

# Parkinson's UK Oxford Branch **OUR NEWS**

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

July  
2022



VIPs  
visit from our charity's HQ  
at the end of March – read about it on page 12

## SUMMER ISSUE

Since we've been able to get back together, it has been a joy to renew friendships and share experiences. In this issue you will find a review of some of the events we have been able to hold over the past few months, and a look forward to our plans for the near future.

Find out about us on our website [oxfordparkinsons.org.uk](https://oxfordparkinsons.org.uk), or see page 2 for more contact details. Parkinson's UK is a registered charity in England and Wales (258197) and in Scotland (SC037554). Registered office: 215 Vauxhall Bridge Road, London SW1V 1EJ.

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## Getting in touch

Our website [oxfordparkinsons.org.uk](https://oxfordparkinsons.org.uk) has contact details for all our Committee officers. You can also phone our Secretary on **07889 437222**.

## Coming soon

Don't miss...

- our **Cake and Produce Sale** in Summertown on 23<sup>rd</sup> July
- our regular annual **Discussion Meeting** on 3<sup>rd</sup> August, with follow-up at the Branch meeting in September
- **Summer Barbecue** in Wytham Woods on 11<sup>th</sup> August
- **Oxford Walk for Parkinson's** on 18<sup>th</sup> September
- and our October **Branch Holiday**, for those who have booked!

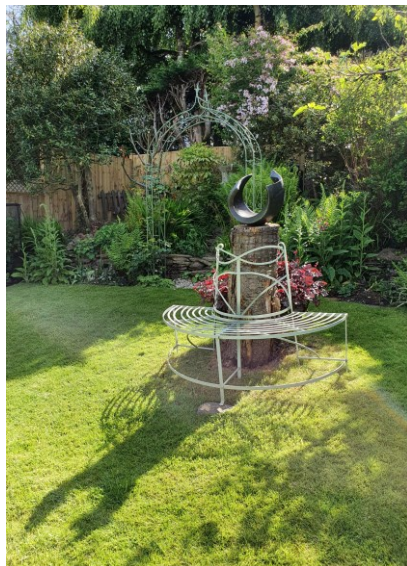
Look out for emails from our Secretary for more news and events.

**Cover photo:** Parkinson's UK Chair of Trustees Gary Shaughnessy, CEO Caroline Russell and a team from our Branch visited Oxford Parkinson's Disease Centre's labs as part of our "Grand Day Out". Read more on page 12.

# Open Gardens at Badby

## Pen Keyte and Joss Hartland-Swann

Pen and Joss live in the rural village of Badby, a few miles north-east of Banbury.



In 2019 we, and other gardens in the village, had over 300 visitors under the National Gardens Scheme, which raises hundreds of thousands for Parkinson's UK and other charities every year. Then came Covid, and no openings in 2020, followed by a dreary time-and-number limited pre-booked opening in rain and wind in 2021. Mostly spent huddling in the garage. Which in itself is a site worthy of display for its 50 year collection of... stuff!

By 2022 however, we were fired with enthusiasm, not least by the addition to the village of a new young gardening family, one member of which had spent 6 years studying at Kew. Kew! We were blessed. So, open we did on May 22, and happily received over 250 visitors, with their babies, dogs, wheelchairs, and teenagers who have yet to learn that the joys and sorrows of gardening far surpass those of adolescence.

# Members' Stories

## Episode 1: Roy Poyser

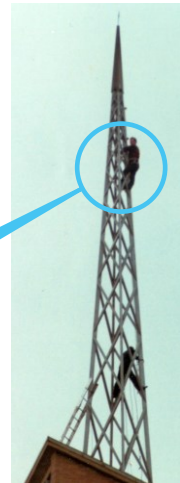
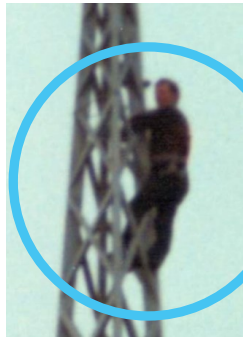


Roy is a familiar and welcome face at our meetings and Friday exercise classes, and many of us have enjoyed his unique line in “Dad jokes” so truly terrible that they make us roll with mirth.

A while ago, Roy lent us some old photographs. The first one was an innocent enough family snap of him enjoying his twin delights of grandchildren and motorbikes, with his usual flamboyance.

But who’s this near the top of the spire? Yes, you got it – it’s Roy doing a little amateur steepolejacking just 40 years ago.

Those who have lived in Oxford for a long time will remember this spire on the top of “Botley Cathedral”, the office development near the Botley Road junction of the western bypass. Nowadays the spire is smartly clad in copper sheet, but back in the early 1980s it had this pylon-like appearance atop Hartwell’s vehicle dealership offices.



In mid June 1982, news came through that the Falkland Islands capital Port Stanley had been re-taken by British troops. Roy and one

of his colleagues at Hartwell's asked their management whether they could fly a Union flag from the top of the spire to celebrate the event, and in Roy's words "he said if you can do it, get on and do it".

No hard hats, no scaffolding, flagpole hauled up to the top by hand. If there's anyone in our Branch who has experience of health and safety legislation, we would love to hear their views about this! Roy tells us that he had to do the same climb again a few weeks later, after the building's maintenance crew foolishly cut the halyard so that the flag couldn't be raised or lowered.

### **A moving postscript:**

When we asked Roy for permission to publish this, he mentioned something he hadn't told us before. In his own words:

*Hoisting the flagpole was really important to me as my brother was serving in the marines fighting in the Falklands and all the family were extremely proud of him.*

*Thanks to Roy for the photos and this lovely story. Please contact him to learn more, and get in touch with Jonathan if you have pictures or tall tales that you would like to share in future Newsletters.*

## **The new normal**

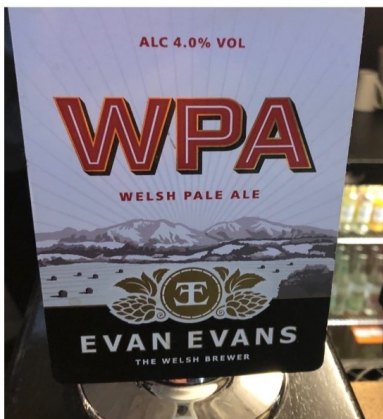
Our monthly Branch meetings, weekly Big Bold and Balance exercise classes, and some other activities are now "hybrid", so that you can choose to take part either by joining us face-to-face or online from your own home. We hope that this flexibility will help many of you to stay involved even if you prefer not to join us in person. Please don't hesitate to get in touch with us if you have any questions about how to participate in any of our activities.



# Walking in Wales

Martin Cowell

For me as a convert to good regular aerobic exercise (reckoned to slow Parky progression by at least 30%) and a trains anorak, the prospect of walking the Heart of Wales Line Trail <https://www.heart-of-wales.co.uk/> was too much to resist. Walking AND lots of train rides – what's not to like?? At 15 of the 31 stations between Craven Arms and Llanelli, you have to hold your hand out to get the driver to stop! And with names like Llangammarch (not to be confused with Llangennech!) and Llandybie (prizes for guessing that it is pronounced Thlan-dee-be-er!!) you know that you are a long way from North Oxford. The countryside is spectacular, and especially if you like sheep you will love it: the birdsong and wild flowers help too.



So in May 2019 I and my three walking mates (including two Welshmen!) set off to travel from north to south. The railway of course takes the flattest and shortest distance between points: the trail has other ideas with lots of climbing (and descending), often well away from the line itself. The promise (to me anyway) of a ride on this iconic line was cruelly dashed on the first day when the train was cancelled! There are only four trains per day each way so with the help of Google we found a taxi – driven by a former member of Rhodesian Special Forces, and ex-bodyguard to Ian Smith!

In October we ventured out again and got as far as Builth Wells – then of course came Covid. We have had to wait two years to resume – but it has been well worth it – even though for the last stages we are down to three and now just two (one dodgy knee and one busy Rotary Vice President!)

## Parky D

Philip Cox

### ***Philip muses on life so far... with his uninvited friend Parky D.***

Two thousand and twenty, that's a year I'll remember, I noticed things going awry. Near the end of that year my feet they did shuffle and I staggered a bit side to side.

The room it did sway when I stood up to walk and my mind, it was foggy on times.

My right arm had stopped swinging, my hands had got weaker they began to tremble and shake without warning.

Now if I was back in my younger days and consumed a nice pint or glass of red wine, I would say that I'd had a good night out. Oh! alas not the case as all I had drunk was shaken not stirred, a spilt mug of my earl grey tea!



Now making a sandwich that became quite a challenge, my aim for the bread often missing. To catch all stray fillings I started using large trays and not plates or the worktop became a food collage.

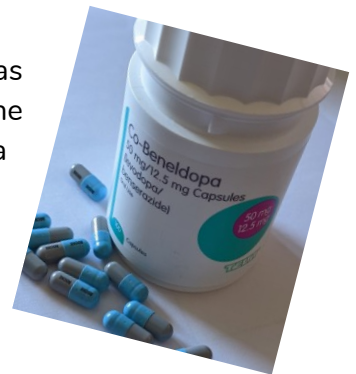
Something was clear I was right off the level and in fact things were fast getting worse. That

scene sprang to mind of Bambi on ice and Thumper's classic but oh so true line.... *Kind of wobbly, aren't you?*

It was February now the year 2021, got sent home from work.... not allowed to return. depression! anxiety! hit me hard. Help now I did need so I saw my GP who said clearly you have complex issues! He carried out tests to tick the boxes he could, then referred me to specialist teams.

Well the Neurologists started their intensive tests to find out just what had gone wrong. The road it was long and the months just rolled by ticking boxes along the way.

A full year had passed almost right to the day, it was February 2022. All the tests now complete, all the boxes were ticked, the Consultant at last had a diagnosis. So not the best news to have PD but I was relieved to finally know. I'm more prepared now when Parky.D. comes a knocking when he visits and sends me skew-whiff! Three times a day I take tablets to stock up on dopamine he steals.



Yes Parky.D. is a real little devil, the proverbial pain in the butt! One thing that I've learnt though is that I am not alone with new friends I've met, through Oxford Parkinson's UK.



# The Trussed-up Trustees

Sally Bromley

Join the Parkinson's UK Board of Trustees, they said. It will be interesting indoor work with no heavy lifting, they said. And then someone had the idea that three of the Trustees might have a go at the longest zip wire in Europe and try to raise a bit of money. So off I went to North Wales with Gary (chair of trustees) and Elaine (trustee for Wales) for a long weekend culminating in a 70-second zoom down a mile-long wire across a disused slate quarry. We had a blast! A big group of other Parkinson's UK members took part, wonderfully supported by the Events team. Thanks to the



*Sally and Elaine getting kitted up*

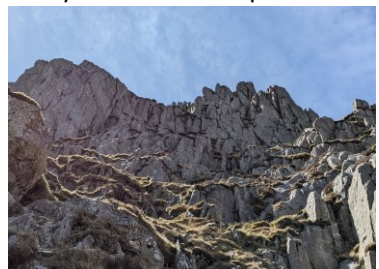


*Launch!*

generosity of many Branch members and others, I raised just over £2000 as well as enjoying a brilliant challenge. You can see a video of all three of us on the Branch website. Warning: it's 15-rated! Contains strong language and mild to moderate peril!

It was also a great opportunity to enjoy the company of two fellow Trustees in a relaxed context, and as an extra bonus Jonathan was able to enjoy a hill walk in Snowdonia the day before. He reports that Tryfan is much steeper now than when he last climbed it 35 years ago.

*Snowdonia  
looking gorgeous*



# Lyndsey Isaacs' Eight Top Tips



Lyndsey Isaacs

We were very excited to welcome **Lyndsey Isaacs** and **Helen Matthews** of Cure Parkinson's to our June meeting. Both gave us inspirational presentations, Lyndsey talking about her life with the amazing Tom Isaacs and Helen covering the exciting research programmes currently being supported by Cure Parkinson's. Both talks are now available on our website as video recordings.

A highlight of the evening was Lyndsey's list of Top Tips for helping people with Parkinson's (PwP) and their carers to have the best possible relationship. They draw on her long experience of supporting Tom through good times and not so good. Can you add your own favourites?

This is a summary of what Lyndsey said. You can hear the full story – often heartening and encouraging, occasionally very moving – in the video recording.

## **Tip No.1: Communication and Ground Rules**

Parkinson's can interfere with relationships between PwP and carer. Don't be afraid to seek support for getting communication right, and establish agreed ground rules not only for your interactions with one another but also for how you expect to interact with others.



**TOP TIP No. 1  
COMMUNICATION**

### **Tip 2: Knowledge is Power!**

Knowing more about Parkinson's symptoms and treatments can help with effective management of medication and other day-to-day concerns.

### **Tip 3: Drug Side-effects and The Agonists**

Dopamine agonist drugs, often used in treatment of more advanced Parkinson's, can have troubling side-effects including compulsive behaviour and mood changes. Be alert to the possibility, and be ready to discuss alternative treatment options with your Parkinson's nurse or neurologist.

### **Tip 4: Parkinson's Nurse Specialists are Gold Dust**

We are very lucky to have access to specialist nurses in many regions of the UK. They are a wonderful resource, especially if you need to go into hospital, and can be a valuable advocate for you, bringing your concerns to your neurologist.

### **Tip 5: Travelling with Parkinson's**

Don't be ashamed to use any support or special assistance that is available!

### **Tip 6: Mobility Issues**

Learn from others' experience to find tips for dealing with freezing and other troublesome mobility problems.

### **Tip 7: Self Care**

Unpaid carers, often a spouse or partner, should reserve time and energy to look after themselves so that they are better able to look after their PwP.

### **Tip 8: Research**

Participating in research projects, even the most simple, can be hugely empowering and rewarding. By doing so you learn more about the condition, and have the satisfaction of knowing that you are contributing to better hope for future PwP.

# The Grand Day Out

Sally Bromley

March 30<sup>th</sup> was a big day for our Branch. We had a rare opportunity to welcome VIPs from our parent charity Parkinson's UK for a day. It gave us a chance to showcase the work of our Branch and introduce them to some of the brilliant research and clinical work that takes place in Oxford. Much of that work was enabled by early funding from Parkinson's UK and it was impressive to see how things have moved on and how much additional funding has been secured.

A packed day for our guests Caroline Russell (Parkinson's UK CEO) and Gary Shaugnessy (Chair of Trustees) began at the new buildings for the Department of Physiology, Anatomy and Genetics (DPAG) where some groundbreaking science takes place to ultimately improve the lives of Parkies worldwide. Oxford Branch began the proceedings with Sally Bromley talking about the branch and its work, followed by Mark Jennings who set out the framework 'Improve Life for PwP and their Carers' that he designed to guide how we go about planning future work. Martin Cowell reported on the value of branches for PwP and how much our members appreciate what we offer. Paul Mayhew Archer then lightened the atmosphere by giving his humorous view of living with Parkinson's before a buffet lunch kindly provided by the lab.

Professor Richard Wade-Martins (online thanks to Covid), Dr Brent Ryan and Dr Charmaine Lang explained the complex work they do, before leading guided tours of the lab. During the tour, we were able to meet the scientists and see new specialist equipment in use.



Our visitors at DPAG

After the tours, Professor Stephanie Cragg informed us of the \$9 million award from Aligning Science Across Parkinson's (ASAP) to the University for a project she leads. We then heard from Richard Wade-Martins about a new £4 million Wellcome Trust Collaborative Award in Science to Oxford Parkinson's Disease Centre (OPDC) which will start in 2022. These multi-million awards have come about following the initial funding by Parkinson's UK. Early smaller grants allowed research to begin. The projects' successful progress has triggered this further funding.



On to the John Radcliffe Hospital ("up the hill", as the scientists say) for an update on clinical research findings from the Discovery Cohort which has been tracking over 1500 patients, siblings and controls over 12 years. Dr Michele Hu (also on Zoom) outlined how digital technology such as smartphone apps and sleep monitoring is helping research into Parkinson's and REM Sleep Disorder.

We also met Dr Gabriele De Luca and Dr Gina Hadley who introduced us to the Expert Patient Tutor scheme, which has involved several members of our Branch in the training of medical students. Among other goals this will help GPs understand our condition and make appropriate referrals for diagnosis.

After a minibus ride to an early supper, kindly hosted by Anne Cowell, we rushed to Cherwell School for our Branch meeting. Caroline and Gary met with Branch supporters from a huge range of organisations and agencies.

Caroline and Gary introduced themselves to our members and impressed us with their determination to strengthen Parkinson's UK's advocacy on behalf of PwPs and to put members at the centre of all they do. They responded frankly and creatively to our questions about Parkinson's UK's work and future plans, and left us with an encouraging sense that the charity is moving forward with new vigour.



# Parkinsons.Me community garden

## Martin Cowell

As a committed attender of the exercise classes run by Wantage-based charity Parkinsons.Me, in November 2020 I was invited to become a trustee. This led me to learn about the fantastic Community Garden where a dedicated team of volunteers has managed to turn **this**:

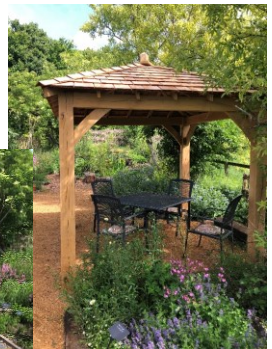


into **this**:

A small group of us from the Oxford Branch paid a most enjoyable visit to the garden which is situated on the edge of West Lockinge, not far off the A417 main Abingdon to Wantage road. I do urge everyone to go and see it. It is open at all times and directions are at <https://www.parkinsons.me/community-garden-west-lockinge>

It is a wonderful resource, not just for PwPs but for the whole community: you can even play table tennis, and the new pergola is perfect for the odd damp moment...

Parkinsons.Me is a brilliant local charity that prioritizes the concerns of younger families that are affected by Parkinson's. You can read more about their work on their website.



# Succession planning

from our Secretary, Pen Keyte

I've been involved with a number of PUK workshops recently, where the lead volunteers of local Branches and the Network Support Officers from PUK get together to discuss... stuff.

One thing that lead volunteers most commonly want to talk about is Succession Planning. This is not, as my daughter would have it, planning the evening when the baby is asleep and her husband is out so she can watch the next episode of Succession with Brian Cox. NO! it's much more important than that. It's managing the future health and success of every branch of PUK. Oxford Branch is just one of the many hundreds of branches throughout the country. Part of the success of the Oxford Branch is because of the enthusiastic participation of its members. In addition, the Branch has a hugely strong and effective Committee. There is no need to mention individuals, because each and every member of the Committee is committed (the clue is in the word!) to supporting and improving the lives of PwPs. I know first hand what energy and creativity goes into these efforts.



So Oxford Branch needs you! I'm taking this opportunity to let you know that I shall be stepping down as Secretary at the next AGM in March 2023. I hope to continue in a minor role on the Committee, but I am hoping that my current role can be divided up, so that it is more manageable, and that people will feel able to say 'I could do that!' (and probably better!)

**Editor's note:** Pen has given extraordinary service to the Branch and its members over the past few years.

Please give careful thought to how we can continue her work as she takes a well-earned break, and don't hesitate to let a committee member know if you think you could help.

# Welcome to new members

We are always delighted to welcome new members to our Branch. We are open to anyone in Oxford and the surrounding area who is affected by Parkinson's, cares for someone with Parkinson's or is in any way interested in what we do. We're happy to have a number of new members since our last Newsletter:

Philip Cox  
Elaine Dale

Denis O'Driscoll  
Ross Mackenzie &  
Susanna Reece

Frances & Mike  
Gotch  
Peter Lloyd

## Farewell

We note with sadness the deaths recently of several Branch members, including:

Doreen Browne  
David Gale

Giles Oldershaw

Chris Adams  
*(mistakenly omitted from  
previous Newsletter)*

### **Photo credits:**

Pages 1, 9, 12, 13: Parkinson's UK

Page 10: Cure Parkinson's

Page 4: Roy Poyser

Page 3: Pen Keyte

Pages 6, 14: Martin Cowell

Others: the Newsletter editorial team