



# Parkinson's UK Oxford Branch OUR NEWS

**PARKINSON'S<sup>UK</sup>**  
CHANGE ATTITUDES.  
FIND A CURE.  
JOIN US.

**January  
2020**

## Highlights



As usual our August and September meetings were devoted to discussion of your concerns, with feedback in September based on input from healthcare professionals and others.



October's Branch Holiday at Holme Lacy in the Wye Valley was a huge success for the 34 members and friends who participated.

Paul, Sally and partners attended a reception in Buckingham Palace hosted by the Duchess of Gloucester to mark 50 years of Parkinson's UK.



Our picnic in the grounds of Blenheim Palace, now a regular annual fixture, was as enjoyable as always.



The Oxford Walk for Parkinson's saw – as usual – a terrific turnout, appalling weather, and fabulous fundraising for local research.



*Look inside for more stories,  
news of other Branch activity,  
and information about  
upcoming events!*

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## More resources available online

Several articles in this Newsletter mention additional resources that you may find interesting or useful. You can find links to all of them, along with downloadable images and much more, in the online edition – just visit our website **[oxfordparkinsons.org.uk](http://oxfordparkinsons.org.uk)** and follow the obvious Newsletter links, or go directly to **[oxfordparkinsons.org.uk/documents/newsletters/2020-01](http://oxfordparkinsons.org.uk/documents/newsletters/2020-01)**.

If you don't have access to the internet but would like to see this information, we may be able to provide paper copies of some of it. Please contact Jonathan Bromley with your request.

## Make our Newsletter better!

This is **your** newsletter. We love to hear about your stories, your news, and your concerns. Any contribution, long or short, is always welcome, especially if you can provide some interesting or entertaining pictures to go with it. Don't worry about layout or fancy formatting – we can look after that – but please **let us have your contributions!** There's no special deadline – we publish a Newsletter as soon as we have material to fill it.

Most contributions arrive by email, but if you're less confident with a computer it's fine to let us have material on paper or even in the form of a voice recording.

Obviously Parkinson's-related material is always of interest, but don't be reluctant to share your other interests too. How about some gardening tips, recipe ideas, theatre and music reviews, or travel stories?

If you have any questions, or want to discuss an idea for a Newsletter article or series, please get in touch with any committee member.

Let's make the Spring 2020 newsletter a riot of new and stimulating contributions from across our membership!

# Parkinson's UK AGM and Members' Day

Paul Mayhew-Archer



I was delighted to co-host the Parkinson's UK AGM again. The event was held in London and streamed to members in the North East, Scotland and Northern Ireland. It was also possible to join us online from your home computer. Were you there? Did you listen in? I'd love to know what you thought.

During the morning we said goodbye to our outgoing Chair of Trustees, Mark Goodridge and we welcomed our new Chair, Gary Shaughnessy. Mark spoke movingly about his pride in helping to set up a local group in the Shetlands and how one member would travel for hours to attend the weekly exercise class. I said I hoped he never turned up to find it cancelled.



He also said something which has really stuck with me. He said he sometimes felt he should apologise for not having Parkinson's. I rather think I'm one of the people who has made him feel that way

because I've gone on about there not being enough people with Parkinson's at the heart of the charity and how only people with Parky really understand what it's like.

Well, the new chair of trustees - Gary - has Parkinson's and at the AGM he was interviewed about his vision and hopes for the charity by someone who also has Parkinson's - me. So if the charity isn't everything you want or need it to be then please tell us.

Some other things that came out of the day included:

These are tough times for charities. PUK's income is down. Fortunately It has healthy reserves.

The charity is embarking on a new five year plan involving a virtual biotech scheme which aims to discover and develop new drugs.

"Live Loud" a speech therapy course pioneered in Wales which featured in last year's AGM is to be rolled out. We are keen to run it in Oxford.

Lots of different activities are available in different places. Are there any we don't have in Oxford that you feel we really should have?

# Branch Holiday

Jenyth Worsley

Thirty-four of us arrived at the Warner Leisure Hotel for a splendid break arranged by Martin Cowell. There was a plethora of things to do.

First, eat: the food was self-service from a central buffet. Breakfast included an array of fruit and juices, muesli, eggs, bacon, sausages, kippers, toast and little pots of marmalade or strawberry jam. (If you didn't like the latter you needed to swap it for the former at another place setting.). Dinners were equally lavish.

The Hotel is set in beautiful grounds and countryside.



**Holme Lacy park**

It has a lake for fish or fishing and water fowl, a putting green, a maze, rare trees, including a monkey puzzle and a sessile oak with a little door inset between the roots known as the Fairy Tree.



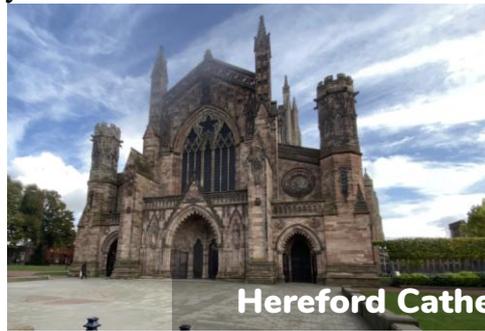
**The lake**

**The Fairy Tree**

Also on offer was a swimming pool and gym, crossbow archery, air rifle shooting and 'an evening of fun with Lisa' which I

didn't undertake. Instead I watched *Bohemian Rhapsody* about Freddie Mercury and Queen in the cinema.

Some of us went on a coach trip to Hereford and to its mediaeval cathedral.



**Hereford Cathedral**



It houses the famous late 13th/early 14th century Mappa Mundi (Cloth of the World) that depicts Jerusalem at the centre of the known world and Paradise at the top, with curious illustrations from classical and biblical literature. Our modern word *map* is derived from mediaeval maps made on a sheet or *mappa*.



**Hereford's Mappa Mundi**

The city itself is full of little lanes lined with shops of bric-a-brac and antiques as well as the usual modern stores.

Jonathan, Sally, Alison and Beverley went further afield and, in their words, “had a grand day out visiting various ecclesiastical buildings and ruins (and a rather fine pub) to the south-west of Holme Lacy. They took in Cistercian Dore Abbey (converted to a church in 1600 after the Dissolution)”. The group then ventured into Wales and “visited the ruined Augustinian priory of Llanthony near Abergavenny, and little Kilpeck church with its astonishingly rich and well-preserved Norman carvings.”

Marian Holmes writes, “How delighted I felt to be asked by Pam Watson to join her in this lovely holiday with your Parkinson's

group. A truly hardy, remarkable group of those affected and their carers. Also, a very great thank you to Mike Greenwood who drove us there and back as well as a day with him to Symonds Yat and Goodrich Castle. It was a great privilege to meet you all and witness your fortitude.”



Pam, Marian and Jenyth

Altogether it was a refreshing break and I look forward to next year's trip.

## Big Band Charity Concert

Martin Cowell



Join us for a fun evening with the fabulous Oxfordshire Youth Big Band, who performed so brilliantly at the Great Gatsby Ball last year. All proceeds will be split between Parkinson's UK Oxford Branch and Down's Syndrome Oxford. Tickets are only £15 per head, or £25 for a

couple. The concert is staged by Oxfordshire County Music Service and takes place in Exeter Hall, Kidlington at **7pm on Saturday 25<sup>th</sup> January 2020**. We look forward to seeing many of you there!

The Hope List contains information about potential therapies for Parkinson's currently under development. After a bit of pruning and addition, the list now has a grand total of 286 projects, with 143 in the research stage and 143 being tested on people in clinical trials. You can read more at [bit.ly/ParkinsonsHopeList](http://bit.ly/ParkinsonsHopeList) .

Exenatide, marketed as Bydureon by Astra Zeneca, is used for the treatment of type 2 diabetes. Interestingly, it also has neuroprotective benefits. Following a successful Phase 2 study published in 2017, a Phase 3 study will soon start recruitment, including in Oxford. The aim is to measure exenatide vs placebo over the course of two years, which will hopefully be long enough to show a statistically and clinically significant difference.

Continuing with the theme of repurposing – taking a drug already used in one indication and testing it in another – scientists have shown that terazosin, used to treat enlarged prostates in men, could have potential to treat Parkinson's. That's because it appears to enhance energy metabolism, which is often impaired in Parkinson's. Not only did terazosin have these effects in different lab models, the researchers examined prescribing databases and found that those patients taking terazosin had a lower incidence of Parkinson's.

Enterin Inc in the US have successfully completed a Phase 2a study on Kenterin, a synthetic form of squalamine, derived from the dogfish shark. It's been shown to prevent  $\alpha$ -synuclein from aggregating; this aggregation is thought to be one of the

major causes of Parkinson's. It's being tested for constipation in Parkinson's, acting locally on nerves in the enteric nervous system. The results showed that the drug worked for 80% of people in the study, increasing bowel movements from an average of 1.2 per week to 3.6.

As the joint editor of the Clinical Trial Highlights section of the Journal of Parkinson's Disease, I've co-written three reviews this year on the state of play in different areas of therapy development. So, if you still don't have enough to read, you can find all the links in the online version of this article, or on the research pages of our website

**[oxfordparkinsons.org.uk/research](http://oxfordparkinsons.org.uk/research)**.

Finally, two new research initiatives are worthy of mention. Aligning Science Across Parkinson's (appropriately, ASAP) aims, as the title suggests, to promote inter-disciplinary collaborative science, generate new resources and share data. It's led by the Nobel Prize winner, Randy Schekman; and funded by, among others, the Michael J Fox Foundation, Parkinson's UK and the Sergey Brin Family Foundation. The first major initiative to be funded by ASAP is the Global Parkinson's Genetics Program (GP2). GP2 plans to analyse samples from 150,000 people either with PD or at risk of PD and healthy controls.



## Our amazing Branch members

### Jonathan Bromley

You know me. I'm the guy running around with all the wires and bits and pieces at Branch meetings and other events. Oh, and the chap who always forgets to silence Sally's medication alarm during meetings... Not very interesting, but it does mean that I've met many of our wonderful Branch members in a variety of situations, and WOW, what an interesting bunch you are! In just a few months I learnt about a former nun, someone who designed particle accelerators, someone who produced children's radio programmes, someone who was in the Merchant Navy, scientists, clergy, a forestry development strategist, and more.

These stories are too good to keep to yourselves! I'm planning a series of items for future Newsletters where we get Branch members to talk about their careers and interesting experiences. If you have a story to tell, or if you would like to interview someone else to help them to share their story, please let me know. Whether it's a single amusing or exciting incident from your past, or a career spent doing something interesting or unusual, or just your entertaining reminiscences, we would love to hear of it and we look forward to reading about it in future Newsletters.

## Keeping Well in Winter

### Notes from Dr Siobhan Becker's talk

Siobhan's first advice was for us to have vaccinations against pneumonia and flu, and to take vitamin C, D and zinc. She suggested we prepare well and to have thermometer and paracetamol to hand, to eat well, to have a warm home and to have a plan for when you may need to ask for help. Take care to manage yourself especially when unwell: keep up your fluid intake so you can pee regularly. Should you have a high fever with shivering, or are confused or breathless you should ask for help. Siobhan suggested you call your GP, but do not be afraid to make a fuss to get an appointment. You can seek advice from the pharmacist or practice nurse. If you need help out of hours, call 111 and say you have Parkinson's and that you're unwell.

Of course, we can all do our best to avoid illness. Exercise, especially in a group so you can socialise too. Check that you are safe in your own home. Avoid trip hazards, have a personal alarm, don't be embarrassed about having a commode. Outside the home be aware of crowds and shop at quiet times. Do use a pole or stick if only to indicate to people that you have needs. Practical help is available from the County or District Councils – see the *Support and assistance* section of our website. Equipment may be borrowed from the Red Cross. If you feel you need further help, do go to your GP and ask if Occupational Health would be helpful.

# Visits and Outings

## Martin Cowell

When Sally caught my eye and asked me to join the Branch Committee (she made me an offer I couldn't refuse...!) I wondered initially what role I might play. Pretty soon though the need for a new 'Visits Co-ordinator' became clear, and I jumped at the opportunity. My retirement hobby (which quickly became a full-time job, at least in the Spring and summer – and latterly a business which I owned and ran) had been driving and guiding (mostly) Americans to the Cotswolds and elsewhere – although we also took fans of 'Midsomer Murders' to the filming locations in south Oxfordshire (thus discovering that most of Australia watches the programmes at least twice a week!) It seemed like very good practice (and useful experience) for taking on this new challenge!



The first visit I organised, taking over from Sally our indefatigable chair, was to Warner's at Lakeside on Hayling Island, in September last year. Although by then I was already booked to go elsewhere, I was able to be on hand to collect the keys from the Reception Office and make sure members found their way to their respective rooms, which were spread out across the extensive site. Jenyth, who is writing elsewhere in this issue, gave a positive report on proceedings and all seemed to go very well.

Our first excursion in 2019 was the Branch Lunch in March, for which we relocated to The Greyhound at Besselsleigh. I had

driven by it many times as I brought touring clients back from Stonehenge & Salisbury, and had noticed that it was always busy, which seemed a good sign. It turned out to be an excellent choice: we were given our own dedicated space, were very well looked after, and nearly 40 members and their partners enjoyed a very good occasion: we even managed the logistics of getting the correct pre-ordered lunches to all the right people. Indeed the toughest part was getting off the S6 bus across the road past the speeding A420 traffic!

In early June we went to the Cotswold Wildlife Park where almost 30 attendees had a fun day out, just managing to stay dry enough for an outdoor picnic, on a cloudy Tuesday. Several new members joined us for this, as well as three from the Banbury branch. Once more the logistics, of marshalling the group past the ticket offices as they all arrived independently, worked smoothly: well done, Cotswold Wildlife Park and 'thank you' for the group concessionary rate.

Attention then turned to the Branch Holiday at Warner's Holme Lacy for this year's trip, in October. I decided that I should make a site visit early in the day so back in April I indulged myself with a trip by train along the Cotswold Line to Hereford. I must say at once that my experience of Warner's staff and customer service has been exemplary at every stage. My new best friend, Debbie at Group Sales

in Hemel Hempstead, could not have been more helpful or attentive, and this followed on with the time I spent on my fact-finding visit to Holme Lacy with national sales manager Sarah (who turned out to be a fanatical football supporter, and friend of the daughter of the current Oxford United Manager!). The baton has been taken up by the splendid local Sales Manager, Yasmin, who has assisted with the detailed planning. Just as an indication of what is involved, I have arranged car shares to and fro from Oxford; bags transfer for a couple of train travellers; a birthday cake and Prosecco for all; allocated tables for dinner for our

group; special dietary arrangements; and for places on the hotel's weekly bus into Hereford. Oh, and a switch of rooms after the hotel had to schedule building work in one of those we had been allocated. All part of the fun!

Our final event of the year was a trip by coach to Winchester Christmas Market at end-November (we were going to Bath, but after the authorities there decreed that buses could not park anywhere near the Abbey, with no concessions for those with mobility issues, we switched locations.

## Exercise really is the best medicine!

Jonathan Bromley

It really does get rather boring, doesn't it? *Everyone* nags you about exercise. Your GP, your partner, your family, random people you meet in the pub -

*everyone* tells you that exercise is good for you, more exercise is even better for you, vigorous exercise is better still. **Yawn.**

The trouble is, *they're right.*

Everywhere you look, expert advice suggests people with Parkinson's should do as much exercise as they can. Your Parkinson's specialist has almost certainly said it. Your Parkinson's nurse has probably said it. There's a great page of resources about exercise on the Parkinson's UK website. But is it real? Where's the science?

Recently a rigorous clinical trial by Bas Bloem, a leading Parkinson's researcher in the Netherlands, has shown beyond reasonable doubt that vigorous aerobic exercise three times a week can significantly slow the progression of

Parkinson's. What's more, he managed to make it fun!

The study compared aerobic exercise done on a stationary home-trainer (aerobic intervention group) with gentler stretching (active control group). Both interventions were home based, requiring 30–45 min training three times per week for 6 months. Both groups received a motivational app and remote supervision. The off-state UPDRS (Unified Parkinson's Disease Rating Scale) motor score revealed a between-group difference of 4.2 points in favour of aerobic exercise in the intervention group. This study gives yet more support to the benefits of exercise in Parkinson's, particularly anything that gets you sweaty and out of breath (as long as it's approved by your doctor). You can read an article on the study by Simon Stott of The Science of Parkinson's – as usual you can find the links on the research pages of our website, or in the online version of this newsletter.

# Reflections on 2019

## Sally Bromley, Chair

As well as wishing a very Happy New Year to you all, I'd like to share a few reflections on the year just ended:

- Paul spread his humour across the country with his one man show
- Kevin has raised awareness of research at conferences
- Nigel and Kevin attended the Kyoto World Parkinson's Conference
- David has got people finding out about PD through his pub quizzes
- Finding 12 volunteers to facilitate our August discussion meeting reveals the close ties we have developed with people interested in Parkinson's
- Kit has raised funds and informed his Huntercombe Golf Club about living with PD as the Charity of the Year
- More people have got involved with Expert Patient Tutor where patients inform Y5 medics about our neurological condition
- Members put on the Great Gatsby Ball
- Members have supported In Control by Design, a set of workshops with members of a lab, the Pitt Rivers Museum and members of Oxford and Banbury branches working together
- Martin and Mark have raised awareness of the branch through the North Oxford Rotary where our Branch is Charity of the Year
- Ian and Diana are facilitators for First Steps
- Ian has spoken to other branches of the benefits of First Steps
- Martin has encouraged more people to go on visits and to join in events, and has organised an enjoyable holiday to Holme Lacy in October
- Kevin is on the research committee at Cure Parkinson's Trust and also he is co editor of Clinical Trials Highlights at Journal of Parkinson's Disease
- Kit has fostered links at the Art Cafe in Whitchurch on Thames
- Nigel arranges a picnic at Blenheim and Kit the BBQ at Wytham.
- More members are involved in research as volunteers
- I have delivered presentations to various groups over the year
- I've wrangled with PUK re First Steps and I think this is resolved...
- I was patient rep on an Oxfordshire CCG Project to report on services for PwP
- First Steps is reaching people across the country
- We have made stronger links with Age UK Oxfordshire, and continue to subsidise exercise classes run by their Generation Games service
- and there have been countless fundraising activities and events run by members

This is an impressive list and we should be proud of our work and all that we have achieved.

### Chapter 4

Word spread like the plague round the  
village  
“Mr P’s got a problem I hear.  
He’s reluctant to share it, but Sparky  
wants help  
So we’ll do what we can ’cause she is such  
a dear.”

The Mayor called a meeting about it  
“There is clearly a need here” he said  
In the war it made all of us stronger  
As each saw to it that all the others were  
fed

And the harder the test was the better we  
liked it  
As time passed we became quite blar-zay  
At the risk of a big head I’d say we had  
cracked it  
Pull together, eyes open, lips smiling this  
way —

And never, but never lose sight of your  
object  
Just keep your feet moving along the  
straight path  
Look after your pals and your kids and the  
wife  
If we lived through this war, we’d be wiser  
by half.

The applause was immediate and  
deafening  
He had such a deft way with words  
It all sounded easier to deal with put like  
that  
And they knew about ploughshares from  
swords.

So they made a big effort to right things  
That had been sort of skew-whiff for years  
Apologies offered, and breakages mended  
Emotions ran high and there were a few  
tears.

In the end it was quite a good effort  
And everyone felt they’d been heard  
The entire community came to their aid  
And the Parks were Celebrities quite lost  
for words.

#### ***Missed earlier instalments?***

*You can catch up with all episodes of  
Park’s Larks on our website at  
[oxfordparkinsons.org.uk/parkslarks](http://oxfordparkinsons.org.uk/parkslarks)*

## A special challenge in May

Gary Shaughnessy, recently appointed Chair of Trustees of Parkinson's UK, is – to say the very least – energetic. Last year he raised thousands of pounds for the charity by cycling all the way from Zurich in Switzerland to his home in Berkshire over 11 days, making use of his contacts in Zurich Insurance to gain matched funding from their charitable foundation. Full details of his next project are still under wraps but we are allowed to tell you that **it will take place in or around Oxford on 2<sup>nd</sup> May, and it will involve attempts on THREE world records.**

Gary needs support from us and our friends to make this a success, as one of



the targets is to have the largest number of people ever participating in a three-legged race and we'll need all the runners we can get, regardless of ability! We will share more details as we have them, but for now please **hold the date** to be a part of this gloriously mad challenge.

## Staying positive – your top tips

**Sally Bromley**



- Give yourself a treat
- Do what you enjoy doing
- Have things to look forward to
- Have a routine to follow
- Enjoy family occasions
- Do little exercises while boiling an egg
- Don't worry about things you can't do or can't change
- Do the things you can do
- Keep positive with your carer
- Keep busy
- Have holidays
- Attend meetings and classes
- Enjoy your hobbies
- Plan ahead