in Ely, when he started to auction a state of the art TV. Naturally enough, he turned the TV on to demonstrate its high quality – only for the picture to immediately go blank, and smoke started coming out of the top. Even with his auctioneering skills, the TV didn't sell!

Other stories included the sale of a vase to an international audience in North London, which he said was decorated with angels – they turned out to be arabs – and a Bargain Hunt episode in Stamford where the item up for auction was also a vase that David said was “hideous”. To make it seem like a more attractive purchase, he made up a completely fictitious story about it, only for the whole thing to be broadcast on national TV!

RECENT EVENTS



DANCE GROUP RAISES OVER £4000, STARTS ‘TASTER’ SESSIONS

On May 21, Romina Vuono and Jeanette Simpson, of the Ensemblé Dance group, presented a cheque for £4,154 to the Chair of Parkinson’s UK Board of Trustees, Mark Goodridge. This donation was made following their successful performances at the Junction in January this year.

Romina and Jeanette (front, left and right respectively) are now piloting Dance Classes for Parkinson’s. Ten people took part in the first of two ‘TASTER’ DANCE CLASSES FOR PARKINSON’S sessions held on Saturday, June 4, at Addenbrooke’s Frank Lee Centre. Both Romina and Jeanette have been trained by the English National Ballet to deliver dance classes for people with Parkinson's.

The ‘dance’ was adapted to suit people’s varied degrees of physical capability. Branch Secretary Caroline Bent, who attended the session, felt that remembering the sequence of movements was more challenging than the movements themselves, which were tackled bravely and successfully by even the most physically challenged ‘dancers’. Everyone enjoyed themselves! Watch the web page (www.parkinsonscambridge.org.uk) and the next Newsletter for future plans for this programme.

SELF MANAGEMENT

The first of the local Parkinson’s Self Management Programmes started at the end of May, one in Cambridge, one in Bury St Edmunds. The Cambridge one is being facilitated by Martin Forbes and Elaine McCaghrey and has 10 local members who meet for half a day per week for six weeks. They are all people at various stages of Parkinson’s or their partners/carers.

Self Management in this context means working out and doing what you personally can in order to take control, live positively and achieve a quality of life that is meaningful for you. The main themes are: Connecting With Others; Looking Ahead; Relationships; What’s Important; Taking Care of Yourself; and Planning Actions for You.

The programme is free and is supported and funded by Parkinson’s UK, who trained the volunteer facilitators. It is anticipated that the programme will be run again sometime in the autumn. To find out more about self management and how to register interest in attending the next programme, see the Parkinson’s UK website and/or email: selfcare@parkinsons.org.uk.

TESCO COLLECTION

Congratulations to all the volunteers who collected for us at Tesco’s Milton store in May. Between them, they worked for seven hours and – as well as charming the customers – collected an extremely impressive £496. A valiant effort, well done!

TEXTILE SCHOOL RAISES £1000

A Cambridge textile and fashion school called MAKE recently held a knitting and sewing day that raised £1000 for research into Parkinson's. Around 70 people took part in the Community MAKE Day, held at the Ross Street Community Centre in Cambridge.

It was organised by Kath Goodwin, a fashion designer, who set up MAKE last year, a school that caters for all ages, from children to adults. The youngest participant at the MAKE Day was just five! Kath was inspired to organise the event after a friend was diagnosed with early onset Parkinson's, aged 45.

On the day, participants brought their own sewing machines and knitting equipment to make items ranging from pillows and graffiti bags to pin cushions and book covers. These were then sold to the public at a shop set up for the event.

EYE TESTS AT HOME

Do you feel you need or want an eye test but have difficulty travelling to a high street optician? East England Eye Care (eastenglandeyecare@gmail.com) could be the answer. They are a community of NHS home-visiting opticians whose work is tailored for people with any physical or mental disability, including Parkinson's, and they offer a free home eye examination for people with Parkinson's. See the website <http://www.eastenglandeyecare.co.uk/> or contact them by email, or on 01206-975032.

APOLOGY

In the last issue, in the report on the AGM, we misnamed one of our new committee members. For reasons unknown – another term for incompetence – Andrew Stevens was turned into Steven Andrews! Humble apologies to Andrew, whose name will be rigorously checked in future.

JOHN LEWIS CHEQUE

As their annual donation to the Cambridge Branch, Jean Delbridge (second from left) of John Lewis, together with her team of colleagues, presented to Chair Charlie Nightingale a cheque for £834. The money was raised through workplace raffles, and the company has been working with Parkinson's Cambridge for more than eight years.



In addition to raffles two or three times a year, Jean and her colleagues have regularly greeted members arriving at monthly meetings with a fine array of refreshments. They have devised a quiz for the Christmas party, supported the Fashion Show in March, and generally constitute a truly committed support system. Our warm thanks to them all.

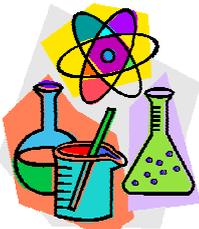
GRETSCHEN LECTURE VIDEO

The Gretsch Amphet Memorial Lecture, given by Professor Roger Barker at Fitzwilliam College on April 12, 2016, is now available on YouTube at the following link: <https://youtu.be/PQMWs6UMUL8>. The subject of the lecture was Stem Cell-based Therapies for Parkinson's.

SCIENCE AND RESEARCH

DRUG APPROVED FOR HALLUCINATIONS

The first drug for treating hallucinations and delusions associated with Parkinson's has been approved by the US Food and Drug Administration (FDA). It is called pimavanserin, trade name Nuplazid, and has been designed to work without worsening patients' motor symptoms.



People with Parkinson's may see, hear, smell or taste things that aren't there, or have thoughts and beliefs that aren't accurate. These experiences are more common in people who have had Parkinson's for a long time, though they can affect both younger and older people. Such symptoms may be caused partly by Parkinson's and partly by some Parkinson's medications.

Dr Beckie Port, Parkinson's UK Senior Research Communications Officer, says: "Hallucinations and delusions are difficult to treat in Parkinson's. There are a limited number of medications available, which are often prescribed with caution and require people to be continuously monitored for side effects. FDA approval is a huge step forward but further regulatory approval is needed before pimavanserin will be available in the UK. We don't

know exactly how long it may take, but hopefully there will soon be one more tool for treating the symptoms of Parkinson's on our pharmacy shelves."

Before pimavanserin can be made available in the UK, it must be approved by the European Medicines Agency (EMA), and there are plans to submit it for EMA approval.

MISLEADING ADVICE ON AMINO ACIDS?

The BBC Radio 4 programme You and Yours recently featured an item about a Website set up by a person with Parkinson's, that was described as misleading by a Parkinson's expert. The website is www.fight-parkinsons.org.uk and is administered by Colin Potter, who was diagnosed in 2011.

He says he is now symptom-free but no longer takes L-dopa. Instead, he says health food supplements, especially amino acids, can reverse Parkinson's and for the last two years he has effectively recovered and is healthy. "You'd hardly know I had Parkinson's," he says.

However, you cannot be prescribed in the UK with the treatments Potter is advocating, and to obtain them from the US, for example, costs £65 a time for consultations via Skype, and £250 a month for the recommended substances. You may need them long term. The US medical regulator, the FDA, says amino acids are not approved for the treatment of Parkinson's and they are classified as a dietary ingredient, not a drug.

Professor David Burn, a consultant neurologist at Newcastle University, has expressed great scepticism about Potter's claims, saying that some of the material on the website could even put lives at risk, if people suddenly stop taking conventional Parkinson's medication.

"The website is making unsubstantiated and quite outrageous claims to a potentially vulnerable group of patients. I think there is no evidence that the treatment being recommended is curative. What really upsets is that the website implies that doctors who are dealing with Parkinson's are actually being almost dishonest."

Potter says he is simply sharing information, and that treating people with Parkinson's alongside L-dopa is now the preferred approach. For more, see <http://www.bbc.co.uk/programmes/b079m0pm>.

PILLS RECORD WHEN THEY ARE TAKEN

Treatments for Parkinson's frequently involve taking an assortment of drugs throughout the day and it can be difficult to remember – even though critically important – whether you have taken the right ones, in the right amounts. A new piece of technology could help. A US company, Proteus Digital Health, has developed a device the size of a grain of sand that sends out a signal when ingested, to record when people take their medication.

The sensor, which can be attached to a pill, contains a silicon circuit that transmits a signal to a patch worn by the patient. Power for the sensor is provided by coating it on one side with copper and the other, magnesium. When these enter the body, they get wet and act like a battery, causing a charge to pass between them.

Once the pill is taken, the patch stores the data required, which can then be checked by the patient's doctor. In an initial study involving more than 100 people with diabetes, researchers found that the device led to impressive reductions in blood pressure and cholesterol.

DATES FOR YOUR DIARY

BARKER LAB OPEN DAY

The next Barker Lab Open Day takes place on Saturday, July 9, from 10pm-4pm, at the Brain Repair Centre at Addenbrooke's Hospital (Forvie Site, Robinson Way, CB2 0PY). It may be fully subscribed, but check with Dr Romina Vuono on barkerlab.registration@yahoo.co.uk or Ms Shannon Tinley-Brown on 01223 331160. See the next newsletter for a report.

HOUSES OF PARLIAMENT

Our visit takes place on Monday, August 8, and tickets costing £15 are still available. To book a place on the trip for you or a friend, please send a cheque to Caroline Bent made out to "Parkinson's UK, Cambridge Branch", to 21-23 Covent Garden, CB1 2HS. Our coach leaves Trumpington Park & Ride at 9am, arriving back soon after 4.30pm. Parliament will be in the summer recess, so the only place available for refreshments is the Jubilee Café situated just off Westminster Hall. Toilet facilities are available by the Jubilee Café and in the lower waiting hall, just off the Central Lobby. For information about disability access and wheelchair loans, see <http://www.parliament.uk/visiting/access/disabled-access/>

MUSIC THERAPY GROUP – NIGHTINGALE SINGERS

A Music Therapy Group that meets every fourth Friday of the month at the David Rayner Building targets the specific vocal symptoms of Parkinson's. It is a friendly, welcoming group that uses a mixture of physical and musical exercises to help with articulation, projection and the facial muscles. No experience is necessary and no need to "be able to sing". Just turn up, support one another and have fun! Contact Music Therapist Alison Shaw on 07936-191655, or Alishaw654@gmail.com.

OCTOBER QUIZ NIGHT

On a date in October yet to be decided, the Branch hopes to host a fund-raising Quiz Night. Please start thinking about soliciting the support of a team from your village; your company; your bank; or wherever. We will be asking for a minimal entry fee but hope that some teams may make a more substantial donation. Watch our web-page for the announcement of date and venue.

CHRISTMAS LUNCH

The date has been set for our Christmas lunch – Friday, December 9, at the David Rayner Building, as usual. Start time 12 for 12.30. Tickets at £17.50 will be available at the Branch Meetings from August 26 onwards, or from Margaret Steane (01223 860128 msteane@msteane.freeserve.co.uk). There will be a choice of two starters, two main courses and two desserts. The choice must be made at the time of booking.

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 – JULY-AUGUST 2016

REGULAR MEETINGS AND ACTIVITIES

Aquatherapy

Thursdays weekly, 14:30-15:30
Chesterton Sports Centre, Gilbert Rd, CB4 3NY
Contact: Caroline 01223 314279

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 each 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: Gabby 01223 356433

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 07770 533948
Numbers limited: PHONE to indicate interest

Nightingale Singers

Speech Therapy through Song
Fourth Friday of month, 13:30-14:30
David Rayner Building, Scotsdales Garden Centre,
Gt Shelford, CB22 5JT
Contact: Charles Nightingale 01223 844763
Alison Shaw hopes to continue through the summer.

Yoga

Mondays weekly, **10:30-11:30**
NB: CHANGE OF TIME
The Meadows Community Centre, Room 2
St Catharine's Road (corner of Arbury Rd & Kings
Hedges Rd) CB4 3XJ
Contact: Michèle 01223 563774

OF SPECIAL NOTE

JULY

- 9: Barker Lab Open Day – *see* article above.
17: Shelford Feast – Can you help on the Parkinson's
stand? Contact Lorna Walker on 844723.
22: Branch meeting:
10:30 Refreshments.
11:00 Speaker, Gavin Moulton, Community
Transport Officer CCC.
11:45 Mayor Jeremy Benstead
12:00 Lunch.
Aromatherapy throughout.
13:30 – Nightingale Singers

AUGUST

- 8: Outing to the Houses of Parliament.**
9.00 from Trumpington Park & Ride
See article above.
26: Branch meeting:
10:30 Refreshments.
11:00 Speaker: Ray Manning, former leader of
SCDC on "*Devolution and the City Deal*"
12:00 Lunch.
Aromatherapy throughout.
13:30 – Nightingale Singers

SEPTEMBER

- 9: Carers' meeting
23: Branch meeting:
10:30 Refreshments.
11:00 Speaker Caroline Williams-Gray,
Clinical Lecturer in Neurology, and PI at
the BRC on "The role of the immune
system in Parkinson's disease and
implications for new therapies."
12:00 Lunch.
Aromatherapy throughout.
13:30 -- Nightingale Singers

OCTOBER

- ?: Fund-raising Quiz Night – *see* article above.
28: Branch meeting:
10:30 Refreshments.
11:00 Speaker Steve Ford, Chief Executive P-UK
12:00 Lunch.
Aromatherapy throughout.
13:30 -- Nightingale Singers

NOVEMBER

- 25: Branch meeting:
10:30 Refreshments.
11:00 Christmas Party
12:00 Lunch.
Aromatherapy throughout.

DECEMBER

- 9 Christmas lunch *see* article above.