

## Cambridge Branch Newsletter – September-October 2016

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### RECENT EVENTS

#### HOUSES OF PARLIAMENT TRIP



Branch members being shown round Westminster Hall in the Houses of Parliament on the trip that took place on Monday, August 8. The Cambridge visitors were divided into two groups, each with its personal guide. The two-hour tour included visits to both Houses, the Commons and the Lords – each of which turned out to be surprisingly small! Members were shown through the “Ayes” and “Noes” lobbies, through elegant ante-rooms, and past innumerable portraits and statues, many of



which allowed the guides to put famous figures into historical perspective. Since opportunities to sit were few, all were grateful to repair to the cafeteria for a cup of tea, and to the souvenir shop, before the safe trip back to Cambridge. Thank you to Charlie Nightingale who made this fascinating event possible.

#### BARKER LAB OPEN DAY

The latest Barker Lab Open Day took place on Saturday, July 9, and as usual was well attended. Opened by Professor Roger Barker, and now organised by Dr Romina Vuono, one speaker featured was Dr Kieren Allison, who is Head of the Cambridge Brain Bank.

The Bank was established to enable brain tissue to be used after death for research into neurodegenerative disorders such as Parkinson's and other diseases. The donation of post-mortem brain tissue for research is of fundamental importance to further understanding of the causes of these disorders and to develop more effective diagnostic tools and treatments.

The Bank needs people with or without neurological conditions to donate their brain tissue and register with the Cambridge Brain Bank. Normal (control) brains from people without neurological conditions are invaluable in helping find the possible causes of neurological diseases. Making a donation is as easy as filling in a simple form, Dr Allison said. For more, contact [brbank@addenbrookes.nhs.uk](mailto:brbank@addenbrookes.nhs.uk), or tel: 01223 217336.

He also showed the audience a series of microscope slides that demonstrated the progress of Parkinson's through the build-up of toxic alpha-synuclein and how it affected the substantia nigra, revealed by the loss of pigmentation.

After a break, Anna-Louis Smith and Richard Windle of the Parkinson's Research Support Network explained how the Network functions and in the case of Richard, who has Parkinson's, what a difference it has made to many PWP's as they realise that their experience of the disease is valuable to research. Your Branch has asked Richard if he will come to talk to us in the New Year. Also, a number of Research Interest Groups (RIGs) have been set up and are running at the local level. Now a new Cambridge RIG is starting (see story below, page 4).

The most pertinent question of the Q&A session was “How will Brexit affect the work of the Barker Lab?” Professor Barker was full of foreboding. The Lab currently benefits enormously from collaborating on projects with many European researchers, and receives subsidies that enable it to bring top scientists to the lab. He said the new government will no doubt introduce, and be applauded for, subsidising “new” research projects, but it cannot begin to equal the vast sums currently enjoyed. He plans to make the most of the next two years!

## PRESCRIPTION CHARGES FOR PEOPLE WITH PARKINSON'S (PWP)

The situation regarding prescription charges is seen by many people as being particularly unfair to those under the age of 60 with chronic conditions like Parkinson's. That is why Parkinson's UK co-chairs the [Prescription Charges Coalition \(PCC\)](#), working with almost 40 organisations who believe no one of any age with long-term conditions should pay for their prescriptions.

We know that PWP often have to take many tablets every day and paying for these can be costly. A survey conducted by the PCC showed that [1 in 3 people](#) in England with a long-term condition have not collected medication due to the cost, and many cut their dosage to save money. This impacts on their quality of life and can have a very negative effect on health.

“There is an exemption list that dictates who does and doesn't have to pay for their essential medication in England,” says Morgan Vine, Policy and Campaigns Advisor (Health) for Parkinson's UK. “Parkinson's is not currently on this list. But in June 2018 the exemption list will be 50 years old! We want to use this opportunity to convince the Government that now is the time for change. The medical exemption criteria are out of date and illogical and we believe they should be reviewed.”

In May the PCC met with Lord Prior at the Department of Health to discuss the situation and pointed out the unfairness of the current exemption criteria.

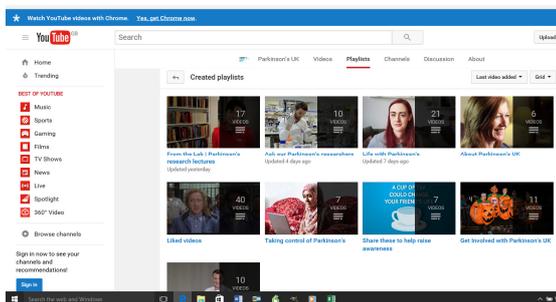
“Lord Prior seemed sympathetic to the issues faced by people with long term conditions, but made no specific commitments. It's vital that as many people as possible [raise this issue with their MP](#) so that the Government are given a clear message that they must act,” Morgan says.

How you can help: join the Parkinson's UK campaign network. This sends emails once a month about various important issues that you can get involved with, including the prescription charges campaign. <http://www.parkinsons.org.uk/content/campaigns-network>. Follow [@PrescriptionCC](#) on Twitter and share messages. If this issue affects you, share your story with [Prescription Charges Coalition](#) and help us illustrate the problems people face.

## NIGHTINGALE SINGERS APOLOGY

We would like to apologise for the mistake that happened recently in connection with the Nightingale Singers, when your singing coach, Alison, did not turn up to supervise the session. This was due simply to an error on her part – confusing the fourth Friday of the month for the last! She apologises to all the people who turned up. So, a date for your diaries: the next session takes place on Friday, September 23, starting at 12.45. All future classes will start at this time.

## PARKINSON'S VIDEOS AVAILABLE



A whole host of fascinating videos – more than 120 at the last count – relating to Parkinson's is now available on YouTube. They include lectures from world-leading researchers to more personal items from people with Parkinson's on topics such as living with the condition, and contributions from well known sufferers such as Michael J. Fox. They vary significantly in length, some a few minutes, others more than half an hour. But well worth giving some a try! See: <https://www.youtube.com/user/parkinsonsUK/playlists>.

## BRANCH MEETINGS

### COUNCILLOR RAY MANNING

The August Branch Meeting featured a talk from Ray Manning, who until May this year was Leader of South Cambridgeshire District Council (SCDC), having held the position since January 2007. In the nine years of his leadership, the Council has become one of the top performing in the country, and was recently recognised nationally for its innovative approach to generating income by setting up its own housing company.

In another unusual move, SCDC has been sharing services with Cambridge City and Huntingdonshire District Councils, which is claimed to have saved taxpayers hundreds of thousands of pounds. This kind of alliance was the main theme of Councillor Manning's talk, centring on the so-called Greater Cambridge City Deal, and Devolution.

The City Deal aims to bring over £1bn worth of investment in transport infrastructure improvements and thousands of new homes, jobs and employment training opportunities to the city region. A key factor prompting the Deal is the fact that the Cambridge area is the biggest economic growth area in the country, generating £43,000 per worker, Manning told members. This generates huge tax revenues for central government.

The Devolution project aims to extend the City Deal concept, by creating a "super council" comprising Cambridgeshire, Norfolk and Suffolk. But Manning is deeply sceptical about its prospects.

"The last time something like this happened we had a King of Mercia," Manning wryly observed. "Put 25 council leaders in one room and you will never get an agreement on anything."

Manning's talk was much appreciated by members, prompting lively discussion after his speech, especially on topics like housing and transport.

## **SCIENCE AND RESEARCH**

### **MAGNETIC BRAIN CONTROL**

Deep Brain Stimulation (DBS) is a proven, effective treatment for symptoms of Parkinson's, but it has the drawback of being invasive, requiring surgery to insert electrodes into the brain. However, potential alternatives that are less invasive are emerging.

One involves using magnets and tiny particles of iron oxide, which are combined with antibodies and injected into the brain (a relatively straightforward procedure). The antibodies transport the particles to the target regions in the brain and then attach themselves to individual cells. The particles can then be activated externally using magnets. Professor Mark Lythgoe, from University College, London, is one of the team that has pioneered the technique.

"Brain cells have stretch receptors in them, and if you put a bit of stretch on them, they will fire. So this technique means we can remotely control the brain in very specific regions, which is the first time this has been done."

So far, it has been used in rats to switch kidney function on and off but Professor Lythgoe says there is no reason it could not be used in humans, not least because the particles are already used in MRI imaging, so are approved as safe.

"We're doing injections in rats where we activate about 2000 neurons. If we can do it on animals at that scale, human stuff is easy," he said. He anticipates the technique being used as a daily therapy, possibly with people wearing a helmet containing magnets. As well as Parkinson's it could help with other conditions such as epilepsy and depression.

Claire Bale of Parkinson's UK said DBS involved major brain surgery, so "any advance that produced similar benefits with a less invasive procedure would be hugely beneficial to patients".

There are other potential treatments that are also less invasive than DBS, for example high intense focused ultrasound (HIFU) combined with MRI scanning. This makes it possible to destroy tissues located deep in the brain. The safety and effectiveness of this method have been observed in parkinsonian and essential tremor as well as in neuropathic pain, researchers say, and the procedure does not require anaesthesia. See <http://www.ncbi.nlm.nih.gov/pubmed/24976088>.

### **EARLY DIAGNOSIS**

The search for a reliable technique for early diagnosis of Parkinson's is making progress, with at least two new developments announced recently. See the next issue of the Newsletter for a detailed look at what is happening.

## **DATES FOR YOUR DIARY**

### **\*\*\* BRANCH AUTUMN FUNDRAISING QUIZ NIGHT \*\*\***

Are you a wiz at the pub quiz? A wannabe Egghead? Or someone who answers lots of the University Challenge questions before the brainy students? You don't have to be any of those to have a wonderful time at our FUNdraising Branch Quiz on Thursday 13 October (6:30 for 7pm -- 9:30) at the David Rayner Building. We are inviting local businesses to submit teams (contributing £150 per team of up to 10 people, inclusive of food); do you know anyone in a company who might enjoy sending a team? If so please let Annabel Bradford know (07950 685307 or [annabelparkinsonscambridge@gmail.com](mailto:annabelparkinsonscambridge@gmail.com)). You have a chance to be a member of the Branch team (at a discount rate of £5 per person which pays for your supper!). Contact Caroline Bent (01223 314279 or [carolinebent@me.com](mailto:carolinebent@me.com)) if you would like to be part of that team. If more than 10 members volunteer we will draw 10 names out of a hat on September 23 at the David Rayner Building meeting – those 10 will form the Branch Team.

### **RESEARCH INTEREST GROUP**

A new Parkinson's Research Interest Group (RIG) is being set up in Cambridge, with the first meeting set to take place on Friday, September 9, from 1.30 to 3.30pm at the Brain Repair Centre, next to Addenbrooke's Hospital (Forvie Site, Robinson Way, Cambridge CB2 0PY). The aim is to discuss the opportunity for local people and researchers to link up and share opportunities to be involved in research. Parkinson's UK supports a series of RIGs across the country, which provide valuable resources for researchers who need people with Parkinson's to take part in many different kinds of research, ranging from full scale clinical trials to filling in questionnaires. Anyone interested in attending should first contact Anna-Louise Smith, Research Support Network Manager at Parkinson's UK ([alsmith@parkinsons.org.uk](mailto:alsmith@parkinsons.org.uk) or 0207-963-9398).

### **SELF-MANAGEMENT PROGRAMME SECOND SESSION**

The Parkinson's UK Self-Management Programme will stage its second Cambridge group session in September. The branch has had only very positive reports from previous participants. The programme asks for a serious commitment, comprising three five-hour meetings on successive Tuesdays: September 13, 20 and 27. The venue is the Meadows Community Centre, St Catharine's Rd, CB4 3XJ. To register an interest, and for further details, contact Sam Fitzgerald on 0207-963-3924 or [selfmanagement@parkinsons.org.uk](mailto:selfmanagement@parkinsons.org.uk).

### **PHOTO APPRECIATION COURSE**

Branch Member and photographer Jennie Grant is starting a Photo Appreciation Course to encourage people to enjoy photography. Her aim is to keep it simple, so she will avoid the more technical side of photography. The course will cover basic framing of shots and show how unusual angles, close ups and different backgrounds can produce interesting results. Jenny's talks will be at the Bring and Share lunches in Milton on the first Tuesday of October and November at 12:30.

### **PARKINSON'S CHIEF EXECUTIVE**

The October Branch Meeting will be well worth coming to, as its main speaker will be Steve Ford, Chief Executive of Parkinson's UK. The meeting is on Friday, October 28, starting at the usual time, 10.30am, in the David Rayner Building. In March this year, Steve won the prestigious Charity Leader of the Year award at the Charity Staff and Volunteer Awards. Having celebrated 10 years at Parkinson's UK in 2015, he was recognised for his work to transform the charity, both strategically and culturally. Under his leadership, Parkinson's UK has more than doubled in size, enabling it to deliver more high-quality services, campaigns and research, all tailored to the specific needs and priorities of people affected by Parkinson's across the UK.

### **FUTURE EAST & PHOTO COMPETITION**

Future East, an organisation that promotes the interests of ageing people (50+), is holding an Open Meeting (as well as its AGM) at the Meadows Centre in Cambridge on Monday, October 17, from 10.30 to 3pm. The event is free but you need to book (Susannah Harris on 07858-456946, or [admin@futureeast.org.uk](mailto:admin@futureeast.org.uk)).

### **DECEMBER CARERS' MEETING**

Please note, there has been a change of date for the December Carers' Meeting. This will now take place on **Friday, December 16**, at the usual time and place (10:30-12:30pm at Davison House, Brookfields Hospital, CB1 3DF). The September meeting takes place on Friday, September 9.

## CHRISTMAS LUNCH

Don't forget the date 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](mailto:msteane@msteane.freeserve.co.uk)). There will be a choice of two starters, two main courses and two desserts: vegetable soup or prawn cocktail; roast beef or turkey; and Christmas pudding or fresh fruit salad. There will as usual be a vegetarian option. You will need to make your choice when you buy your ticket(s).

## DANCE CLASSES PLANNED FOR 2017

Plans are going ahead to start up a new dance based exercise programme for Branch members and any others living with Parkinson's in our area. This follows on from two successful taster sessions in June, organised by Romina Vuono and Jeanette Simpson, who founded and performed in the dance show, Take a Step, in January of this year. They are planning a twice-a-month 'dance' activity called Engage, geared specifically to the needs and limitations of those with Parkinson's, for which they have had special training. Activities with a rhythmic component, and exercise with dance-like qualities, are recommended by Parkinson's UK as aids to help with the most common symptoms of the condition. We hope members will find this activity very helpful. This dance programme, supported by Parkinson's UK, will not start until the New Year. See the next Newsletter for more details and how to enrol in Engage.

## DISABLED EXERCISE

Nicky Young is a woman injured serving in HM Forces who took up exercise and became a qualified instructor. She wants to help disabled people to exercise and invites anyone with Parkinson's to visit her at [Nuffield Health Cambridge Fitness & Wellbeing Gym](#), Cromwell Road, Cambridge, CB1 3BA. She is at the centre on Wednesdays and Thursdays from 9am-3pm, and can organise an initial meet and greet with a tour of the facility, a gym induction or a taster session (individual or group) free of charge, all abilities welcome. She can also deliver a short talk to any disability groups about the benefits of exercise. After her injury, she says she found going to the gym and exercising helped her through tough times and aided her recovery in many ways, mentally and physically. She now has CYQ Level 3 qualifications as a Personal Trainer, Exercise & Disability and Strength & Conditioning Coach. Contact her on [nickyyoung381@yahoo.co.uk](mailto:nickyyoung381@yahoo.co.uk) or book an appointment by calling the centre direct: 01223 245200.

## TWITTER AND FACEBOOK ACCOUNTS OPENED

The branch now has a twitter and a Facebook account: <https://twitter.com/CambBranchPUK>, and <https://www.facebook.com/parkinsonsukcambridge/>. If you're on either, please follow the accounts as we will be sharing details of upcoming events and news via them! Any queries, email our Publicity Officer, Annabel, at [annabelparkinsonscambridge@gmail.com](mailto:annabelparkinsonscambridge@gmail.com).

## GOODBYE RHONDA

We are sorry to say goodbye to Rhonda Waters, our Parkinson's Local Adviser for the last few years. She is moving to take over the same role in Suffolk. Rhonda's concern for everyone she dealt with was obvious, and always professional and friendly. She had years' experience of working with different charities before joining Parkinson's UK when she moved to Newmarket in 2013. One important aspect of her role was liaising with Parkinson's nurses both in the community and in hospitals. Rhonda ran a regular session at Brookfields Hospital, part of the course for those newly diagnosed with Parkinson's. We shall miss you Rhonda, and many thanks for everything you have done!

**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](http://www.parkinsonscambridge.org.uk)**

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## PARKINSON'S UK – CAMBRIDGE BRANCH CALENDAR – SEPTEMBER-OCTOBER 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]  
**NB: see article above re. Photograph Appreciation**  
Contact: Gabby 01223 356433

#### Carers' Meeting

Programme of support, chat, information and friendship  
Quarterly, second Friday of the month  
**NB Third** Friday in December 2016  
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, 12:45  
**NB: CHANGE OF TIME**  
David Rayner Building, Scotsdales Garden Centre,  
Gt Shelford, CB22 5JT  
Contact: Charles Nightingale 01223 844763

#### Yoga

Mondays weekly, **10:30-11:30**  
The Meadows Community Centre, Room 2  
St Catharine's Road (corner of Arbury Rd & Kings  
Hedges Rd) CB4 3XJ  
**No meeting Sept 5 or 12, Oct 24**  
Contact: Michèle 01223 563774

### OF SPECIAL NOTE

#### SEPTEMBER

- 5: No Yoga
- 9: Carers' meeting
- 9: Research Interest Group. *See* article above
- 12: No Yoga
- 13: Session 1 of Self-Management Programme  
– *see* article above
- 20: Session 2 of Self-Management Programme
- 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."
  - 11:55 Ruth Brannan, Project Facilitator of "You Can Bike Too"
  - 12:00 Lunch
- Aromatherapy throughout
- 12:45 -- Nightingale Singers
- 27: Session 3 of Self-Management Programme

#### OCTOBER

- 4: Bring and Share Lunch:  
Photograph Appreciation, *see* article above
- 13: BRANCH QUIZ NIGHT. SEE ARTICLE ABOVE**
- 24: No Yoga
- 28: Branch meeting:
  - 10:30 Refreshments
  - 11:00 Speaker Steve Ford, Chief Executive P-UK
  - 12:00 Lunch
- Aromatherapy throughout
- 12:45 -- Nightingale Singers

#### NOVEMBER

- 1: Bring and Share Lunch:  
Photograph Appreciation, *see* article above
- 25: Branch meeting:
  - 10:30 Refreshments
  - 11:00 Christmas Party
  - 12:00 Lunch
- Aromatherapy throughout

#### DECEMBER

- 9: Christmas lunch. *See* article above
- 16: Carer's Meeting **NB** not 2<sup>nd</sup>, but 3<sup>rd</sup> Friday
- 19: Last Yoga until January 9, 2017

#### JANUARY, 2017

- 7: To be confirmed, the first meeting of "Engage",  
Dance for Parkinson's. *See* article above.
- 9: Yoga resumes

#### APRIL

- 10-16: Parkinson's Awareness Week
- 23: Tulip Fun-Run 2017