

Cambridge Branch Newsletter — January-February 2019

Editor
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BRANCH MEETINGS

CHRISTMAS PARTY IS FOLLOWED BY RECORD ATTENDANCE FOR LUNCH

Branch members clearly enjoy the festive season, at least if the last two events of 2018 were anything to go by. A successful party took place near the end of November, featuring as usual a quiz, followed by a special raffle – special, because there are so many prizes, virtually everyone wins something! (No complaints from the unlucky few, please).

As usual, the event was managed by our friends from John Lewis, to whom we are extremely grateful, as we are for their help and work throughout the year. As ever, many thanks for all your efforts!

The party was followed three weeks later, on December 14, by our Christmas lunch. This attracted what could be a record attendance, around 70, probably the maximum our location, and caterers, can manage.



Clearly, the new subsidy for the lunch, introduced this year, has proved popular. If you were a paid-up member of Parkinson's UK, the cost was just £5. With wine included! If this signalled the End of Austerity, it clearly went down well with everyone. So Happy New Year to all members. And dare one say: time to forget about Brexit for a few days!

TULIP DRAW WINNERS

The Tulip draw winners for November were: Rosie Meikle (ticket no. 6); and Trish Carne (36); and for the special draw in December, where the prize is £30: John & Margaret Ardley (34); and Eileen Shipp (12)

NEWS AND EVENTS

VOLUNTEERS NEEDED TO SHAPE FUTURE OF RESEARCH SUPPORT NETWORK

Parkinson's UK is looking for new volunteers to join its Development Team, to help shape the future of the Research Support Network (RSN). This brings together people looking to help find a cure and better treatments for Parkinson's. Through the Network, anyone can take part and have their say in Parkinson's research.

The RSN Development Team acts as a steering group, helping to shape the Network's communications, projects and events, and setting development priorities. The Development Team volunteers represent the views of the wider RSN, advising and supporting Parkinson's UK in the effective delivery and improvement of the Network.

The team's main aims are to: champion the involvement of people affected by Parkinson's in research; review their involvement in the charity's research strategy, plans and activities; and identify gaps and propose ways of addressing them. Volunteers meet with staff at Parkinson's UK's London head office four times per year (some join in via Skype too). They also offer feedback on projects and documents on an ad hoc basis over email.

"We're currently recruiting up to four people to make our team of 12 volunteers complete," says Liz Nash, Research Support Network Manager. "We're especially interested in hearing from people under represented in the RSN, in particular those from diverse backgrounds and working age people."

"Anyone is welcome to apply, including partners, carers, family members, healthcare professionals and researchers. No experience is necessary, just a willingness to champion research and have your say."

Volunteers' travel costs to and from meetings are reimbursed. If you'd like to find out more about joining The Development Team, contact Liz Nash, on lnash@parkinsons.org.uk, 020-7963-9398.

'FLAGSHIP' LECTURE FROM PARKINSON'S UK FOCUSES ON ELECTRONIC APPS

Described by Parkinson's UK as its 'flagship research event', the Florence Pite Memorial Lecture took place on November 7, with a live online stream provided for supporters and the public. Florence Pite was a member of the Guildford Parkinson's branch who left a generous legacy, and the lecture is in her honour, held annually at the Institute of Chartered Surveyors in Portland Square, London.



The lecture series has typically showcased developments in clinical research sponsored by Head Office. But this one focused on another vital area of work being supported by Parkinson's UK – technology to beat Parkinson's. "Two things make this lecture different," said Mark Goodridge, Chairman of the Board of Trustees for Parkinson's UK. "One is that the subject matter is electrons not molecules" (ie, digital electronics rather than brain chemistry). The second difference, he said, was time – talking about things available now, as opposed to years in the future, so often the case for drug development.

The main speakers were Julie Dodd, Director of Digital Transformation and Communication at Parkinson's UK; Jackie Hunter, Director of Artificial Intelligence at BenevolentAI (above); and Emma Lawton, now Devices and Apps Strategist at Parkinson's UK.

Jackie said a fundamental problem faced by medical science today is the sheer growth in information. This is generating some remarkable

statistics: for example, some **90% of the data ever produced** was published in the last two years. A new research paper is published **every 30 seconds (24/7)**; and 10,000 biomedical research papers are uploaded on to the Internet **every day!** No organisation, let alone an individual, can keep abreast of this tidal wave of information, Jackie said.

Powerful AI-based tools and techniques are now vital in enabling us to make good use of this explosive growth in data, she said. Her company recently started working with Parkinson's UK to help to accelerate a project for People with Parkinson's (PwP), and in the process, demonstrate best use of BenevolentAI's software platform.

Emma Lawton – who spoke, memorably, at our August meeting last year – talked about the development of the Apps and Devices Library recently set up by Parkinson's UK (see the website using that title).

Already, this features products to help with activities ranging from walking and exercising, to sleeping and communicating. Items are not included in the library lightly, Emma said: "It's similar to recommending a medication. We have to be sure it's going to help people."

SCIENCE AND RESEARCH

So much is happening in R&D – here are some brief summaries, with links to more details:

ARTIFICIAL INTELLIGENCE DIAGNOSIS

Chinese technology enterprise Tencent has joined forces with UK healthcare company Medopad and the Centre of Excellence in Parkinson's and Movement Disorders at King's College Hospital in London, to create AI software that may be able to diagnose Parkinson's in less than three minutes. <https://www.bbc.co.uk/news/technology-45760649>

HORSE TRANQUILISER FOR DYSKINESIA

US neurologists at the University of Arizona are trialling a horse tranquiliser, ketamine, an anaesthetic drug that is also used by people recreationally. The hope is the drug will help to treat PwP who have developed dyskinesia by taking L-dopa. <http://www.parkinsons-newstoday.com/2018/07/23/>

APPENDIX REMOVAL LOWERS RISK

People who have had their appendix removed early in life have a lower risk of getting Parkinson's decades later, researchers report. That is possibly because the appendix seems to store the protein alpha-synuclein, a feature of Parkinson's.

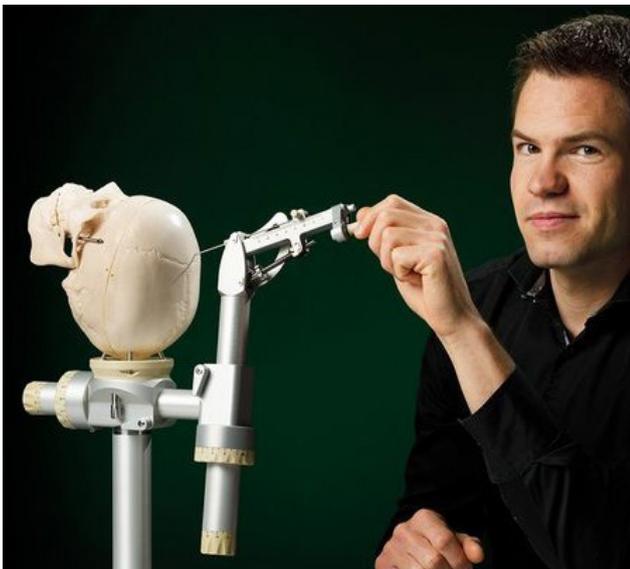
<https://parkinsonsnews-today.com/2018/11/05/>

PFIZER LAUNCHES NEW COMPANY

Pharmaceutical company Pfizer has formed a new biopharmaceutical company called Cerevel Therapeutics that will develop drugs for Parkinson's and other conditions. It will begin working on phase three clinical trials of an agonist drug designed to increase levels of dopamine in the brain. Cerevel will also develop several Pfizer drug programmes that the company closed earlier this year. www.pharma-ceutical-technology.com/-news/pfizer-cerevel-therapeutics/

TOOL PRECISELY POSITIONS ELECTRODES

A Dutch engineer at Eindhoven University, Marc Janssens, has developed new instruments for precisely positioning the electrodes used in DBS. They should enable more brain surgeons to perform the operation, and help to shorten waiting times.



The key feature is a disc that is placed on the back of the head using three surgical screws. This provides the vital fixed reference point. Eindhoven Medical Robotics intends to further develop the instrument and bring it to market. <https://www.tue.nl/en/research/>

NON INVASIVE APPROACH TO DBS

A non-invasive technique for DBS is under development at Imperial College, London, which involves placing electrodes on the scalp, rather than inside the brain. Called Temporal Interference (TI) stimulation, it uses electric fields of different frequencies to simulate brain activity. A study involving mice showed that TI can activate neurons in the hippocampus, which is deep in the brain. TI stimulation is precise, only stimulating the targeted neurons. A clinical trial is planned. <https://www.imperial.ac.uk/news/1877-26/experts-discuss-sensors-stimulation-method-treat/>.

Meanwhile a study has shown that DBS based on focused ultrasound not only helps with tremor but produced benefits for people in several aspects in their quality of life, including mood and cognition. <https://medical-xpress.com/news/2018-11-scalpel-free-surgery-quality-life-parkinson.html>

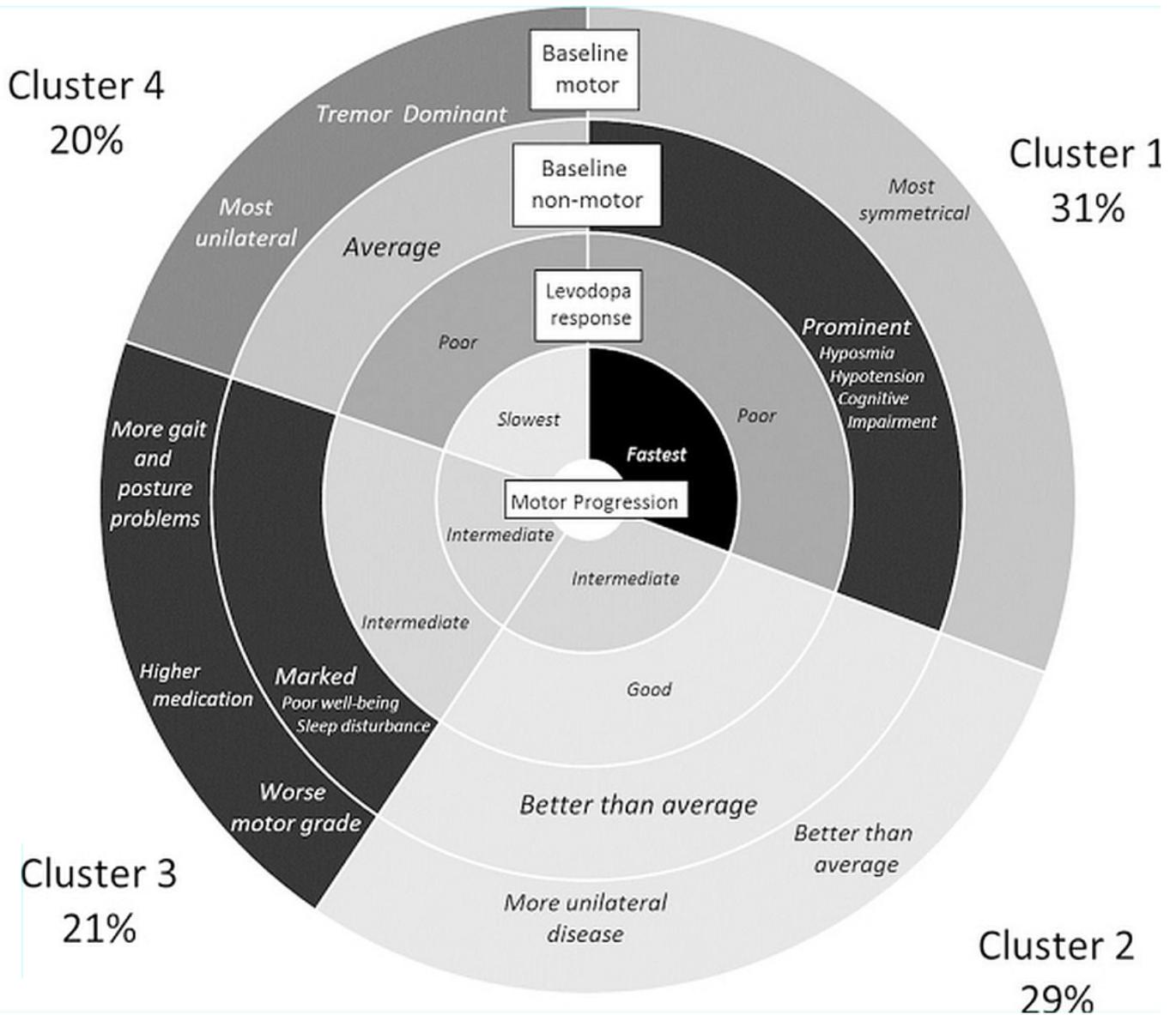
SUB-TYPES THE KEY TO TAILORED TREATMENTS – LIKE CANCER

An excellent article is available on the Parkinson's UK website, arguing that a key to better treatments is the increasing awareness that Parkinson's should be divided into several sub-types. It compares the situation with cancer years ago, when all cancers were typically treated with chemotherapy, radiotherapy or both. Then it was realised that not all cancers are equal, and that targeting the biological features of the particular cancer could provide the key to better treatments. Cancers needed to be sub-typed.

To sub-type Parkinson's requires examining things like patterns in symptoms, response to treatment, and progression. It means studying large numbers of people over time, which two studies funded by Parkinson's UK are now doing: Tracking Parkinson's, and the Discovery Study. Recently, the two teams joined forces and used powerful data analysis to identify possible sub-types.

Analysis showed that four clusters of people with similar symptoms at the start tended to progress in similar ways (see diagram). For example, those with a tremor mostly on one side, an average level of non-motor symptoms, and who respond poorly to L-dopa, seem to have the slowest progressing form of the condition.

“What's most exciting about identifying these clusters is the potential they may bring to provide the right treatments and support – whether that



be drugs, exercise or other therapies – to suit individuals and their form of the condition best,” says Deputy Research Director at Parkinson’s UK, Dr David Dexter.

It may be that different biological problems lie at the heart of the sub-types and require varying treatment approaches. One example is genetics, where the discovery of one of the most common genes known to be involved in Parkinson’s – LRRK2 – has led to the development of new drugs, LRRK2 inhibitors. One is due to be tested on PwP in 2019. Encouragingly, recent research suggests that treatments reducing LRRK2 activity may be beneficial for people with other forms of the condition too.

Sub-typing could improve the testing of new treatments in clinical trials. That is because in trials

today everyone with Parkinson’s is included, so the result is a mix of people, some who progress slowly, some rapidly. Not surprisingly, this often means that results show a range of responses, with some people responding well to the new treatment and others poorly.

This inconsistency makes it very difficult to assess the ability of new drugs fairly. Is a drug useless or does it only work in certain sub-types? Much more accurate assessment of sub-types will enable trials to test the right treatments in the right people. This has the potential to massively accelerate the hunt for new and better treatments and ultimately a cure.

VIEWPOINT

Have non-motor symptoms been ignored?

We all know the classic symptoms of Parkinson's: tremor, rigidity, bradykinesia, and postural instability – even though each individual case can differ widely. A good proportion of PwP never have a tremor, for instance. But these are all motor symptoms. What about non-motor symptoms? These might include fatigue, bowel and bladder control issues, apathy, sleep disorders, and loss of sense of smell. Such symptoms are less specific, but as anyone with the condition knows, they are often major aspects of what having Parkinson's involves. Yet some people feel they are still not taken seriously enough, seen as more of an adjunct to the central, motor, symptoms.

This is certainly the view of one person with a special perspective on Parkinson's, Dr. Jon Stamford. Special, because for 20 years he was a Parkinson's researcher – before he got it himself. "I had to become a patient before I really understood this condition," he says. "My research papers as a scientist were testaments to what we **could** measure in Parkinson's, not what we **should**."

Stamford's view is that it is easier to treat Parkinson's as a movement disorder, because the symptoms are relatively simple to identify, and in clinical terms, to try to treat. For example, a reduction in the amplitude of tremor is something numerical and therefore 'scientific'. "Results are visible and quantifiable by physicians," he says. "And in a research culture where early success or failure can build or blight a career, it's easy to see why some areas of research are more fashionable than others." In contrast, symptoms like apathy and fatigue remain less amenable targets.

There is a tendency to believe that the non-motor symptoms of Parkinson's are being newly identified. The use of quantifying scales has put the spotlight on them, and the medical research community has begun to show interest. But non-motor symptoms are nothing new. In his original essay on the shaking palsy, Dr. James Parkinson described non-motor symptoms: he knew they were part of the condition.

Non-motor symptoms are often difficult to define and treat, as they are often interlinked. But ask most patients and you find non-motor symptoms impinge as much on their quality of life as mobility. "They are vital components in Parkinson's," Stamford says. "That is because it is a truly broad-spectrum, neuropsychopathological condition."

REACTIONS TO LAST ISSUE'S VIEWPOINT

The newsletter is delighted to have received several replies from readers to the last Viewpoint column, by Jill Hartley. She was unhappy about the term 'carer', and asked for suggestions about names for people involved with someone who has Parkinson's. We may not all agree, but following are some ideas. And many thanks for the varied contributions. Keep the correspondence coming!

FROM KAYE RIGLEY

Hi Jill,

I have just read your article. My husband was diagnosed with Parkinson's in February whilst in hospital recovering from a stroke. So all this is new to me. I so agree with your article. David introduces me as his PA, and I find this quite acceptable. Caring is a given, having been married 49 years.

FROM MARGARET STEANE

Dear Editor,

I enjoyed reading your correspondent's Viewpoint in the recent edition of the Newsletter. As someone who has no close personal connection with a PwP, perhaps I should not take part in this discussion. But I like thinking about words so here, in alphabetical order, are a few ideas:

Arranger
Backer
Back-up
Boost/er (sounds like a rocket!)
Encourager
Personal Assistant/PA
Shield

I hope you receive lots of suggestions!

FROM ALIX ALLAN

I read Jill's article in the newsletter. What is wrong with just being called 'wife'? Wives have been carers, lovers, friends, protectors, guardian angels, Mums, workers, nurses, gardeners, cooks: you name it, we do it, and since time began. I have beaten you Jill by a few years: we have been married for 48 years now – I was a child bride! Like you, we have been through thick and thin, and while we are no Darby and Joan, we care for each other. When illness rears its ugly head we are always there for each other.

FROM MARK HOFFMAN

David/Jill,

I have just read your wife's column, (which was headed 'WHAT'S IN A NAME?'). That's easy! Your wife Jill is your 'PARKINSON'S PARTNER' – just as my wife, Mary Jo, is my 'Parkinson's Partner'.

FROM ROS JACKSON

Dear Editor,

Having worked as a registered nurse until retirement, I have always been proud of working in 'The caring profession'. Since Jerry's Parkinson's diagnosis, I have no qualms about being his carer regarding form filling for certain entitlements.

However, as his wife of 45 years, I consider myself his partner, confidante and friend. I don't think I need a label. If Jerry was on his own with a paid, live-in carer, it would be different. I hate the word 'enabler', it sounds mechanical, like something from a garage or workshop! 'Supporter' sounds a bit rowdy and 'footbally'! And a protector sounds like an item for birth control! I am happy to be known as Ros, Jerry's wife. Whatever it takes, I will be there for him, barring deterioration of my own health. So if you want to call me a carer, so be it. But I am Ros, and Jerry, my husband, has Parkinson's.

DATES FOR YOUR DIARY**HELPLINE HOURS OVER CHRISTMAS**

Parkinson's UK will be operating its Helpline over the Christmas period, in a limited form. It says it can be very busy during this time, so the Helpline's focus will be on dealing with medical enquiries as these are the greatest priority for PwP. The opening hours will be:

December 22: 9-7pm

December 23: 10-1pm

December 24: 9-12.30pm

December 25-26: closed

December 27-29: 10-2pm

December 30-January 1: closed

January 2: 9-7pm

You can contact the free helpline on 0808-800-0303.

LIGHT SHOW AT CANARY WHARF

A Swedish designer and a scientist are creating a project using light-art to raise awareness of Parkinson's. Malgosia Benham, is a multi-disciplined designer of architectural lighting and visual designs, and Grazyna Söderbom is a specialist in science communications. They have co-founded SciLuminArte and its first project, Shadow Movements of Mind and Body, focuses on Parkinson's. "We want to raise public awareness of Parkinson's and, through light-art installations, inspire understanding of how it feels to be affected by it," explains Grazyna.



Their maiden project will take place at the Winter Lights Festival, to be staged at Canary Wharf in London from January 15 to 26, 2019. This is a free event featuring light sculptures, structures and installations by international artists. To help with their project, they would appreciate hearing from anyone who could give them a deeper understanding of the true impact of Parkinson's on daily life.

"We're also keen for some short quotes that we might use in the light installation and/or to provide information about our work and Parkinson's," says Malgosia. "So if you'd like to help us understand how Parkinson's affects you and/or your loved ones, we'd be delighted to hear from you." Please contact Malgosia at malgosia@sciluminarte.com (07816-773431) or Grazyna at grazyna@sciluminarte.com.

Winter Lights returns for a fifth year bringing together some of the most imaginative and exciting

international artists working with light art today. The festival draws upon state-of-the-art light technology to deliver spectacular artworks, installations and experiences – many of them interactive or responsive – and has continued to gather pace with bigger and brighter installations every year.

PROFESSOR BARKER SPEAKS IN MARCH

The speaker at our Branch Meeting on March 22 will be Professor Roger Barker, well known to us through many events, such as Open Days at the Lab, part of the Brain Repair Centre. A must for the diary!

TULIP FUN RUN: SUNDAY, APRIL 14, 2019

Please get this date in your diary for 2019 and share the information with family and friends. The Tulip Fun Run continues to be the largest fundraising activity that our Cambridge branch organises – and is the only Parkinson's UK Fun Run staged by a Branch! We need your help to encourage everyone you know to take part next spring.

People able to walk, jog or run the four-mile route, which starts from the David Rayner Building can register online at www.active.com/cambridge/running/distance-running-races/tulip-fun-run-2019, or

complete and return the paper application form, which will be available at forthcoming Branch Meetings. Entry fees are £10 for adults, £5 for under-16s.

We encourage all members to spread the word – particularly over the Christmas holiday period – to get as many participants as we possibly can. And encourage them to work really hard at getting sponsors for the event! Our aim is to make 2019 the best year yet, and to raise more funds than ever.

SURVEY ON PUBLIC'S PERCEPTION

Parkinson's UK is conducting a survey to find out more about the public's perception of Parkinson's. It says research consistently shows that people don't understand the severity of Parkinson's. "We want to change this perception. We need information about the true challenges of the condition, to build media stories about its lesser known aspects, and how it affects everyday life." The survey takes only about 20 minutes to complete, and responses are confidential and anonymous. Please take part and encourage others. It is available at <https://mipro.li/Fn98MzT>. For paper copies, email pr@parkinsons.org.uk or call 020-7963-9370.

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 (Replacing @ symbol with ('at') and . with (dot) in the email address reduces the possibility of spam)
 Gabby Farrow (Honorary member): 01223-356433

USEFUL CONTACTS

Parkinson's Local Adviser – Candy Stokes 0344-225-3618 cstokes@parkinsons.org.uk
Facebook: www.facebook.com/parkinsonsukcambridge/
Twitter: <https://twitter.com/CambBranchPUK>
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: for help and information contact the Parkinson's Nurse Team on 0330-726-0077
Addenbrooke's Hospital Parkinson's Nurses 01223-349814
Branch Website: www.parkinsonscambridge.org.uk
Parkinson's UK 020-7931-8080 enquiries@parkinsons.org.uk www.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 — JANUARY-FEBRUARY, 2019

REGULAR MEETINGS AND ACTIVITIES

Aquatherapy

Thursdays weekly, 14:30-15:30
Chesterton Sports Centre, Gilbert Rd, CB4 3NY
Contact: Laurie 01223 295711

Aromatherapy

Alix Allan will be at the Branch Meeting and at the Milton Bring and Share Lunch every month.

Branch Meeting

Fourth Friday of every month except December
10:30-13:30,
David Rayner Building, Scotsdale's 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

NOT 1st January

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

Music Therapy

NB: CURRENTLY ON HOLD

Fridays weekly, 14:00 to 16:00
The Arbury Community Centre, Campkin Road,
Cambridge CB4 2LD
Contact: Alison 07936 191655

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
Contact: Denise 01954 202235

OF SPECIAL NOTE

DECEMBER

27: No Aquatherapy
28: No MusicTherapy
31: No Yoga

2019

JANUARY

1: No Bring and Share lunch at Milton
3: Aquatherapy resumes
7: Yoga resumes
18: Collection at Tesco Milton
25: Branch Meeting
11:00 Speakers: representatives of "Forever Active", including Davina Mee, FA instructor; and possibly someone from the NHS falls team.
12: Lunch
Aromatherapy throughout

FEBRUARY

15: Collection at Tesco Bar Hill
22: Branch Meeting
11:00 Speaker: Grazyna Söderbom of "SciLuminArte" – see article above
12: Lunch
Aromatherapy throughout

MARCH

22: Branch Meeting
10:30 AGM
11:00 Speaker: Dr Roger Barker of the Barker Lab at the Brain Repair Centre
12: Lunch
Aromatherapy throughout

APRIL

11: World Parkinson's Day
Collection at Waitrose, Trumpington
14: TULIP FUN RUN – see article above

Suggestions for April and May speakers would be welcome. Speak to Caroline Bent.

On 28th June the speaker will be the Lord Lieutenant of Cambridgeshire, Mrs Julie Spence.

On 26th July Horry Parsons will continue his fascinating story of the building of the Millennium Tower at St Edmondsbury Cathedral