

Cambridge Branch Newsletter – November-December 2015

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

MARATHON CYCLE TRIP



Branch member David Johnston has completed his massive cycling trip, starting from John o'Groats and finishing at Land's End on September 16. David did it in stages, but travelled alone, without support, finding accommodation as he travelled and camping when needed. He hopes to raise £1,000 each for his two charities, Parkinson's UK and the Dystonia Society, who have both helped enormously with his condition, he says. He was diagnosed with Parkinson's in 2014, having previously been diagnosed with dystonia in 2013.

“My main symptom is my facial tremor. I cannot control my eyelids so I have difficulty seeing. I cannot control my jaw so I have difficulty talking. My eyes are kept open by botox injections in my eye lids. I also jam my eyes open with specially

adapted glasses known as ‘Lundie loops’ so that I can see the road. I use special UVF filters to cut out glare.”

He says he did the trip for various reasons: “I have always enjoyed cycling and long distance expeditions, they make me feel normal again. I don't have to talk too much and exercise helps my tremor. I did enjoy it very much. In my small way, I wanted to demonstrate a few things to help other Parkinson's sufferers. Concentrate on what you can do, don't dwell on what you have lost. If you enjoy doing something, do your best to continue doing it as long as possible. There is excellent care available within the NHS. Persevere until you find it. Do not be fobbed off with sub-standard care. It took me 18 months to find a doctor who could inject my eyelids correctly, after many painful failures. Charities fill the gaps left by the NHS. Use and support them. The Dystonia Society recommended the Lundie loops and the RNIB provided a UVF shield. Without these items, I could not have completed the trip.”

EXERCISE PROJECT

Interested in having a serious target for the amount of exercise you are taking? Have a look at a new website recently launched by the Brian Grant Foundation and the World Parkinson's Coalition (WPC) called the Power Through Project <https://www.powerthroughproject.org/en/home>. The foundation is working in conjunction with the WPC to get people with Parkinson's exercising. The idea is that people convert hours of exercise into mileage to achieve a total of 3000 miles (the distance from Montreal, the location for the last World Parkinson's Congress in 2013, to Portland, next year's venue), over the next 12 months. Full details are on the above website. Another contact is our own branch member, Andrew Curran (andrew_curran23@yahoo.com) who is an ambassador for the WPC.

BRANCH MONTHLY MEETINGS

ROBERT SAYLE/JOHN LEWIS HISTORY

Sarah Ingram, PR and Marketing Coordinator for John Lewis, came to speak to those attending the David Rayner Building branch meeting on Friday, September 25. She accompanied her talk with projected pictures of Robert Sayle, his original shop on St Andrews Street and later expansion of it, and of John Spedan Lewis who succeeded his father, John Lewis, in the Department Store business.

Sarah's audience was spell-bound as she told us how Robert Sayle ran his store at first from one building, later from three; how his staff were accommodated on site; how customers could buy a complete funeral package from coffin to mourning garments; could have their hair cut and dried by an ingenious early drying system that consisted of long

tubes attached to a central hot air system that emerged into single cubicles like snakes out of a hole; could buy home-brewed beer, or borrow books from the circulating library; but menswear could not be sold alongside women's, and shoes were still exclusively the province of cobblers.

When Robert Sayle's business came on the market in 1934 it was initially bought by Selfridges, but soon after, as war approached in 1939, Selfridges were happy to sell it on to John Spedan Lewis. He was the founder of the John Lewis Partnership, an employee-owned business model that is as innovative today as it was when Spedan first implemented it in 1916.

A monumental change came about in 2000 when the Grand Arcade development was approved. The Co-op on Burley Street became a temporary home for the stock which the Partners carried, wheeled and transported themselves over one weekend. Similarly, returning to occupy the new and current Downing Street premises required only one day of closure. During the demolition of the original shop the circular staircase and chandelier went missing – can anyone tell John Lewis what happened to them?

DEEP BRAIN STIMULATION A SUCCESS

At the August Branch Meeting, a Dutch member, Matthieu Visser, described his experience with deep brain stimulation (DBS), having undergone the operation in Amsterdam a few months ago. Matthieu was diagnosed with Parkinson's seven years ago at the age of just 36, with the first symptoms being a tremor in his arm. He did well for several years on medication but in 2014 his condition worsened, with disrupted sleep, hallucinations, and increasingly severe 'off periods'.

"I could not cope even part time at work. Half of the day I was practically paralysed, waiting for the next dose of dopamine to start working," he said.

The operation lasted three hours, with Matthieu under local anaesthetic, and involved his head being held rigid through the use of a special frame. Recovery initially was quite slow, but he first noticed a significant development when he was walking in the Netherlands with his brother – his sense of smell returned, which had been missing for about a decade.

Now Matthieu says his condition has improved significantly, enabling him to play tennis again to a good standard, and he has asked to be able to work again, at least part time. He has a PhD in experimental biophysics and has worked in healthcare for the Dutch multinational, Philips. Even so, he recognises DBS is not a cure, and that his long term prospects are uncertain, as they are with everyone who has Parkinson's.

"My Parkinson's is not gone, it has just been set back," he says. But he feels the DBS operation has definitely been a success, and as a result he is more determined than ever to get the most out of life.

SCIENCE COLUMN

LIVER DRUG SHOWS PROMISE

Parkinson's UK funded researchers have found that a drug traditionally used to treat liver conditions may also have promise for treating Parkinson's. The research, published in the Journal of Neurology, concerns the drug ursodeoxycholic acid, or UDCA, which has been in clinical use for decades treating individuals with liver conditions.



Professor Oliver Bandmann and his team at the Sheffield Institute of Translational Neuroscience have been studying an inherited form of Parkinson's caused by changes to the gene LRRK2. The changes cause problems with cells' energy producing batteries, the mitochondria. The team screened thousands of drugs and identified UDCA as a possible candidate that might rescue the function of the mitochondria.

In collaboration with Dr Chris Elliot's research team at the University of York, the Sheffield researchers have now shown that UDCA can restore the function of mitochondria in a fruit fly model of Parkinson's. They also showed that the drug helped the dopamine producing nerve cells affected in Parkinson's to survive.

These results provide further evidence that UDCA may have promise for treating Parkinson's. Dr Arthur Roach, director of research for Parkinson's UK, said the testing of drugs like UCDA, which are already approved for other uses, was extremely valuable.

"It can save years, and hundreds of millions of pounds," he said. "It's particularly encouraging in this study that even at relatively low concentrations the liver drug still had an effect on Parkinson's cells grown in the lab. This type of cutting-edge research is the best hope of finding better treatments for people with Parkinson's in years, not decades."

CLINICAL TRIALS INITIATIVE



A few weeks ago, Parkinson's UK Chief Executive, Steve Ford (left), and director of research, Arthur Roach, went to the US to launch a groundbreaking new initiative to improve clinical trials for Parkinson's. The Critical Path for Parkinson's will bring together researchers, drug companies and regulators to change clinical trials so they're smarter, more likely to succeed and deliver new treatments for people with Parkinson's.

As with all conditions, new treatments must be carefully and thoroughly tested in people to prove that they are safe and effective before they can be approved and made available to everyone with the condition. This is the most costly and lengthy part of the whole process and in recent years, several promising new treatments for Parkinson's have failed to show benefit in clinical trials.

"We believe clinical trials can work better so we're bringing the right people together to make trials faster, cheaper and more likely to succeed," says Parkinson's UK. The organisation is working with the Critical Path Institute in the USA to bring together pharmaceutical companies, regulators, and academic partners to work towards establishing best practice and more efficient ways to plan and carry out clinical trials for Parkinson's.

"Despite huge scientific progress, there have been no major advances in the treatments available for Parkinson's in the last decade," says Steve Ford. "If successful, the Critical Path for Parkinson's will mean more successful clinical trials, and ultimately help us achieve our mission to deliver new and better treatments in years, as opposed to decades. At Parkinson's UK, we're adopting a new approach – tackling the critical road blocks standing in the way of the scientific breakthroughs that could have a huge impact on the lives of people with Parkinson's.

"It's our goal that Critical Path for Parkinson's will improve the clinical trial process and deliver new and better treatments, faster, to the people who urgently need them. Our research initiatives are completely reliant on your donations - help us get new, better treatments to people with Parkinson's, sooner." See more at: <http://www.parkinsons.org.uk/news/15-october-2015/initiative-improve-clinical-trials-parkinsons-launches#sthash.HZyKK7Ku.dpuf>.

BIRMINGHAM COURSE

The University of Birmingham has created a free online course about Parkinson's, which is an introduction to the key concepts of the human brain and is designed for the non-specialist. It gives you basic information and explanations, so that you may better understand your own amazing brain. Good Brain, Bad Brain, Parkinson's has been available from October 11, and anyone can take part. It is aimed at everyone interested in finding out the fundamentals of Parkinson's; how it affects people, what causes it, what we can do to tackle the symptoms and what we don't yet know about it. Find out more about the course here: <https://www.futurelearn.com/courses/good-brain-bad-brain-basics>. If you do the course, Parkinson's UK would be interested in feedback at rsn@parkinsons.org.uk.

DATES FOR YOUR DIARY

NEW SINGING GROUP



A new Parkinson's singing group has been formed in Bury St Edmunds called the Parkinsongsters. As with our own Nightingale Singers, the aim is to help people whose Parkinson's has weakened their voice. The first get together was in early October, and the next is very soon, on Monday, November 2, at the Moreton Hall community centre

(Symonds Rd, Bury St Edmunds, Suffolk IP32 7EW tel 01284 763402,) starting at 2.30pm. Anyone with Parkinson's, and/or their carers, is welcome to attend.

The group has a guest conductor, Nicola Wydenbach, who is coming from London for the session. Nicola is a professional soprano singer, who has performed in many operas and other musical roles. Next year she is due to sing the soprano solos in Bach's St Matthew Passion with the Bristol Choral Society, among many other roles. If you are interested, please contact Trisha Cole on 01449 771922.

BARKER LAB OPEN DAY

The next **Barker Lab Parkinson's Open Day** will take place on November 7, from 10am until 2pm, at the Brain Repair Centre. For more information, email barkerlab.registration@yahoo.co.uk, or call 01223-331160. Details about speakers will be available soon.

CHRISTMAS PARTY AND LUNCH

Our two Christmas events, the Christmas Party and Christmas Lunch, are set for November 27 and December 4 respectively. The first is arranged by John Lewis, who provide refreshments and there is usually a very good raffle, plus other events.

Our **Christmas Lunch** is the next Friday, December 4, starting 12 for 12.30, at the David Rayner Building. This will be our only meeting in December, as the fourth Friday is Christmas Day! Lunch tickets cost £17, and can be bought until November 21 from Margaret Steane at 109 Waterbeach Road, Landbeach, Cambridge CB25 9FA. Make cheques payable to Parkinson's UK Cambridge Branch.

RESEARCH SUPPORTERS' CONFERENCE

Registration has opened for this year's Parkinson's Research Supporters' Conference, which takes place on Saturday, November 14, from 11 to 4pm, at the Crowne Plaza Hotel, Birmingham. The audience will hear first-hand about some outstanding Parkinson's research. Book your place at the conference here: <http://bit.ly/RSNconference>.

DANCE PRODUCTION FOR PARKINSON'S UK

Dance Ensemblé presents 'Take a Step' - the story of Parkinson's illustrated through dance - at the Cambridge Junction on January 8 (7.30pm) and 9 (2pm and 7.30pm) with all proceeds going to Parkinson's UK. During the evenings/afternoon of the show, there will be the opportunity to enter a raffle and win fantastic prizes generously donated by local businesses such as Cambridge University Press, Cambridge University Botanic Garden, David Lloyd, Ocado, Cath Kidston, Heffers, Ark, Catesbys, Fudge Kitchen, Attitude and Capezio. There is even the chance to win a two night stay on the Suffolk coast. All proceeds from the raffle will go to Parkinson's UK. Tickets for the show are £16, available at the Cambridge Junction: Box Office: 01223 511 511 (10am-6pm Mon - Sat) or <http://www.junction.co.uk/take-a-step>. Book before Sunday 1st November to take advantage of the early bird discount (£13.50). If you can't make the show, you can still 'Take a Step' and make a difference to someone's life by visiting www.virginmoneygiving.com, search for 'dance ensemblé' and make a donation to Parkinson's UK - to find out more visit www.dance-ensemble.org.uk or email info@dance-ensemble.org.uk.



NEW TREASURER NEEDED

The Cambridge Branch is urgently in need of a new treasurer. As with all other committee posts, this is an entirely voluntary position, and we badly need to find someone willing to take on the task, which is not particularly onerous but vital to keeping the Branch operating! Experience with general accounting methods is required. If you think you fit the bill – or have a friend or colleague who does – we would love to hear from you! Please contact Ian McKee on 0344-225-3614 mobile 07900-918027 imckee@parkinsons.org.uk.

WINTER CURRY NIGHT

Fancy a curry on a cold winter's night, and raising funds in the process? Join us for just that at the popular Zara Restaurant at 1, Hinton Way, Great Shelford, on February 8 next year, 7-30 for 8-00 pm start (www.zara-cuisine.com/). To book a place, ring Charlie Nightingale on 01223-844763. Cost is just £20 for three courses, great value! A licensed bar will be available.

JOHN LEWIS FASHION SHOW 2016

John Lewis Cambridge will again sponsor a Fashion Show on behalf of the Cambridge Branch of Parkinson's UK on **Wednesday 9 March, 2016**, at 6pm in the Brasserie of the 10 Downing Street shop in Cambridge. Tickets cost £10, include a glass of wine and light refreshments, and can be ordered from Caroline Bent: carolinebent@me.com or 01223 314279, or from February 1 at the Personal Styling Dept. of John Lewis Cambridge.

BRANCH AGM 2016

Next year's Annual General Meeting will take place around 11am on Friday, March 18, at the David Rayner Building, before that day's Branch Meeting. **NOTE: THIS IS NOT THE FOURTH FRIDAY SINCE THAT IS GOOD FRIDAY.**

TULIP FUN-RUN

This annual event, marking the conclusion of Parkinson's Awareness Week, will take place on **Sunday 24 April, 2016**. The four-mile route, departing at 10:30 from the David Rayner Building at Scotsdales Garden Centre in Shelford, can be run, walked or strolled. 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.parkinsoncambridge.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.

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.
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A charity registered in England and Wales (258197) and in Scotland (SC037554).

PARKINSON'S UK – CAMBRIDGE BRANCH CALENDAR – NOV-DEC 2015

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 24 OR 31 DECEMBER

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
NB: NO MEETING ON 5 JANUARY 2016

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

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
NB: NO MEETING 2 JANUARY

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
NB: NO MEETING 26 OCT, 28 DEC or 4 JAN

OF SPECIAL NOTE

NOVEMBER

7: 10am: Open Day at the Brain Repair Centre
27: Branch meeting: CHRISTMAS PARTY,
courtesy of our John Lewis friends –
food, fun, raffle and quiz.

DECEMBER

4: CHRISTMAS LUNCH. *See above*
No additional Branch meeting
24 & 31: No Aquatherapy
28: No Yoga

JANUARY 2016

2: No Nightingale Singers
4: No Yoga
5: No Bring and Share lunch in Milton
8 and 9: DANCE SHOW for Parkinson's
at the Junction – save the date! and *see*
article above
22: Branch Meeting:
10:30 Refreshments
11:00 Dr Lucy Collins of the Brain
Repair Centre "The Use of
Stem Cells in PD Research"
12:00 Lunch
Aromatherapy throughout

FEBRUARY

8: A Curry Night at Zara Restaurant, Hinton
Way, Great Shelford
see article above
26: Branch meeting:
10:30 Refreshments
11:00: Talk by Arthur Brookes, Retired
Interpretive Guide at the American
Cemetery: "So you think you know
the American Cemetery"
12: Lunch
Aromatherapy throughout

MARCH

9: Fashion Show at John Lewis (to be fixed)
18: MAKE A NOTE NOW: THE BRANCH
MEETING AND AGM 2016 WILL BE
ON FRIDAY 18 MARCH (because the
fourth Friday is Good Friday).

APRIL

18 – 24: PARKINSON'S AWARENESS WEEK
24: The Tulip Fun-Run.