

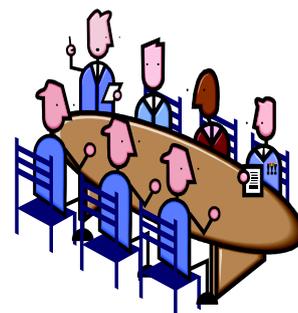
## Cambridge Branch Newsletter – July 2014

This month's editors

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**Committee News:** The committee is pleased to have David Boothroyd join it as an observer. We hope to co-opt him if his volunteer first role of editing with this newsletter does not frighten him away.



**Parkinson's Together Event June 2014** – Julia and Margaret attended the Eastern Region event on behalf of the branch. As always it was well attended by representatives from most branches and groups as well as regional and national staff. We began with an uplifting speech from Jo Evans who runs the Billericay Branch. Jo is full of energy, enthusiasm and ideas. Perhaps national office can clone her. One brilliant idea was to get younger members of families involved at an early stage, not only to understand better the disease which a parent or grandparent has, but to get them involved in branch activities and fund raising. Jo called it 'succession planning'.

Chief Executive, Steve Ford spoke next with a radical idea of throwing away the rule book; asking if some of the charity's rules stop us getting on with our aims. National Office is already addressing some issues with trials on shared transport, befriending and home visiting.

The consultation with members on what they want to see in the next five year strategy has resulted in the 2015-2019 aims being formulated. Three big priorities stood out: people want a cure and better treatments, access to high-quality services and to be able to take control of their lives.



### Treasurer's Column

Special thanks go to the family and friends of the late Richard (Colin) Campbell and Mrs I E Robinson for generous donations made in their memory.

**Fund Raising** The **Tulip Run** held in April has so far raised a stunning net figure of £2,038.67

**Tulip Club** –The winners in April, May and June were Pam Dockerill, Betty Moss, Alan Varty, Bill Penfold, Mary Penfold and Margaret Steane.

**The Singing Group** has been casting around for a new name. Known in the columns of this publication as Sing Loud it has now settled on ... no not Charlie's Angels... but The Nightingale Singers.



## **Parkinson's Nurses**- an update from Ian McKee

As many of you will know, Jacqueline Young, Parkinson's Service Clinical Lead for Cambridgeshire is leaving the Community Parkinson's Service to take up a new Specialist Parkinson's role in Addenbrooke's Hospital. Jacqueline has been instrumental in developing local Cambridgeshire services and CCS NHS Trust wish her the very best for this career move. She will still be making a significant contribution to Parkinson's care in this new role.

Carolyn Noble, currently Parkinson's Service Clinical Lead in Peterborough, will become the Clinical Lead across Cambridgeshire and Peterborough with immediate effect. We also have other vacancies in the team due to recent retirements. We have successfully recruited to these vacancies and all the new staff will be in post by the autumn. During this period of transition, we would value your patience and understanding as we try to continue to deliver the service. This may involve some people having clinic appointments offered instead of a home visit or you may not speak to the nurse you are used to but all the nurses will be able to respond to your query. We have made arrangements to ensure all urgent work is covered.

Please continue to contact your local team through the usual route. Tel: 01223 723014

## **Parkinson's nurse at Addenbrooke's**

A new specialist Parkinson's nurse working at Addenbrooke's Hospital, Karen MacGinley, spoke at the Branch monthly meeting on 23<sup>rd</sup> May.

Karen stressed that her role is restricted to working within Addenbrooke's; helping people with Parkinson's who are admitted to the hospital for whatever reason.

"Going into hospital can be an anxious time for anyone. If you have Parkinson's, you may have additional concerns that will increase your anxiety, such as being cared for by people who may not be familiar with your condition."

In her talk she discussed a series of things Parkinson's patients being admitted should consider, such as: How can I prepare? How can I make sure I get my medication on time? Should I take information about me and my condition with me? Can I take my own medications into hospital? Do I need to tell staff about the side effects of my medication?

For further information about going into hospital, call: 01223-245151 ext. 59814

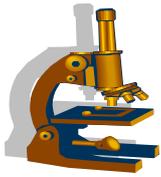
[karen.macginley@addenbrookes.nhs.uk](mailto:karen.macginley@addenbrookes.nhs.uk)

## **Telling Your Story**

Personal stories are essential in helping to raise awareness of what it is really like to live with PD. PUK is seeking members and their families willing to tell their stories and make use them in publications, the media, fundraising and marketing. They emphasise that they will only use your story with your permission and in ways that you feel comfortable with.

If you are interested Julia Ewans has the paperwork.

Please take a look at some of the stories already shared on the Parkinson's UK website.



## Science Column

**Two members of the Cambridge Brain Repair Centre**, Clinical Research Fellow Sarah Moore and Research Assistant, Patricia Vázquez Rodríguez, gave an excellent presentation at the Branch Meeting on 27<sup>th</sup> June.

The Centre's full title is the John van Geest Centre for Brain Repair (BRC), and it is part of the Department of Clinical Neurosciences at the University of Cambridge. The ultimate aim of the work done at the Centre is to understand, and eventually to alleviate and repair, damage to the brain and spinal cord which results from injury or neurodegenerative disease. Parkinson's is one of the main research subjects.

The speakers covered a lot of ground in their talks, ranging from an initial overview of Parkinson's to descriptions of specific research studies undertaken at the Centre. Some interesting statistics were cited: 98% of Parkinson's cases are 'idiopathic', that is, the cause is unknown; there are around 120,000 people with Parkinson's in the UK, and an estimated 5 million worldwide, although this is probably an understatement; and 5-10% have a genetic link.

Several research projects were described, including: the CamPaIGN study, which followed 239 individual cases within Cambridgeshire over years; one examining cell based treatments, TRANSEURO, and another, ProSavin, covering gene therapies.

The talk ended on an optimistic note, looking at the potential of induced pluripotent stem cells, which could have a major impact on many diseases in the future including Parkinson's. It was followed by an enthusiastic question and answer session.

The Barker Lab, part of the **Brain Repair Centre** is to hold another Parkinson's Open Day, on Saturday 18<sup>th</sup> October.

This follows the success of the previous event staged in March. The Lab, which specialises in research into Parkinson's, is named after its founder and head, Professor Roger Barker. As before, the Open Day will feature several lectures from Lab members and an invited guest speaker, Dr Heike Laman, from the Pathology Department at Cambridge University. She will give a special presentation explaining what role genetics may be playing in Parkinson's and how her research is focusing on this.

The lectures will cover topics such as sleep disturbances in Parkinson's, and how skin cells are being turned into dopamine neurons. There will also be a question and answer session, together with poster presentations, including ones describing work being done by the Lab.

The event is to become a twice yearly occurrence, as organiser Simon Stott explains.

"Given the positive feedback we have had from our Parkinson's Open Day in March, the Barker Lab has decided to make it a regular event, one during Awareness Week in April and a second in the autumn."

The October Open Day starts at 10am, and takes place at the Brain Repair Centre, located at the back of Addenbrooke's, at the Forvie Site, Robinson Way, Cambridge CB2 0PY. Anyone interested in attending should contact Simon Stott on 01223-331160 or email [barkerlab.registration@yahoo.co.uk](mailto:barkerlab.registration@yahoo.co.uk)

**A study of a potentially new drug for Parkinson's, Exenatide, is now open for recruitment.**

Exenatide is a licensed treatment for patients with diabetes mellitus. Laboratory work has shown strong, reproducible evidence that this drug has beneficial "disease modifying" effects when given to animals with a range of experimental models of Parkinson's.

Funded by the Cure Parkinson's Trust (CPT), a pilot study involving 40 patients with moderate PD symptoms has already been completed. Half the patients received Exenatide and half acted as controls. Those receiving Exenatide had improved results in a number of assessments compared to the controls.

The new project aims to confirm these initial results, in a randomised, double-blind trial. Sixty patients, again with moderate PD symptoms, will be recruited and randomised to receive Exenatide or placebo injections once weekly.

Detailed assessments will be made of all patients at baseline and periodically for a total of 60 weeks. Aside from these assessments, all patients will continue their regular PD medications throughout the trial with adjustments made only according to clinical need. Anyone interested in joining the trial should contact the CPT or click the link at <http://www.cureparkinsons.org.uk/exenatide-trial-now-recruiting>.

**The Gretschen Amphlet Memorial Lecture is now available online.** The lecture took place at Fitzwilliam College, Cambridge, on March 18. Those unable to attend can now watch the complete event online at <http://www.parkinsons.org.uk/content/protecting-precious-nerve-cells-breaking-through-barriers-find-cure>

Entitled 'Protecting precious nerve cells: breaking through barriers to find a cure', it featured two presentations, the first from Dr Mark Ungless, of London University's Imperial College, and then Professor Matthew Wood, of Oxford University.

Ungless described his research into how dopamine neurons work, and how they are affected in Parkinson's. Wood's talk focused on the blood-brain barrier, and how to make drug treatments potentially far more effective by overcoming it.

**A new DVD about Parkinson's featuring the actor Michael J. Fox** has been produced by the American Academy of Neurology and the American Brain Foundation.

The DVD starts with an introduction by Fox, one of the most famous Parkinson's patients, and then proceeds through several sections featuring topics such as: What causes Parkinson's Disease? How do I know if I have Parkinson's Disease? And Caring for a Person with PD. Other sections discuss medicines, deep brain stimulation, and other steps you can take like exercise, acupuncture and massage.

Each section is short, around five minutes, and the whole approach is to keep things relatively simple and very accessible. Case studies of people with Parkinson's are featured throughout, and two US neurologists provide expert commentary. The DVD comes packaged in an informative booklet.

The branch now has three copies of the DVD but there may be a waiting list to see them. To obtain a copy of your own contact the American Academy of Neurology ([www.aan.com](http://www.aan.com)) Tel. 001-612-928-6000. It is also available online at <https://www.aan.com/practice/patient-education-videos/> and on <http://youtube/fGlmOaC5Jko>

**Ricky Rayment, star of the award winning TV show The Only Way is Essex (TOWIE)**, plans to raise money for the Cure Parkinson's Trust by skydiving.

He will do the sky dive on Sunday, August 17, at the North London Skydiving Centre, which is situated at Chatteris Airfield, near March, Cambridgeshire.

Rayment, whose grandfather had Parkinson's, is now an ambassador for the Cure Parkinson's Trust (CPT).

"I'm delighted to be supporting the CPT and am looking forward to raising much needed funds with the Ricky Rayment team to help find a cure and hope everyone gets behind me on this," he said.

Anyone wanting to join him and do a sky dive (subject to availability) can register for £70, plus optional insurance of £28. For sponsors spending a minimum of £395, the sky dive is free. Contact the CPT on 0207-929-7656 or [anna@cureparkinsons.org.uk](mailto:anna@cureparkinsons.org.uk).

## **DATES FOR YOUR DIARY**

19<sup>th</sup> July 1 – 5pm Billericay Branch Family Fun Day Emmanuel Church Field, Laiden Road, Billericay CM12 9LD

Tea at the Dovecote: Pam and Chris Holt plan good weather and delicious scones at their lovely home at Haslingfield on Sunday 7<sup>th</sup> September 2-5pm.

18<sup>th</sup> October- Barker Lab open day – see above

South Cambridgeshire District Council plan a disability open day at its offices in Cambourne on Friday 31<sup>st</sup> October 10am-4pm. We will be there with an information stall. Come along it is open to all.

Christmas Lunch – 5<sup>th</sup> December

Parkinson's Awareness Week 2015 will be 20<sup>th</sup> to 26<sup>th</sup> April

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

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**Information and Support Worker - Rhonda Waters—0844 225 3618**

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**Help Line - 0808 800 0303** (free phone call). Helpline specialist advisors can answer your questions on any aspect of Parkinson's

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**Parkinson's Nurses** - 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 (Lorna 07770533948 Eileen 078889319961)**

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Parkinson's UK 215 Vauxhall Bridge Road, London SW1V 1EJ

**T** 020 7931 8080 **F** 020 7931 8080 **E** [enquiries@parkinsons.org.uk](mailto:enquiries@parkinsons.org.uk) **W** [parkinsons.org.uk](http://parkinsons.org.uk)

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A company limited by guarantee. Registered in England and Wales (948776)  
Registered office: 215 Vauxhall Bridge Road, London SW1V 1EJ  
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## **PARKINSON'S UK – CAMBRIDGE BRANCH CALENDAR – July 2014**

### **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 07770533948

#### **Sing Loud (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  
Performance 25 April

**NO MEETING IN JULY OR AUGUST**

#### **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**

#### **JULY**

**25:** Branch meeting

Speaker: Joan Hallifax on  
Climbing Kilimanjaro for PD  
12:00 Lunch  
ART with Vicky and  
Aromatherapy throughout

#### **AUGUST**

**2: NO SING LOUD**

**22:** Branch meeting  
"Healthwatch" and the Clinical  
Commissioning Group explained.  
12:00 Lunch  
Aromatherapy throughout

#### **SEPTEMBER**

**26:** Branch Meeting  
Speaker to be advised  
12:00 Lunch  
Art with Vicky Hunt and  
Aromatherapy throughout

#### **OCTOBER**

**24:** Branch Meeting  
Speaker: Harvey Levinson on  
Current First Aid Techniques  
12:00 Lunch  
Aromatherapy throughout