

Parkinson's UK Oxford Branch
OUR NEWS

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

**December
2022**



Bembridge
lifeboat station, just a few
steps from our Branch Holiday hotel – see page 6

WINTER ISSUE

Looking back over a busy summer and autumn,
and looking forward to a happy Christmas and New Year
for all our members, supporters and friends

Parkinson's UK Oxford Branch

MERRY CHRISTMAS



artwork ©2016 Korky Paul

In this issue

Getting in touch	2
Helping you to join in	3
Our new phone number	3
2022 Oxford Walk for Parkinson's.....	4
Members' Stories.....	5
Branch Holiday, Isle of Wight	6
Farewell to Robin	8
Parkinson's Research NEEDS YOU	10
Ray Dorsey Comes to Summertown.....	11
Welcome to new members.....	12
Farewell.....	12

An extended edition of this Newsletter, with additional material, clickable web links and a longer version of the Research article, is available on our website at oxfordparkinsons.org.uk/our-news

Getting in touch

Our website **oxfordparkinsons.org.uk** has contact details for all our Committee officers.

You can also call our new phone number **0300 772 7003** – see facing page for more details.

*Find out about us on our website oxfordparkinsons.org
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.*

Helping you to join in

The winter months bring dark evenings and harsher weather, so travel to meetings may not be so easy.

Almost all 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.

Our new phone number

As part of our preparations for Pen handing over her Secretary role in March 2023, your Committee felt it was appropriate for the Branch to have a single telephone number to act as a point of contact for any enquiries, both from Branch members and from people outside the Branch. We have now set up our new phone number

0300 772 7003

Most callers will be invited to leave a voicemail message. We are currently building a small team of volunteers who can commit to checking the voicemails on just one evening each week, and returning those calls to provide what support we can. Often our response will be to refer callers to the Parkinson’s UK helpline or some other service, but sometimes we may be able to help directly – especially if the call relates to our Branch’s activities or events.

If you think you may be able to help, or if you have ideas for how we may best use this facility, please get in touch with Martin or Jonathan.

2022 Oxford Walk for Parkinson's

The Oxford Walk for Parkinson's was back in the delightful setting of Wytham Woods for 2022. The period of mourning for the late Queen caused it to be postponed from mid-September to early October, but it was still well-supported and raised more than £13,000 that will go to supporting local research projects.



Special congratulations go to Nick Wrigley, who had collected over £1000 sponsorship. He could not participate on the altered date, but instead created his own challenge by walking 6 miles of the Thames Path to fulfil his promise to sponsors. Here he is between Henley and Shiplake.

Nick says *"One day, I hope I can say I HAD Parkinson's!"*

The weather on the day was perfect. The event organization, masterminded by Katy Slade of Parkinson's UK, was excellent, and as you can see from these pictures, the atmosphere was fabulous.



Members' Stories

Episode 2: Malcolm Thick



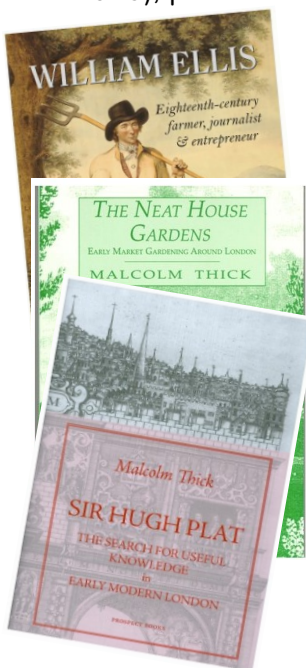
Jane Card tells us:

Malcolm was a civil servant but worked part-time for many years so that he could write history. His research area was 16th-17th century market gardening and agriculture; now he has diversified into food history. This is appropriate: he is an excellent cook but no gardener, except in theory. He is a Fellow of the Royal Historical Society.

His first book was published in 1998, followed by various academic papers. Having got his much-desired early retirement in 2008, he was diagnosed with Parkinson's in 2008/9. Since then he has, among other things, produced a major book on the Elizabethan entrepreneur, inventor, foodie (and more) Sir Hugh Plat, won an international prize for food history writing (the Sophie Coe Prize 2019), published articles in *Petits Propos Culinaires* (a food history

publication) and written two privately printed detective stories and a pantomime (Dick Whittington) which can be seen on YouTube.

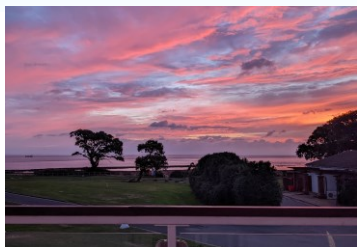
Malc wrote a comedy about the Elizabethan humorous writer and traveller Thomas Coryate, which the Didcot Phoenix Drama Group staged in Coryate's birthplace Odcombe in Somerset. He also produces humorous monologues for the group – but won't act himself. In the pipeline are another pantomime, another detective story and, eventually, more history about vegetables, recipes, cookbooks and food.



Editor's notes: Curiously, Neat House Gardens were only a stone's throw from the current location of Parkinson's UK HQ, near present-day Victoria Station. The panto is at [youtube.com/watch?v=WJ6t7guYcPc](https://www.youtube.com/watch?v=WJ6t7guYcPc)

Branch Holiday, Isle of Wight

Mark and Sarah Wilson



We were a group of 27 who stayed at the Warner's hotel in Bembridge. Our room was delightful as we had an upstairs room, with balcony, overlooking the sea.

We woke the first morning to sunshine that followed us to the visit to Osborne House (run by English Heritage). It was somewhere I had always wanted to visit. For me it was a personal one as I have long connections with India and was thrilled to see so much represented there by way of statues, paintings, stunning silver and jewels and of course the famous Durbar Room. The top floor was closed due to staff shortages and the basement closed also – but this time due to damp.



We walked to the Swiss Cottage and round the gardens admiring the gardens and the ancient trees including a couple of cork trees. We noticed that there were electric minibuses available.

Another day saw us visit Carisbrooke Castle, again well worth a visit especially as the introductory talk was given by a donkey (cartoon one)! If you're good with heights, then launch yourself up to the battlements – and good luck coming down to a really good cup of tea and cake.

There are amazingly eight Roman villas on the Isle of Wight. We visited the only one that can be visited, at Brading. I'm not a person who enjoys 'piles of rocks' but this took my breath away. We had the

most fantastic volunteer telling us all about the site, the history and the stunning architecture – and even the fact that they had to water the sedum roof this summer because of the extreme heat. The coffee and cake were spectacular, the café run by volunteers.



Martin loves steam trains

Every boy's dream was our trip on the Isle of Wight Steam Railway. The journey itself was great fun and for us made all the more special as we shared our carriage with two older ladies from Ukraine with whom we shared smiles and a little bit of English. The workshop where the carriages were being repaired and renovated, plus the museum, topped off one particular boy's happy day.

Our evenings were great fun. We all got together before dinner for a catch-up and an occasional cocktail or beer and then on to dinner. We had an area set aside and moved around tables each evening and breakfast. The buffet had themed evenings and there was plenty of choice both at dinner and for breakfast. There was also evening entertainment, which for us involved watching others ballroom dancing, and then a versatile band, followed by a singer, who played familiar music to put a smile on our faces.

This was our first visit with the Parkinson's Oxford group and we loved it. In no small part because of how well Martin had organised us – thank you. We look forward to hearing about next year's trip and encourage others to come along for the ride.

Editor's note: We are planning another Branch Holiday for next summer or autumn, probably much closer to home. Look out for announcements next year!

Farewell to Robin

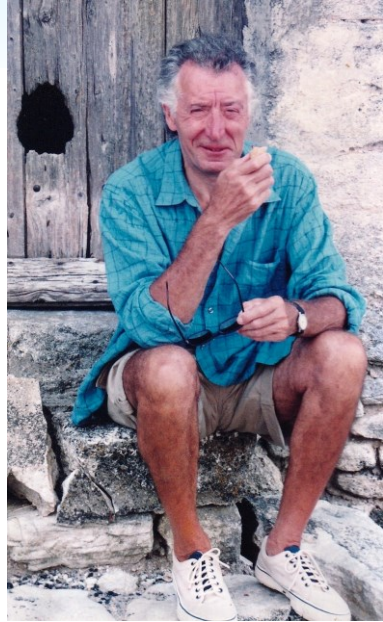
Branch member Robin Dean died earlier this year. In glorious weather in early July there was a lovely celebration of his life at the family home. This charming poem was written for the event by a friend.

And just like that
he was gone.
Up in the Oxford smoke
on a Monday mourn.

And that's when Joy
came and sat with Sorrow.
She knew he was taken
to spare him from the morrow.

His mind had observed his body slowly fail
as strong arms hugged life and battled the frail.
Undignified fall after undignified fall,
the cruel disease, it took it all.
And towards the end, when there was little left,
it stole his words. Then his final breath.

But he hadn't really gone.
He'd just thrown off his coat,
hopped on a bike and was cycling home,
waving and smiling at those he'd meet,
as he flew round corners towards Henley Street.



Robin Dean

You see, he heard they were having a party for him.
And there'd be cake and quiche and rhubarb gin.
There'd be family and friends from far and wide
who'd raise a glass and laugh and cry.

And he wanted them to know that he'd be there too,
silently hugging them, just out of view.
Thanking each one, but not aloud
as he made his way through the gathered crowd.

Some could feel him drawing near,
bringing love to those he held so dear.
Wife, brother, son-in-law, daughter.
Precious grandchildren from across the water.
Old friends, new friends, neighbours and more
from healthier and happier times of yore.

(And those in his heart who couldn't be there,
he knew, deep down, did really care.)

And then, when all the guests had gone,
he grabbed a sweet treat and danced down the lawn.
He skipped up the ramp that led to "the shed",
waltzed through the door and bounced on the bed.

He picked out a film and cranked up the projector.
(Cultured in life, now a cultured spectre.)
Then he kicked up his feet – everything felt so light.
And thought tomorrow he might fly a kite.

He could prune the fig tree another day.
Now he was free. Now he could play.

Pip Farquharson

Parkinson's Research NEEDS YOU

Jim Sheridan

Sadly, limits on space forced us to shorten Jim's material. The full article – a fascinating read – is available in the online version of this newsletter at oxfordparkinsons.org.uk/our-news

We naturally direct our expectations at researchers conducting these trials, in academia, drug companies and hospitals. However, the fulfilment of our hopes is also very dependent on our participation ... YOUR participation. Without participants there is no trial ... no hope. With too few participants the trial may not be as effective ... reduced hope.

To find a trial suitable for you, you could ask your consultant or go online to the PUK research hub

parkinsons.org.uk/research/takepart-research

It is worth noting that there are also many trials where age matched controls are desperately needed. This could involve a partner or friend.

Participating and contributing to Parkinson's research gives me the sense that I have some control over how this awful condition impacts my life. It makes me feel good to be involved and, as a side effect of feeling good, my symptoms improve. Every new trial is a new hope – and I'm as hopeful for trials that I am not on as the ones I am. Plus I have learned more about the disease from talking to researchers ... more about how it is impacting on my own life ... and what I can do about it. Furthermore, I will go so far as to say that most of the non-drug trials are actually fun. The enthusiasm of the young researchers is contagious.

Please participate in trials and make your contribution to transforming hope into a cure.

Ray Dorsey Comes to Summertown

Martin Cowell

In early September I had a message from Helen Matthews, Deputy CEO of Cure Parkinson's. She was very keen to interview Ray Dorsey, co-author of *Ending Parkinson's* (and who along with Bas Bloem contributed to our successful webinar in February 2021), whilst he was in Oxford, for a documentary being created by Rob Hayworth about Guy Deacon's epic journey from Freetown to Cape Town.

Guy has Parkinson's, and having retired as a colonel from the Army in 2019, he has been travelling overland to fulfil a lifetime's ambition and demonstrate that the condition need not stop you undertaking such activities or stop you pursuing your dreams. Working as an ambassador for Cure Parkinson's and Parkinson's Africa, the film of his journey will show him meeting many along the route who also have Parkinson's and letting them tell their stories to a world-wide audience.

What Helen was missing was a venue to film the interview with Ray – so I stepped in and offered our kitchen/diner, which as turns out has the sort of natural light from above that the film-makers would normally have to use a £30k camera to provide! Paul Mayhew-Archer joined me for the morning, and we also fitted in a Zoom with Omatola Thomas, Founder and Director of Parkinson's Africa www.parkinsonsafrica.com. As well as being incredibly tall, Ray is also charming, and a very accomplished interviewee. Most of his responses were filmed in a single take, and film-makers Rob and Jack were delighted – as were we all, as I hope this happy picture shows!



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:

Geoff & Lynne Allen	Jennifer & Neville East	Eddie Parker
Val Mitchell & Rebecca Berry	Simon & Hazel Hislop	Janet & Michael Read
David & Stephanie Bullock	Patrick & Penny Hobson	Colin Smith
Joanna Clark	Tom & Marion Martin	Geoff & Karin Woodruff

Farewell

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

Howard Cork	Denis O'Driscoll	Richard Linaker
Robin Dean	John Grain	Robin Stainer

Photo credits:

Page 4 (top): Nick Wrigley

Page 4 (foot): Parkinson's UK

Page 5: Jane Card

Page 6 and cover: Jonathan Bromley

Pages 7, 11: Martin Cowell

Page 8: Judy Hammond