

OUR NEWS

Oxford and District Branch quarterly newsletter

Chair's Chat: **Sally Bromley**



Due to a range of complications we were unable to produce a newsletter in December, and I apologise. I do not think I could launch into Spring without commenting on the concerts in November and December.

Daniel Harding conducted the Oxford University Orchestra at the Sheldonian Theatre for a wonderful concert of Mendelssohn's Violin Concerto with soloist Carolin Widmann, and Berlioz' Symphony Fantastique. It was a memorable evening of high quality music and we thank Daniel and Carolin for their generosity.

In December we enjoyed the Christmas Concert from Christ Church Cathedral. With Ian Hislop, Rory Bremner, Paul Mayhew Archer, John Foster, Tom Poster and Clemmie Franks performing alongside Commotio Choir, with a world premiere carol by Bob Chilcott and starting with the song 'Refuge' performed by the Parkinsingers, it couldn't go wrong! The cathedral was packed with about 840 people. We were delighted so many people enjoyed the evening and so many commented that they found out a great deal about Parkinson's.

Our year to March 2017 raised substantial sums (details inside), most of which will be passed to a project at the OPDC. Raising money is not for the faint hearted and Kit has held the fundraising reins for about three years with each year raising more than the one before. Our thanks for his devotion, organisation and sheer determination.

I anticipated this year would not be so busy, but I was wrong. In March alone we had two coffee mornings, a poetry and music evening 'Pity of War' and a concert of traditional folk music.

The branch spring lunch at the Doghouse was another success arranged by Jem. It is always so warming to see members chatting with each other over a meal. Plans for this year are under way and we have just produced the new Branch Leaflet. Please note the new logo we have to promote our branch. We are also working hard on the new Oxford Branch web site, which should be set up in the coming weeks (oxfordparkinsons.org.uk)

I am delighted to welcome Pen Keyte, who has volunteered to take over as Branch secretary, and Diana Townsend, as Membership Secretary. Their appointments were confirmed at our AGM in March. They replace Diane & Ian Pearson, who retired at the AGM. My personal thanks to Diane for her quiet and most efficient service over the past few years, and best wishes to them both for the future. We also said goodbye to Jim Sheridan who has kept us up to date with all things to do with research. Though moving to Reading we are hopeful he'll still be coming to meetings. He is replaced by Kevin McFarthing.

Spring 2017

NEW MEMBERS

A warm welcome to :

Jesmond Blumenfeld;
Peter & Valerie Burns de Bono;
Charles Gibbons; Patricia Hudson;
Nicholas & Doris Pinnock,
Pam Watson,
Philip & Marion Hawtree;
Edward Carter;
Mohan & Teresa Francis,
Roger & Nina Marshall;
Eileen & Brian Murphy;
Peter & Irene Snook
Bill Atkinson:
Binal & Monika Prodhon;
Richard & Rachel Hawes:
Nigel & Elizabeth Bridle:
Cyril & Chris Tennant

We are sad to record the deaths of
Edward Fletcher, Mary Turner,
David Rich, Rob Medcalf,
John Taylor, and Alan Bryden.
Our sympathy to all their families

COLIN DEXTER, the creator of Morse
& Lewis, died two weeks ago.
Colin was a good friend of the Branch,
sometimes coming to start our walks
or present prizes. We shall miss his
cheerful support

200 CLUB WINNERS

Jan:

£25.00 - Jo de Goris

£12.50 - Brian Murphy

Feb:

£25.00 - Paul Mayhew-Archer

£12.50 - Laurence Devlin

March:

£25.00 - Paul Weaving

£12.50 - Diana Townsend

*This year commemorates 200 years since Dr James Parkinson recorded his observations in his "Essay on the Shaking Palsy". To mark this important date we are holding a conference on Mon September 18th at Wesley Memorial Methodist Church in Oxford. Most exciting is that The Bodleian Library are likely to put on an exhibition to run alongside our conference, at the Weston Library September 15-19. Further info inside.
Happy reading,*

HEALTH AND WELLBEING

by Sally Bromley

oxford.sally@gmail.com

01865 311302

Many of you will have heard of First Steps, though some may not be aware of what it actually is. Do you recall the feelings you had at the point of diagnosis and the days and weeks following?

First Steps is a two day workshop for newly diagnosed people and it aims to inform about Parkinson's, to explain what you can do to help yourself, and to raise awareness of gaining a good quality of life. The initial inspiration came from the European Parkinson Therapy Centre in Italy. It was apparent from early on that replicating such a centre in the UK was not yet feasible, but addressing the needs of people new to Parkinson's and their families was an area that needed attention. Nothing like it had been done before.

Having first got an outline for the workshops, Alex Reed, from Italy, Peter Harling who lives near Witney and had been to the Italian centre, and I, wrote the workshops. They were verified by PUK, tested on members of our branch before a check on newly diagnosed people. Having ascertained its effectiveness it has now been running in Witney Lakes for two days a month for over a year. So, what does it cover?

Day One:

Facing the impact of diagnosis, addressing fears, knowing where to find services, gaining better insight into the condition and planning for the next session.

Day Two:

Reviewing progress from day one, understanding of practicalities – employment, driving, etc, finding out about the benefits of an exercise programme and planning for the future.

The sessions are led by two facilitators both of whom have Parkinson's. There is plenty of time for group discussions and gaining support from each other. By now you are aware that the whole scheme has the hallmark of Parkinson's throughout having been thought of, designed by, written and tested on people with Parkinson's, and delivered by people with Parkinson's.

Feedback continues to be most positive with scores being 95% and above.

Typical comments:

"Excellent and informative"

"Reassuring, encouraging, valuable. useful, vital, humorous, outstanding, supportive.....and more".

And personal comments:

"My husband is in much better spirits than he was and I am much better too. It has helped me considerably – I am more relaxed and able to cope with it all".

"I would strongly recommend that this sort of course is made available to as many people as possible as its overwhelmingly positive tone and outlook sets the tone for the rest of people's Parkinson's journey".

PLANS for 2017 include training more facilitators, using Witney Lakes as a demonstration site for people to appreciate its value, introduce new venues in other parts of UK so more people can benefit from taking part.

IF YOU KNOW of anyone who is newly diagnosed, or if you'd like to train to become a facilitator, please contact Kathryn McLoughlin on 020 7963 9381 or email kmcloughlin@parkinsons.org.uk

EXERCISE

We are delighted to report that over 300 names are on the registers of our exercise classes throughout Oxfordshire. The classes are subsidized or fully funded, specifically for people with Parkinson's

VOICE

Currently there is just one class addressing voice issues. It is run at our Botley WI hall, on Fridays at 11.45, and it has a keen regular following. It includes some voice sound work in addition to singing together

MINDFULNESS

New to us is a pilot course of Mindfulness, again for people with Parkinson's, run by Azize Stirling for a group of about eight people – 10 sessions with a break in the middle. When given the option to stop or carry on, only one fell out. Azize is also an Alexander Technique teacher, and she has guided the group to "mindful walking". Most feel this has been of benefit to them.

RESEARCH CORNER

by Jim Sheridan

parkinsonsoxford.research@gmail.com



New Research Advisor for Oxford Branch

This will be my last Research Corner, following my recent move to Reading. The good news is that Kevin McFarthing has offered to take over as Research Advisor. Hilary and I won't miss any of you ... because we'll still attend Oxford Branch meetings and events.

OxQUIP Trial to Quantify Parkinson's

Prof Chrystalina Antoniades and Dr James FitzGerald, who are close friends of the Oxford Branch, have set up a new research trial to quantify



Parkinson's. The Oxford study of Quantification in Parkinsonism (OxQUIP) is recruiting subjects with Parkinson's and Progressive Supranuclear Palsy (PSP). The study is directed at the use of technology to develop new ways of measuring symptoms as precisely as possible so that when new drugs are ready to test, researchers will be able to very accurately measure their effectiveness in clinical trials. Hopefully, once the value of the tests has been assessed, we may even see some of them being used in routine clinical consultations to assess patient response to established medication.

The team was interviewed on 31 October by BBC South, Jack FM and Oxford Mail. Oxford University Hospitals Communications Manager, Oliver Evans, has provided the following links:

<http://www.ouh.nhs.uk/news/article.aspx?id=553>

<https://www.youtube.com/watch?v=dHTJu9xvcFk>

For further information or to volunteer to participate see the link:

<https://www.ndcn.ox.ac.uk/research/neurology-lab>

Opicapone – a new COMT inhibitor

A new drug treatment for Parkinson's called opicapone (trade name ONgentys®) has been launched in the UK by international pharmaceutical



company Bial. A recent study showed that taking opicapone alongside levodopa is helpful for people who experience 'wearing off.' Opicapone is a COMT inhibitor - which reduces Parkinson's symptoms by blocking an enzyme that breaks down levodopa, prolonging its effect. However unlike other COMT

inhibitors, opicapone only needs to be taken once a day and so could reduce the overall number of tablets required. It is also smaller than other COMT inhibitors which may be beneficial for people with Parkinson's with swallowing problems.

<https://www.parkinsons.org.uk/news/18-october-2016/new-drug-treatment-opicapone-launches-uk>

4th World Parkinson Congress, Portland, Oregon 20-23 Sept 2016

The World Parkinson Congresses provide an international forum for dialogue on the latest scientific discoveries, medical practices, and caregiver initiatives related to Parkinson's. Each Congress brings together physicians, neuroscientists, a broad range of other health professionals, care partners, and people with Parkinson's (PwPs) for a unique and inspiring experience. Cross pollinating members of the community is important in the effort to expedite the discovery of a cure and cultivate best treatment practices. You can access speaker's slides through the following link:

<https://wpc2016.quickmobile.center/#/event/4c8f9b66a9a829867de478f7b3fa69b3/123474/Schedule>

Caffeine and Parkinson's

It has been recognised for some time that higher caffeine consumption has been associated with reduced risk of Parkinson's. In Italy, a 4 year observational cohort study investigated motor and non-motor effects of caffeine consumption in 79 newly diagnosed, drug naïve Parkinson's patients. The average daily caffeine consumption was about 6 espresso cups per day (300mg of caffeine). It was found that higher caffeine consumption was associated with a lower rate of starting L-Dopa treatment and each additional espresso cup per day (50 mg of caffeine) was more likely associated with 5-point lower UPDRS part III total score.

[http://www.prd-journal.com/article/S1353-8020\(16\)30289-9/abstract](http://www.prd-journal.com/article/S1353-8020(16)30289-9/abstract)

In a separate study, researchers in Canada set out to make compounds that could protect the dopamine-producing cells that are lost in Parkinson's. Using a yeast model of Parkinson's, they found that two of their caffeine-based molecules were able to target the alpha-synuclein protein (Alpha-synuclein is a protein that naturally occurs in our brain cells. In Parkinson's, alpha-synuclein becomes misshapen and forms sticky clumps that cause problems inside nerve cells, eventually leading to their death). In this study, the researchers found that their caffeine-like compounds could stop these clumps, called Lewy bodies, forming.

<https://www.parkinsons.org.uk/news/4-october-2016/study-finds-caffeine-compounds-tackle-parkinsons>

Alpha-synuclein has a normal role

Although the specific function of α S is still unclear, a general consensus is forming that it has a key role in regulating the process of neurotransmitter release, which is associated with the mediation of synaptic vesicle interactions and assembly.

<http://www.nature.com/articles/ncomms12563>

RESEARCH NEWS

by Nigel Hamilton

On Monday 20th March the 4th Oxford Parkinson's Disease Research Day took place in the heart of the University's Science area in Parks Road. As members of the Oxford Parkinson's UK Branch we were invited to attend.

In a packed lecture theatre with over 170 participants we listened to 18 research presentations. These introduced us to the wide range of scientific approaches being used to improve our understanding of what leads to the breakdown of normal dopaminergic functions in Parkinson's Disease and the identification of potential mechanisms for modifying or reversing this process. What struck me (and I am not a scientist) was the range of academic disciplines represented. The four sessions of the day (Clinical Research, Protein Mechanisms of Disease, Cellular & Molecular Biology and Models of Parkinson's) covered all the different aspects of the OPDC research programme, which aims to find ways of predicting the onset of Parkinson's, establish how to measure the progression of the disease, find better treatments to alleviate the symptoms and ultimately realise a cure. Ewan Stutt gave a view of living with Parkinson's with a young family. John Foster read some amusing poems and also a thoughtful one expressing a sober view of his life now. Sally had the honour of awarding the prize to the winner of the poster competition.

Although I had to admit defeat in my attempts to follow the twists and turns of scientific language and floundered in my attempts to unlock acronyms and terms such as LAARK2, CDFN & Complex Ca²⁺, there were Keynote Lectures to keep everyone engaged. I particularly enjoyed the lecture on "Memory and Motivation in Parkinson's disease". There were plenty of opportunities to ask questions and talk to speakers over lunch or during the coffee and tea breaks. A further stimulus was the exhibition space featuring almost 40 poster presentations.

You can find out about research in much more detail by going to the website www.opdc.ox.ac.uk. Altogether I came away with a definite sense that the day had been a great opportunity to hear about the progress being made here in Oxford in getting to the bottom of the condition that Dr James Parkinson identified 200 years ago. There was a real emphasis that people with Parkinson's have an important part to play in the ongoing research.

CARERS' CORNER

by Delia Wells

Parkinson's Local Adviser - Oxfordshire

Phone: 0344 225 3679 Email: dwells@parkinsons.org.uk

Oxfordshire Social Services have produced a publication titled **Live Well Oxfordshire**, this publication is packed with fantastic information on local care Homes, Care agencies and other very use full contacts and local information.

To request a copy of this Publication phone 0845 050 7666

I will also be bringing along copies to the May Branch Meeting

For example there is an entry about :-

The Small Repairs Service (page 20). Available to owners, and occupiers, who are aged 60 and over, disabled and suffering from long term health conditions. This service covers small plumbing, electrical and basic household repairs.

There is a labour charge which is very reasonable as well as the costs of any materials used.

EG. A friend and neighbour had a key safe fitted and a washer replaced in her tap for £15 labour last year plus materials which she was very pleased with.

Stop press

I will be available on a call in basis in the office on the Thursdays after the Branch Meeting for general enquires from 8.30 to 4.30 pm and not during my lunch break between 12- 1pm

You also can contact me at any other time and leave a message for me or email me to say you would like a call.

FUNDRAISING

by Kit Marriott

kit@kitmarriott.com

Last year saw record amounts being raised within our Oxford Branch, largely through the leadership and enthusiasm of our Chair Sally, not to mention Paul Mayhew Archer's major contributions, and a great deal of help from many of our members for which grateful thanks. Our treasurer Carys has highlighted our income in her report.

The 2016 Oxford Walk 200+ walkers was commendable considering the wet weather, and Income of £23,000 was excellent. (Compare with 2015, when we raised £28,000 with over 250 walkers), A big thank you to all members who helped with marshalling, registration, baking cakes and selling their wares which all adds to the success of the event

This year the Walk will take place on Sunday September 10th with a slightly modified route to vary the interest to regular walkers within our historic city. We can register on line now at parkinsons.org.uk/walkoxford and start looking for sponsors. Our magic income target figure is £30,000 so let's see if together we can achieve this figure with a substantial percentage of income going to fund Research Projects at OPDC who usually have a number of researchers joining us on The Walk.

The other highlight amongst many last year was our concert in Christchurch Cathedral where a verger told me that we had 840 people in the Cathedral. We were indeed fortunate to be gifted the Cathedral which reduces our cost overhead.

So having finished on a high we should not forget simpler and less onerous FR events. In February we held a coffee morning in Whitchurch on Thames, South Oxford raising nearly £500 and in March Elizabeth and Bill Pyke together with their local church held a White Elephant stall in a pub car park in Chilton, raising just over £500. Frankly we don't always need to be targeting high income as all our events are important to make people aware of Parkinsons as we endeavour to find a cure.

Jenyth Worsley organised a most interesting evening of poetry and music "The Pity of War" with members of the University Choir in the University Church of St Mary the Virgin. These three recent events show just what members can do in their local communities when quite often communities are looking for charities to support so don't hold back with looking for simple local events which we are always willing to help you arrange.

Last year was a big concert year for us; this year so far, only the Donkey House players on March 31st in South Hinksey (see report below), and possibly a December concert with the Wessex Male Voice Choir who are keen to get involved with us again.

Talking about support, we are always conscious to limit the occasions when we ask members to financially support events, as being a branch member is as much about companionship and receiving care from the Branch and PUK. Our prime aim is to try to ensure that "no one has to face Parkinson's alone"

CONCERT MAR 31st. **The Donkey House Players & Friends** took us on a **Trip Round the Tradition**

The Concert at St.Lawrence Church, South Hinksey on 31 March was a great success. South Hinksey must be Oxfordshire's best kept secret- not easy to access and, amazingly, having the same name as the equally ancient church in North Hinksey. A very picturesque setting for a round-England set of folksongs - some well-known and others not. Most folk concerts feature songs from Ireland, Scotland, Wales and North America. A Trip Round the Tradition was a welcome change – songs from all the English Counties. The Donkey House Players make their distinctive music from Concertina, Accordion, Flute, Recorders, Violin, Cello & Guitar- and several good voices.

They gave a spirited rendition of all kinds of material: notable were Alan with his 'Bladon Races' and Carol with 'Streets of London'. People always like joining in the choruses and the audience here did so with gusto, with a few chuckles at the occasional 'fa la la' element. Oxfordshire was well represented, with university songs such as 'The Boars Head Carol' and 'Old Tom'. Some counties were less promising: notably Derby and Rutland; good to hear virtually unknown material, all the same. A wonderful raffle, and refreshments were provided. A great evening in a beautiful setting.

George Philip



ANNOUNCEMENTS

Volunteers needed for help with two university research projects.

We are fortunate to have been asked to participate in two research projects. One, based in Oxford, is investigating emotion and motivation in Parkinson's Disease; the other, based in Reading, is a brain training study, using games to exercise mental muscles. If you are interested in hearing more about either of these two research projects, please email Pen at oxfordparkinson@gmail.com

And a chance to visit the MRC Brain Network Dynamics Unit at the Oxford University labs. Paul Bolam is arranging a tour, with talks on what the work involves, on June 19. There are only 10 places available. Let Pen know if you are interested in the visit, and we shall hold a ballot if over-subscribed.

Blenheim Palace Picnic – Monday July 10th

This picnic will take place in the Pleasure Gardens where the palace staff will set picnic tables to one side for us to use. They are sited close to the cafeteria so you can easily get drinks. We thought it would be nice to each bring something for us all to share. We will provide plates and napkins but drinks can be purchased. While there you may visit the butterfly house and then get lost in the maze!



We will provide a pass for you to enter the grounds – you make your own way there or offer others a lift. Once inside the palace entrance, the Pleasure Gardens are on the left where you'll find plenty of parking. There are loos. Should you decide to visit the palace tour, by showing the pass you may have a reduced entrance fee of £10. You may enjoy your time there as you wish and ask that we share our picnic together from 3.30 onwards. (I sent a photo of a signpost)

Oxford Branch Conference – “Parkinson's at 200 : 1817-2017 and beyond” to commemorate the publication of Dr James Parkinson's “Essay on the Shaking Palsy” Monday September 18th 12.30-5.30 at Wesley Memorial Church, Oxford.

This promises to be an interesting day. Leaders in treatment and research will inform and inspire both health professionals and people with Parkinson's to live a better life, now and in the future. Further details to include how to get tickets and the help we'll need will be in the next newsletter, - BUT please put it in your diaries.

Contact:

If you have vascular Parkinson's do call Hilary Case who would love to chat with someone else with this . 01235 5222567 email: terry.case@btinternet.com. Tony Russell has PSP and he too, would be happy to share his thoughts with others with PSP. **01865 876415 email: lyehill@hotmail.co.uk.**

And Finally....

Membership of Parkinson's UK.

If you are not already a member of the national body, Parkinson's UK, may I take this opportunity to encourage you to subscribe. Parkinson's UK provides information and support throughout the UK, campaigns to ensure that people living with Parkinson's are treated fairly, and funds ground-breaking research into the understanding and treatment of Parkinson's. Members receive a quarterly magazine of general interest as well as a twice-yearly magazine focussing on current research projects. As a local affiliated branch our members benefit from being covered by their public liability insurance when we organise trips and events.

I have some application forms or you can subscribe online and find out more by following the link www.parkinsons.org.uk

May I also remind some of you that our local branch subscription of £4, was due at the beginning of the year.

Diana Townsend (Membership Secretary.)

COMING UP...

OXFORD AND DISTRICT BRANCH MEETINGS, TALKS AND OUTINGS

OXFORD BRANCH MEETINGS

On the 1st Wednesday of each month at

Botley WI Hall

North Hinksey Lane OX2 0LT

Talks on general & medical topics
Group discussions

SUMMER PROGRAMME 2017

May 3	Mitophagy in Parkinson's Hopes for the future. An introduction to the role of mitochondria in energising the brain. Professor Jo Poulton will be making everything clear
Jun 7	Walking by Water Dick Mayon-White heads up a project to get people of all ages and those with medical conditions out walking on the Thames path. He has always been keen on keeping fit
Jul 5	The Linked Trials Dr Richard Wyse & Helen Matthews of The Cure Parkinson's Trust explain how using selected drugs that already have approval for use with other conditions may have a role to play in the treatment of Parkinson's.
Aug 2	How can we help? Branch members! It's over to you! Please bring your needs to share at the August meeting

OTHER EVENTS

Mar 31	Donkey House Players at South Hinksey
Apr 10 -15	Parkinson's Awareness Week (Apr 11 World PD Day)
Apr 19	Trip to 'Symfunny' at RAH
Jul 10	Picnic at Blenheim Palace
Jul 23	Piano recital at Wigmore Hall
Aug 17	BBQ in Wytham Woods
Sep 10	Oxford Parkinson's Walk
Sep 16-17	BOXCAM cycle ride
Sep 18	Oxford Branch conference
○	(Call Pen for details)

ACTIVITIES

Zumba, Physiotherapy, Voice, Dance for Parkinson's (Ballet with ENB) and other activities; outings & holidays

FUNDING CARE & RESEARCH

We continue to support people with Parkinson's in our area and some of the research being conducted in Oxford as part of The Oxford Parkinson's Disease Centre

200 CLUB

£12 per year buys chances to win £25 or £12.50 at each monthly draw.
Malcolm Benson 01865 873843 runs it.
Call Malcolm to enter.



BRANCH COMMITTEE

Chair

Sally Bromley 01865 311302
email oxford.sally@gmail.com

Secretary

Pen Keyte 01865 556032 / 0788943722
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Vice Chair

Jem Appleton 01491 837331

Fundraiser

Kit Marriott 01189 844582

Treasurer

Carys Redmond 07817 597623

Membership

Diana Townsend 01865 751362

Research News

Kevin McFarthing 07802 25618

Media & Publicity

Paul Mayhew Archer

Programme

Nigel Hamilton.

George Philip, David Salisbury,
Martin Tims and Jenyth Worsley

TAXIS

Talk to Lin on 01235 520573, if you cannot get to a branch meeting, this is a one off emergency aid.

FINANCIAL SNAPSHOT

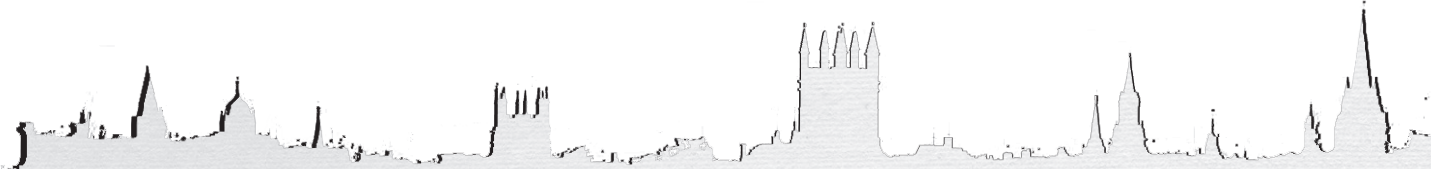
by Carys Redmond our Treasurer

2016 was a phenomenal year for branch donations and fundraising with over £96,000 received in total including over £23k raised by the Oxford Walk. A HUGE THANK YOU to everyone for all their energy and generosity. The branch used these funds to give £56k to the local OPDC research project "understanding GABA co-transmission from dopamine" and also a donation of £5k to the brain bank.

The usual branch activities in 2016 (including outings, branch meetings and concerts) have been enhanced by the Merrett legacy which has enabled us to set up the respite care scheme with our service provider Bluebird offering up to 30 hours care funded by the branch, free weekly Voice classes on Fridays in Botley and subsidised physio/exercise classes across the county of Oxfordshire. For further details on any of the services the branch offers please contact the branch secretary, Pen at oxfordparkinson@gmail.com

This new financial year 2017 has started well with some very successful coffee fundraising mornings and further income from concerts held in 2016 still coming into the branch together with some generous donations. To date we have received nearly £10,000 as well as further Merrett legacy funds.

Parkinson's at 200: 1817 to 2017 and beyond



Parkinson's UK Oxford branch presents a half day conference to mark 200 years since the publication of

AN
E S S A Y
ON THE
SHAKING PALSY.

BY
JAMES PARKINSON,
MEMBER OF THE ROYAL COLLEGE OF SURGEONS.

1817.

Leaders in treatment and research will inform and inspire both health professionals and people with Parkinson's to live a better life, now and in the future.

SEPTEMBER 18th 2017.
from 12.30pm

PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.

Wesley Memorial Chapel, New Inn Hall St Oxford OX1 0DN