



Parkinson's UK Oxford Branch

OUR NEWS

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

January
2019

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Happy 20th Birthday To Us!



Sally Bromley

Yes, our Branch's 20th Anniversary was on 1st January. At our first branch meeting we'll ask you how you'd like to mark this grand birthday, as we plan to celebrate as much as we can this year!

Park's Larks continued

Wendy Benson

Chapter 2

Sparky knew that her husband was ailing
She'd been watching the symptoms
for weeks.

Just last month she'd noticed him
missing his turn
On the rota at Darts, where his week
reached its peak.

He was eating quite well, but his waistline
Seen from side view was now shrunken in.
If she had time to think,
she'd have been worried pink
“He's beginning to look rather thin.”

The business would have to be easy,
and almost self-regulating.
Of course she would help,
and the twins might as well,
But she feared that the strain
would do Mr Park in.

Missed the first instalment?

*You can catch up with earlier and current
episodes of Park's Larks on our website:
oxfordparkinsons.org.uk/parkslarks
And look out for more in future Newsletters!*

Sparky had a good grasp of his mindset
and knew how to manage her man.
If she waited until he had made up
his mind
He'd ignore her and flush her advice
down the pan.

Since her ideas were few and unhelpful
And she must remain serene and calm,
She invited the twins
to contribute some thoughts
And together they drew up a
“Dad Action Plan”.

Dad Action Plan

Kiss reason goodbye
Enter the world of make-believe
Expect anything to happen
Pray for success

Charge around looking busy
Arrange for plenty of time off
Look for any signs of hope
Make contingency plans tomorrow

Branch Christmas Party

Sally Bromley

We held our party in December and as usual, so many of you turned up, laden with tasty food and gifts. We have never requested each person to bring a particular contribution and instead ask you to get festive food and every year the table is groaning with mixed food types.

Emily, who leads Finding Your Voice, came and led us all singing some jolly

ditties and the highlight was a visit by Santa who distributed the gifts for Secret Santa.

The evening closed with us all wishing ourselves a very happy Christmas as we went on our way. Did anyone see Santa as he drove his sleigh?

Parkinson's UK AGM and Members' Day

Paul Mayhew-Archer

Our parent charity
Parkinson's UK held its 2018 annual general meeting in Birmingham on 20th October. The event included a new Members' Day. Paul Mayhew-Archer acted as VIP Host for the whole occasion.



Someone once told me the secret to a good AGM. "Send out paperwork so full of bewildering acronyms, jargon and complicated computations that no-one can understand it. Then make the meeting so unutterably dull that no-one is conscious by the time of the vote. With luck, by year 3, you'll be able to hold the AGM in an under stairs cupboard."

So hurrah for Parkinson's UK. The charity is keen to make its AGM entertaining and involving in the hope that *more* people will come. This year they even decided that a comedian should host the event and since Billy Connolly was unavailable I got the job. Why? Am I mad?

It's for others to decide if the initiative worked. All I can do is make a few observations.

Attendance figures doubled (from 60 to over 120) and it seemed to make a difference to people that someone who *has* Parkinson's was so heavily involved in the event.

I loved having the chance to meet and greet lots of people at the start of the day. As ever the PUK staff and volunteers were wonderfully welcoming and friendly and hard-working. The technical facilities were excellent but there was a very serious shortage of chocolate. Since the AGM was taking place near Bourneville this was

inexcusable. I have asked that next year's AGM take place in the factory itself.

The schedule was pretty packed and although there was time for questions I think the charity is so keen to tell us about the great things it has been doing on our behalf (quite rightly) that it forgets that we are also there to tell each other about the great things *we* have been doing.

The highlight of the day for me was hearing about a new speech therapy course being practised in Wales that was enabling people to communicate better. It was called "Learning English". No. It was called "Live Loud" and what made the presentation so effective was that it was delivered by three people who had benefited from the therapy.

Ideally I would have loved two or three such presentations. I hope we can develop a "Live Loud" course here in Oxford.

You can find more about Live Loud at oxfordparkinsons.org.uk/news#liveloud

What came out of the day above all is that we all want the same thing but don't as yet know how to achieve it. The reason PUK wants to increase attendance at the AGM is that it wants to harness the skills and initiative lying in its membership at branch level. Many members at branch level also want to be more involved (with other branches and with Head Office). But how do we do it? PUK has an Excellence Network for doctors and researchers and professionals. How do we set one up for us? Answers please on a piece of paper wrapped round a very large bar of Cadbury's Whole Nut.

Research update

Kevin McFarthing

A lot has happened in Parkinson's research since our last newsletter. Here are some highlights, from new drugs to smoking via the appendix.

The research landscape

According to the latest edition of the Hope List, there are (at least) 264 projects for new therapies in development. Of these, 132 are in the research phase and 132 are in clinical trials.

New drugs for 2019

Two “rescue” therapies, inhaled levodopa (INBRIJA) from Acorda Therapeutics and thin-film apomorphine (APL-130277) from Sunovion, are under final review by the US FDA. Both are designed to give fast relief from “OFF” episodes. Hopefully both will be approved and launched in the US and rolled out into other countries including the UK soon thereafter.



LATE NEWS:

FDA approval was granted for INBRIJA on 21st December 2018. It is expected to be available on prescription, at least in the USA, in the first half of 2019.

What about the appendix?

Some of you may have read about the recent links between Parkinson's and the appendix. Researchers in the US studied two large patient databases which showed a 19% reduction in the incidence of Parkinson's in those people who had had their appendix removed. Interestingly, this reduction was almost totally explained by the reduced incidence in those people living in rural areas.

The team also found that the appendix contains relatively large amounts of α -synuclein, one of the molecules strongly implicated in Parkinson's. This observation is supportive of the Braak hypothesis, which suggests that Parkinson's starts in the nerves supplying the gut (the enteric nervous system) and moves up the vagus nerve to the brain.

Whilst this observation is interesting and potentially important, nobody is advising any of us to have our appendix removed. It's another example of correlation that isn't necessarily causation. You can find the original paper [here](#).

PARP is not just a trumpet noise

PARP - Poly (ADP-ribose) Polymerase - is an enzyme involved in DNA repair that normally lives in the cell nucleus. When the cell is stressed, it can move to the cytoplasm (the main part of the cell). Recent work has shown that α -synuclein fibrils may be killing nerve cells through over-activation of PARP. This opens up the opportunity to use PARP inhibitors, which already exist, in the treatment of Parkinson's. You can find an abstract of the original paper [here](#).

Rewiring and gene therapy

Gene therapy is one of the approaches aimed at replacing what we have lost. A US team introduced key genes for synthesising dopamine into a small group of patients in 2011. A recent follow up study showed that new neural pathways had formed in a process they term “adaptive rewiring”. You can read an article about this from New Scientist [here](#).

Smoking

A paper in the International Journal of Epidemiology showed that smokers have a 50% reduction in the chance of getting Parkinson's. You can find the paper [here](#). On the other hand, results of a clinical trial on nicotine patches in Parkinson's were announced recently, showing no benefits. You can read about it [here](#).

Given the great hazards of smoking, nobody is advising us to start smoking, but these observations suggest there may be other molecules worth looking for.

Inhibiting inflammation

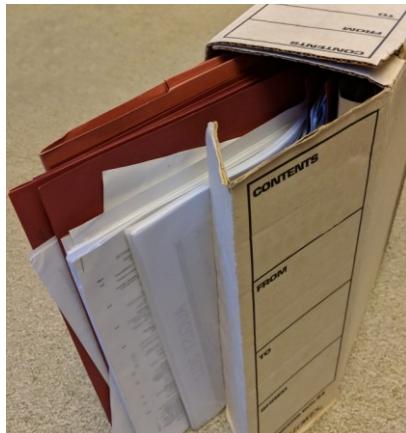
Inflammation is thought to be one of the processes involved in nerve death in Parkinson's. Part of this process involves the formation of the inflammosome, containing a protein called NLRP3. Recent work from an Australian team has shown that MCC-950, a NLRP3 inhibitor, stops α -synuclein mediated nerve death in mice. You can read more on the Science of Parkinson's blog [here](#).

BB Box (Bye Bye)

David Paul

You might like to consider this simple way to ease your departure for those you have left behind.

A container, such as a file box, can hold essential photographs and documents in one easy-to-find place. This list of suggestions is by no means complete.



Example contents

- Location of your will
- Photos of treasured items you are bequeathing
- Insurance documents
- DW&P details such as National Insurance number
- Contact information for people and bodies who need to be told about your passing
- Last letters to loved ones
- Your funeral wishes such as songs, readings, and destination of any collection monies

Individual Fundraising

2018 was a bumper year for individual fundraising efforts by members and friends of our Branch. You can find information on all those events on the [sponsorships page of our website](#). Each one represented not only a significant personal challenge for the participant, but also heart-warming generosity from their sponsors and supporters.

Jonathan Bromley

We are thrilled to report that this amazing variety of initiatives raised well over **£18,000** for our Branch and other Parkinson's charities. To walkers, runners, abseilers, cyclists, performers, and their sponsors: **thank you**.

Can we look forward to an equally exciting programme of challenges in 2019?

Dignity In Care award

At the Oxfordshire Caring Matters conference on 30th November 2018, our Chair was honoured to be joint winner of the Josie's Award for "someone making an exceptional difference to dignity in care". The awards, along with several others for Dignity in Care, were presented in a heart-warming celebration of top-quality care activity and initiatives hosted by Paul Mayhew-Archer.

*Photo credit:
Anna McKay,
Age UK*



*More pictures from this event at
oxfordparkinsons.org.uk/special_events*

Free courses for carers

At the Oxfordshire Caring Matters conference we also heard of an exciting programme of free courses offered to carers by Abingdon and Witney College. The short courses can be taken individually to match your needs and opportunity, but they build up into a comprehensive programme of information, support and education to help carers do their vital work more effectively and safely, while also attending to their own needs. The 3-hour modules cover not only

practical topics such as First Aid and safe moving and handling, but also "softer" skills such as massage and techniques for building up your own resilience to the stresses of caring. Full details, including course schedule and registration, can be found on our website at oxfordparkinsons.org.uk/documents/support/carers-courses (or simply follow the "Financial and other support" link on our home page).

Welcome to new members

Diana Townsend

We welcome everyone who has joined us recently:

David & Diana Axford
Robert & Helen Dallimore
Felicity Feeny
Pauline Graystock
Barry Haines

Francesca & Tony Hinton
Pamela Hutchinson-Collins
Giles Oldershaw
Mike & Hazel Payne
Peter & Pat Stephenson

Customer Service Excellence Award for First Steps programme

Ian Sargent

The First Steps Course for people newly diagnosed with Parkinson's has been awarded the highest accolade in the recent annual Customer Service Excellence Assessment carried out on the Parkinson's UK Charity. This government scheme, previously known as the "Charter Mark", is designed to promote customer services that are "efficient, effective, excellent, equitable and empowering – with the customer at the heart of service provision". Overall, Parkinson's UK passed the accreditation process with flying colours and First Steps received a special "Compliance Plus"

A great recommendation for this course designed and piloted in Oxford

award for performance above and beyond the CSE Standard. The CSE Assessor attended a day 1 First Steps session held at the Witney Lakes Resort. She was impressed by how comfortable the participants were made to feel in an environment where people could openly share their fears and feelings with others. She thought the programme had a great mix of activities and was able to observe how people's moods changed positively through the day. She was also impressed by the positive evaluations received at the end of the day from participants. She has already asked if next year she can sit in on day 2 to see how the course develops!

News from Swindon Branch



Sally Bromley

We're delighted that we continue to build good relationships with our friends in Branches near and far. We recently received a copy of Swindon Branch's colourful Christmas newsletter *The Swindon Parkin Lot*, which you can find on their website at [this link](#).

Working Together meeting

Sally Bromley

Working Together is a day conference organised by Parkinson's UK to give nearby branches the opportunity to meet together on a regular basis. The main focus is to inform each other about the activities with which we are involved, but at our latest Thames Valley meeting in October, we were encouraged to establish

more meaningful relationships among our branches. However, it will take time, effort and determination to really get this started. Joint working, sharing good ideas and visiting each other could bring about a positive development for each branch. Are we ready for this challenge?

Pocket money for Parkinson's

Martin Tims

One of my earliest memories of Parkinson's was struggling to get money out of my pocket to pay for something in a shop. I found it easier to give a larger single denomination - a note, £1 coin, or a 50p - than to try and struggle sorting through small value coins, with a queue building behind me. Does that sound familiar? Do you end up with pockets or purses full of loose change? I have done so for 15 years now since I was first diagnosed, and therefore each night I have emptied my pockets of loose change, and the 10p and 20p



*Handing over
the proceeds*

coins ended up in Parkinson's UK collection boxes. It has amazed me how quickly it mounts up, and yet how little I notice it in my overall cash flow.

Our USP is that the scheme should make it easier and quicker for PwPs when doing shopping, and raise funds at the same time. We have kept it as simple as possible: simply pop your spare 10p and 20p coins

into a box, and when a box gets full please get some reusable coin bags, fill them as required, and pass them to our Treasurer, Carys. Parkinson's UK collection boxes are available at any Branch meeting.

A fuller version of this article is available online at oxfordparkinsons.org.uk/articles/small-change

OxWAG – the Oxford Working Age Group

Laura Tilt

2018 was the year of revival for OxWAG, the Oxford-based support group for People with Parkinson's of working age and their families. My husband Ashley, who has Early Onset Parkinson's (diagnosed almost two years ago at the age of 35), and I are the coordinators of this group, which now boasts almost 30 members.

Last year we focused on reviving the group's membership and everyone getting to know one other. Our meetings, usually held once a month, were mainly social occasions including Sunday brunch or lunch and a walk (for some, a Nordic walk) across Port Meadow. We also conducted a number of informative seminars, hosted by St Hugh's College, where speakers such as Thomas Barber from the Oxford Parkinson's Disease Centre came to share their research.

Our new years' resolution was to make our monthly meetings more regular, with a consistent venue. We are excited to announce that OxWAG meetings will now be held **every second Sunday of the month** from **2:15pm to 3.45pm** at the **Mary Town Room, West Oxford Community Centre, Botley Road Oxford OX2 0BT**.

Our first meeting for the year will be held on Sunday, 10 February 2019. Each meeting will aim to have a different focus on working age life with Parkinson's, as well as provide a time for sharing experiences and giving one another support.

If you would like to join OxWAG or have any questions about the group, please contact Laura and Ashley: 07939 308258 or wag@oxfordparkinsons.org.uk.

Membership and subscriptions

Diana Townsend

It's that time of year when we'd like to remind you to renew your subscription to your local Oxford Branch of Parkinson's UK. Thinking about all the stimulating monthly meetings we've had and the enjoyable social events that have been organised you must admit it's great value for £5 a head. I shall be happy to receive cash or cheques made payable to Parkinson's UK Oxford Branch at the next few monthly meetings or sent to me at:

Membership Secretary

2, Langley Close, Oxford, OX3 7DA

While we renew annually in January, if you pay through Parkinson's UK, then your subscription runs from the month you joined. In this case, I would appreciate knowing this fact so that I can keep the membership list accurately up to date.

I wish you all a peaceful New Year.

NOC Pumpkin Competition From our Agriculture Correspondent



Cathy Jenkins, a physiotherapist at the Nuffield Orthopaedic Centre, helps to run a Pumpkin Competition in both her department and in her village of Horton-cum-Studley. The competition raises



money from sale of the young pumpkin plants, and this year the proceeds of £200 were kindly donated to our Branch. The winner was our green-fingered member Richard Hawes, with a 141lb (64kg)

monster. Richard has a track record - he's already won his village pumpkin contest four times!

Oxford Walk 2018

Sally Bromley

Over 200 walkers signed up for the Oxford Walk and I am pleased to inform you that, to date, well over £17,500 has been raised. The walk is a Parkinson's UK event, so the money goes to the central charity, but we have agreed with them that it will be used to help fund an Oxford research project. Initial feedback included the

appreciation of having a warm welcome back with a fresh cup of tea and home-made cakes. Thanks to all of you who in any way contributed to making the day run smoothly. Special thanks go to Malcolm Benson who co-ordinated it all.

The 2019 walk will take place on **Sunday 22nd September**.

Branch Holiday in Hayling Island

Jenyth Worsley

With contributions from

Ros & Paul Swadling,

Wini & Anthony Brown and Sally Bromley



Sixteen of us from the Branch went on a four-night break at Warner's Lakeside Holidays on Hayling Island, courtesy of Martin Cowell who arranged it all. I owe special thanks to Martin for sorting out my cold toes beforehand: 'I have just checked with Warner's: there is no microwave or fridge in the rooms we have booked, so I am afraid it will have to be the hot water bottle!'

"It was a really lovely holiday which gave us the opportunity to socialise with our lovely Parky friends. The venue was good with us each living in a chalet - rather well done up with en suite facilities and with the luxury of meals cooked for you, evening entertainment if you wanted it, and set in the beautiful Hayling Island. When we arrived we instantly expected something like *Hi-de-Hi!* but were nicely surprised to find our chalets were fitted out to hotel standard and were very comfortable. Food and service in the restaurant was extremely good and we very much enjoyed our evening meals with our Parky gang. The indoor pool was very good too. There were various other activities such as bowling and archery".

R&PS

The chalet site ran down to the lake which was brimming with ducks, geese and a

family of swans who were befittingly aloof. I made friends with a handsome pair of mallards who fed quite gently from my hand from the bird food on sale at the shop.

Next day

Jonathan and



Sally drove

Clare Hayes and me to a fascinating village on the mainland, with a Roman villa, mediaeval thatched huts and contemporary livestock.



We are planning another Branch Holiday in similar style for autumn 2019. Please let Martin Cowell know if you are interested in taking part.

“Particularly remembered was our group on the dance floor jigging away to live



music, Sally and Wini's excellent game of bowls and the kindness of the group members who drove us there and back and took us for a day's outing. Using our own transport meant we were

independent and we shared where we'd been with each other over supper.”

W&PB

“All the Parky people gathered every evening for drinks and chats before dinner. We had musical entertainment each night, the highlight being when most of us wobbly people got up to boogie together to the music which was great fun.”

R&PS

“I found being able to really get to know people in our branch most interesting, and sharing our Parky stories helpful. I'd recommend going on such a break.”

SB

Financial and fundraising highlights

Carys Redmond

It's been another amazing year with members' enthusiasm and support providing a vast array of fundraising in a wide variety of areas. Members' fundraising activities since the last newsletter include Jenyth Worsley's poetry evening, proceeds from a pumpkin competition and yet more sponsored events including Jo de Goris' walk around Farmoor reservoir, the Oxford Walk and Carys Redmond's Royal Parks half marathon. The overall numbers for the year are yet to be finalised, and a full summary will be provided at the AGM, but we estimate fundraising activities and donations this year will be a brilliant £30,000 not including the Oxford Walk sponsorship. **Thank you!**

This money is used to help to support the branch's many activities and services. In addition to branch meetings and outings, these include up to 20 hours of respite

care a year, subsidised exercise classes and voice classes. Furthermore the branch offers a grant towards trips to the European Parkinson Therapy Centre in Italy. We would encourage you to make use of these services if of interest and further details for each of them are available on the branch website.

In addition from January 2019 a new grant scheme will be available from Parkinson's UK to fund things to improve quality of life. Again further details of this and how to apply can be found on our website – just follow the **Financial and other support** link on the home page.

Editor's note:

Carys Redmond has acted as our volunteer Honorary Treasurer for many years. We are enormously grateful for her expertise, commitment and support, including her recent half-marathon run. Thank you Carys!

Farewell

Our sympathy goes to the families and friends of our members who have died recently:

Adrian Moyes

Joan Greenwood

Agenda for our 2019 Annual General Meeting **Sally Bromley, Chair**

As usual, our AGM takes pride of place at the March meeting. Please be sure to come along, use your vote, and be part of your Branch's future.

Parkinson's UK Oxford and District Branch

Annual General Meeting – Wednesday 6th March 2019 at 7.15pm

AGENDA

1. Apologies for absence
2. Minutes of the Annual General Meeting 2018 - draft available on our website at oxfordparkinsons.org.uk/archive/records
3. Chair's report
4. Financial statement
5. Election of the 2019 committee (see nominations below):
Helen Old, Branch Volunteer Support Officer, will take the chair for these elections.

Position	Candidate	Proposed	Seconded
Chair	Sally Bromley	Jenyth Worsley	Martin Cowell
Vice Chair	Paul Mayhew-Archer	David Salisbury	Martin Cowell
Secretary	Pen Keyte	Sally Bromley	Kit Marriott
Treasurer	Carys Redmond	Sally Bromley	Kit Marriott
Membership Sec.	Diana Townsend	Pen Keyte	Ian Sargent
Media/Publicity	Paul Mayhew-Archer		
Research advisor	Kevin McFarthing		
Fundraiser			
Programme	Nigel Hamilton		
Trips & outings	Martin Cowell		
First Steps links	Ian Sargent		
Committee members	David Salisbury Jenyth Worsley		

These positions
to be elected *en bloc*
from the floor

6. Welcome to the new committee (*Helen Old*)
7. Speaker: **Aimee Petrie**, Falls Prevention Practice Educator with our local NHS Trust, will give a short talk on how you can minimise the risk of falls when at home or out and about.
8. Meeting closes, followed by cheese and wine