

Cambridge Branch Newsletter – January-February 2016

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

SEASONAL GREETINGS!

Happy New Year to all our members!

BARKER LAB OPEN DAY

Another successful Barker Lab Open Day took place on Saturday, November 7, at the Brain Repair Centre, next to Addenbrooke's Hospital. After opening comments from Professor Roger Barker, the first speaker was Professor Maria Grazia Spillantini, Professor of Molecular Neurology, whose presentation centred on Lewy bodies, alpha-synuclein and Parkinson's, and posed the question: do protein aggregates really matter? Her clear answer is: yes! Professor Spillantini made a major discovery in 1997, when she showed that alpha-synuclein was the key component of Dementia with Lewy bodies.

"Parkinson's and Dementia with Lewy bodies (DLB) are very common neurodegenerative disorders," she said. "Records of people suffering from them go back thousands of years. They are characterised by the presence of abnormal filamentous deposits, named Lewy bodies, within some nerve cells, which are believed to degenerate as a result. The Lewy body filaments contain alpha-synuclein as their major component, and alpha-synuclein is involved in the release of dopamine."

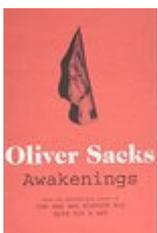
The build-up of too many alpha-synuclein aggregates effectively 'traps' neurons, reducing the amount of dopamine that is released, causing the symptoms of Parkinson's. Apart from Parkinson's and DLB, alpha-synuclein aggregates are involved in several other brain diseases, such as REM sleep disorder, Alzheimer's, and multiple system atrophy.

The second speaker was the Barker Lab's Dr Caroline Williams-Gray, whose topic was the role of the immune system in Parkinson's. It is thought that the immune system is involved in Parkinson's, and also in other conditions including Alzheimer's and strokes. She said the speed of progression of these conditions varies greatly from patient to patient, and it is possible that the immune system is at least part of the cause of this variation, influencing the rate of cell damage and hence progression of the disease. The immune system is involved in controlling inflammation in tissues and previous studies have shown that regular use of anti-inflammatory drugs reduces the risk of Parkinson's by about a third over six years. So, the immune system could become the target for new drug therapies to slow down the progression of Parkinson's.

Other speakers included Julie Wilson, Parkinson's UK's Area Development Manager, who described the aims of the Parkinson's Links project; Simon Stott, who talked about detecting Parkinson's through a breath test; and Natalie Valle Guzman, who described the Transeuro Trial, that is based on fetal cell therapy.

SCIENCE

CANCER DRUG'S REMARKABLE EFFECTS



A drug previously used to treat cancer has produced some amazing results in a small trial with Parkinson's patients. Its effect has even been compared with what happened to people with Parkinson's in the book, *Awakenings*, by neurologist Oliver Sacks. In the trial, people who had been unable to walk or even talk found their condition improved dramatically, in some cases after only a few weeks of treatment.

The drug is called nilotinib, and has until now been used to combat leukaemia. The trial took place at the Georgetown University Medical Centre in Washington DC, and researchers now hope it might work with other conditions such as Alzheimer's. The fact that the drug has already gone through extensive testing in cancer patients should speed up its approval for treating other conditions.

It is thought nilotinib clears away toxic proteins that accumulate in the brain cells of Parkinson's patients, so freeing the cells to make dopamine. The daily dose of the drug for six months had dramatic effects, with some of the participants' worst symptoms being reversed, the Society for Neuroscience's 2015 conference heard. Three patients regained the ability to talk, one was able to walk again and another could feed herself once more. The leader of the trial, Dr Charbel Moussa, said: "We've seen patients at end stages of the disease coming back to life."

The research team found subtle but encouraging signs in the participants' cerebrospinal fluid – the fluid that surrounds the brain and spinal cord – showing that the drug reaches the brain and has beneficial effects. A researcher in the trial, Dr Fernando Pagan, said the drug seemed to be the first to reverse some of the symptoms of Parkinson's, but that larger studies were needed to determine its true impact.

Dr Arthur Roach, Director of Research at Parkinson's UK, echoed this: "The small size of the trial (12 patients) and the lack of controls - people who did not take the drug - means that we cannot be certain if there were positive treatment effects," he said. "The placebo effect with Parkinson's symptoms can be very strong. Just someone's belief that they are taking a new drug could produce these effects. Larger trials would provide a final answer as to whether nilotinib could actually reverse symptoms of Parkinson's – something no current treatment can do. These findings certainly do not suggest people with Parkinson's should start taking nilotinib. Much more exploration is needed to determine how safe the drug is."

But Tom Isaacs, President and Co-founder of The Cure Parkinson's Trust, commented: "The nature of the improvements experienced by the people on the trial were so marked, it seems to me unlikely that these positive results could be attributed solely to a placebo effect."

INHALED LEVODOPA TRIAL

A research study led by Dr Paul Worth at Addenbrooke's Hospital, part of a multi-national research trial, is investigating whether the compound CVT-301, an inhaled form of levodopa, can help people with Parkinson's when they are 'off' – when their medication does not work properly. The researchers aim to understand not just how well CVT-301 can help with 'off' times, but also how quickly it is absorbed into the body when inhaled, and its safety. If successful, the study could lead to a new medical treatment for people with Parkinson's who experience 'off' periods, which is fast working and non-invasive.

To take part in the study, potential participants must meet the following criteria: experience a minimum two hours 'off' every day; live in the Cambridgeshire area and be able to travel to the research site; be on a stable dose of levodopa (also called Madopar or Sinemet); and have no history of asthma or breathing problems. If you meet these criteria, you will first need to attend two screening visits to check you are eligible. If you are, and decide to participate, you will be randomly assigned to either the treatment or the comparison group. The first group will receive inhalable levodopa, while the comparison group will simply be monitored throughout the period of the study without receiving the inhalable levodopa.

Both groups will need to come in to the clinic for regular visits for assessment of their symptoms and lung function, and are allowed to change their background Parkinson's medications (including other available therapies) throughout their participation with a few restrictions. Travel expenses will be reimbursed and the observational comparison group will receive £29 payment for each clinic visit. The closing date for taking part in the study is March 31, 2016. Once the study is completed, researchers will send participants a summary of the main research findings.

For further information, contact the research team directly: Paul Worth or Jacqueline Young, Department of Neurology, Addenbrooke's Hospital. Tel: 01223-348914 or email Jacqueline.young@addenbrookes.nhs.uk.

BRANCH MEETINGS

DANCE FOR PARKINSON'S AND SPECIALIST NURSES

Our October meeting on October 23 heard two presentations. The first featured the Parkinson's Specialist nurses now working in our region: Carolyn Noble, Amanda Eady, Liz Terry, Hazel White, and Lorna Woor. Following four retirements in the last two years, a major reorganisation of the nurses' service has taken place.

Amanda described how the nurses play a vital role in supporting the Parkinson's consultants working in our area. Because the nurses can prescribe Parkinson's drugs, they can effectively manage the handling of patients' medication. They are also crucial in helping to meet the stipulation of NICE (National Institute for Health and Care Excellence), that people with Parkinson's should be seen at least once a year, and typically more often, like every six months.

The other presentation was by Dr Romina Vuono, who described how the organisation, Dance Ensemblé, is a community dance group based in Cambridgeshire that uses dance to raise funds for health related charities (www.dance-ensemble.org.uk). They are due to stage their Take a Step show on January 8 and 9 at the Cambridge venue, The Junction. (See previous newsletter for details, or go to <http://www.junction.co.uk/take-a-step>).

Romina said the benefits of dance for Parkinson's patients were well known, and supported by scores of academic studies into the subject. The Take A Step shows are the product of over 12 months' work focused on increasing awareness of Parkinson's, and raising vital funds for Parkinson's. Dance Ensemblé's regular classes take place at the Frank Lee Leisure & Fitness centre, at Addenbrookes Hospital.

CHRISTMAS PARTY AND LUNCH



Christmas got off to an early start this year, with branch members enjoying two events in consecutive weeks. The first was the Christmas Party, hosted as ever by John Lewis, which took place on Friday, November 27. The party was well attended and included the usual refreshments, raffle and Christmas-related quiz. Again, many thanks to John Lewis for its generosity and continual support for the branch. The party clearly helped put everybody into a festive mood, being followed a week later by the Christmas Lunch (left). This was equally well attended, with more than 50 members enjoying a three-course lunch with wine.

CARERS' GROUP

Changes are being made to the scheduling of the Carers' Group meetings, as Parkinson's nurse Amanda Eady explains: "For some time we have been concerned that the Carers group that we have been running at Brookfield's Hospital on the second Friday of each month has not been reaching many of the Carers. We have decided to change the format of the group so that it will meet quarterly, with the next meeting now set for March 11, 2016. This will allow us more time to reach people who we are not reaching at the moment.

"We are very interested to hear of any other support groups that members attend so that we can point people towards a range of services that may be able to help them. We look forward to hearing from your members as we know that there is a lot going on in different areas that we do not know about. We would request that people call us on the usual number (01223 723018) to confirm that they would like to attend. We are trying to book a speaker on the subject of First Aid in the Home for the March meeting.

"Lorna Woor would like to thank everyone at the branch meeting in November for their support with the stall. We reached the grand total of £170. The proceeds will be going to the Cambridge branch."

SOCIAL MEDIA

We would very much like to know how our members feel about social media systems such as Twitter and Facebook. Does this matter to you? Do you use it a lot, just occasionally, or have nothing to do with it at all? Does it appeal or appall?! Please contact us to tell us how this phenomenon of the 21st Century affects you or does not.

DATES FOR YOUR DIARY

OUR BRANCH AT VOLUNTEER FOR CAMBRIDGE

Your branch has succeeded in getting a stall for the Volunteer for Cambridge event, which takes place on Saturday, January 30, from 11am to 4pm, at the Guildhall in Market Square. Volunteer for Cambridge is a city-wide fair that will bring together 80 Cambridge-based organisations who work to create positive social and environmental change through volunteering.

The fair will feature a marketplace of charities, voluntary organisations and student societies, as well as a programme of talks from high profile individuals and community groups. Two of the speakers at the 2015 fair were the Mayor of Cambridge, Councillor Gerri Bird, and Dame Mary Archer. There will be refreshments available, and even an activity area for children.

The aims of the fair are to get more people involved in volunteering, and bring together organisations with shared aims. Anyone and everyone in Cambridge is welcome to attend. We will need branch members to come to help on the stall and talk to the public, so if anyone can spare an hour or two, it would be very much appreciated! Please contact Caroline Bent on 01223 314279, mobile 07922-479289, or email: carolinebent@me.com The event is organised by the Cambridge Hub, managed by Anna Malan.

SINGING AND PARKINSON'S COURSE

A special training course taking place at Snape in Suffolk in January aims to offer a unique opportunity for musicians and emerging artists to gain invaluable experience and knowledge in how to run a singing group for people with Parkinson's and their carers.



The course will be led by Grenville Hancox, Honorary Professor in Music, Health and Well Being at Kent University, co director Sidney De Haan, from Canterbury Christchurch University, a world renowned expert in singing and wellbeing, and Nicola Wydenbach, an experienced Parkinson's and Singing practitioner.

The aim is to give participants a greater awareness and understanding of Parkinson's and singing. As well as gaining practical experience of working in this context, those doing the course will work alongside people with Parkinson's and their carers each afternoon. (People with Parkinson's who come for the afternoon can come to either or both days). There will be practical workshops and demonstrations on how to lead warm-ups and songs, and other activities, as well as practical advice about how to set up and run a group once the course is finished.

Singing and Parkinson's is a two-day event, taking place on January 25 and 26, from 10.00 to 4.00pm at the Snape Maltings, Recital Room, Snape, Suffolk IP17 1SP. Tea and coffee will be provided but not lunch. There are local sandwich shops nearby, or you can bring your own. To book a place please contact Nicola Wydenbach at nicolawydenbach@yahoo.co.uk or 07967-442935.

JOHN LEWIS FASHION SHOW

Following the success of last year's event, another Parkinson's Fashion Show supported by John Lewis is set for Wednesday, March 9, taking place in the Brasserie at the John Lewis department store in Cambridge. Doors open at 6pm, and the show starts around 6.30pm, lasting about half an hour. It's late opening night at the store, so everyone will have another hour to visit the rest of the store until 8pm.

As before, some of the models for the show will be Parkinson's Cambridge members, others will be supplied by John Lewis. Anyone wanting to come must have bought a ticket, costing £10 each, which 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.

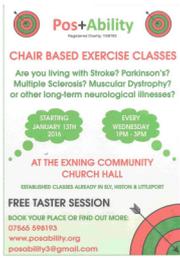
Tickets will be available from Caroline Bent, 01223 314279, 21-23 Covent Garden, Cambridge CB1 2HS carolinebent@me.com; at Branch meetings at the David Rayner Building, and from the Personal Styling Dept of John Lewis. The John Lewis store is at 10 Downing Street, Cambridge (tel 01223-361292), and parking is available in the Grand Arcade car park, with blue badge parking on the ground floor. The Brasserie is on the third floor of the store.

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 Monday, February 8, 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.

NEW EXNING EXERCISE CLASS

A new chair based exercise class for people who are living with Parkinson's, have multiple sclerosis, had a stroke, or suffer from any other long term neurological illness, is being set up by Pos+Ability, who already run similar classes in Histon, Littleport and Ely. The new class starts at 13.00 on Wednesday, January 13, and takes place at the Exning Church Community Hall. The first taster session is free, then the charges are £4 per two hour session for the first six weeks, to February 17 inclusive, then it goes up to the standard charge of £8 per two hour session. For more information, see <https://posability3.wordpress.com/>, or email Linda Neate at linda.neate21@gmail.com



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, April 24**. 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 (from January) 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. Everyone is welcome and if you don't want to run – or walk – stewards will be needed to help with the start and finish, distributing posters, or making the tea!

PROFESSOR BARKER TO GIVE GRETSCHEN AMPHLET LECTURE

The 2016 Gretschen Amphlet memorial lecture, given annually, is due to take place on Tuesday, April 12, in the auditorium at Fitzwilliam College, Cambridge. The speaker will be Professor Roger Barker, the head of the Barker Lab, which is sited at the Brain Repair Centre, next to Addenbrooke's Hospital in Cambridge. The lecture, now in its seventh year, is funded by John Amphlet, in memory of his late wife Gretschen, who had Parkinson's. The lecture will start at 7.30pm. To reserve a free place call 020 7963 9309 or email: rsvp@parkinsons.org.uk.

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.
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 – JAN-FEB 2016

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
Quarterly, 10:30-12:30 – see "Of Special Note"
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 28 DEC or 4 JAN

OF SPECIAL NOTE

DECEMBER 2015

No 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: NO Carers' Meeting

8 and 9: DANCE SHOW for Parkinson's at the
Junction – please support if you can!

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

12: NO Carers' Meeting

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 ; *see* article above.

11: Carers' Meeting

18: Branch meeting **NB: THE THIRD FRIDAY**

10:30: Refreshments

10:45: AGM

11:15 Speaker TBA

12: Lunch

Aromatherapy from 11:00 – 13:00

APRIL

12: The Gretchen Amphlet Memorial Lecture
see article above

16 – 24: PARKINSON'S AWARENESS WEEK

22: Branch meeting Speaker TBA

24: The TULIP FUN-RUN. *See* article above