

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

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

Spring  
2022



# WELCOME BACK

*We've missed you!*

This special edition of our Newsletter celebrates what we've been able to achieve together during two challenging years, and looks forward to renewed friendship and reinvigorated activities in 2022.

Find out about us on our website [oxfordparkinsons.org.uk](http://oxfordparkinsons.org.uk), or see the back page for more contact details.

Parkinson's UK is a registered charity in England and Wales (258197) and in Scotland (SC037554).

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## Our first Newsletter for a while



It's been a strange two years. We tried publishing an online newsletter featuring some of the ways you have been keeping yourselves busy and active during these challenging times, but not everyone has easy access to online material.

We decided to send this Newsletter to everyone by post so that nobody is left out. We think it's worthwhile to encourage all our members to remember that your Branch is still here for you, and that each of us can support one another in whatever way works best for us.

We would like future Newsletters to be shaped by **you**. Tell us about things you've been doing! They don't have to be Parkinson's related. We know that many of you have interesting hobbies and fascinating stories to tell. We can look after the editing – just let us have your words and pictures, and we'll do the rest. Get in touch with Jonathan or Pen to talk about your ideas. Contact details are on the back page.

# Pole Position

## Paul Mayhew-Archer

“Apparently, Nordic Pole-walking is very good for people with Parkinson’s,” said an old friend one day last year. “Type it into your search engine and see what comes up.”



I did as he suggested and thanks to a combination of predictive text and some mistyping what came up was a world of Scandinavian pole-dancing. I have to say, Birgitte and her class of well-oiled writhers were very welcoming and excited at the

prospect of someone with Parkinson’s giving it a go, but I politely declined and found my way onto a pole-WALKING website.

To my amazement it turned out there is an active Nordic walking group in Sutton Courtenay, just down the road from me. What’s more they are eager to help people with Parkinson’s. Graham Wells, the man in charge, was more than happy to give me an introductory lesson during which I learnt that:



- a) It’s excellent for posture and balance and co-ordination.
- b) The poles help to propel you forward if you’re having a freezing episode.
- c) The poles are made of carbon fibre so it’s probably unwise to pop out for a pole-stroll during an electrical storm.

I’ve now been pole walking three days this week and I love it. If you fancy having a go then here’s what to do.

The introductory classes will take place on the **second Wednesday of each month starting at 9.45am** (so March 9th 2022, April 13th 2022, May 11th 2022 etc)

Simply contact Graham's colleague Annalie Thomasson **annalie.thomasson@southandvale.gov.uk** and say you'd like to come to the next introductory class. It's also a good idea to give permission for your email address to be put on the list held by Anne Whitehead **anne.whitehead284@gmail.com** so Ann can email you to say a walk has been cancelled because of the weather.

Then, on the day, come along to the Sutton Courtenay recreation ground at 9.45. (If you're heading towards Didcot, the recreation ground is off to the left down a narrow single-track lane. But you can drive down it and there's a carpark at the end.)

Graham will provide the poles for your initial session and if it takes your fancy he will also provide one-to-one training at pretty well any time you like. He will also sell you a pair of poles at cost – about £21 and far, far cheaper than the ones I got in a shop. The bad news is mine cost £90. The good news is my son paid.

Graham is also setting up a Parkinson's group walk every other Wednesday so once you've been through "basic training" you can join that. And if Wednesday doesn't suit then pop along to Steventon village hall on a Friday at 9.45 where you will find Pole-walks of varying lengths and abilities setting off. Meanwhile, someone else I met this week will soon be leading walks in Wantage and others will be leading walks all over Oxfordshire. I tell you, watch this space because it won't be a space for long. It will be full of people with poles following delightful folk like Graham, whose only dream is to spread the word about the activity they love.

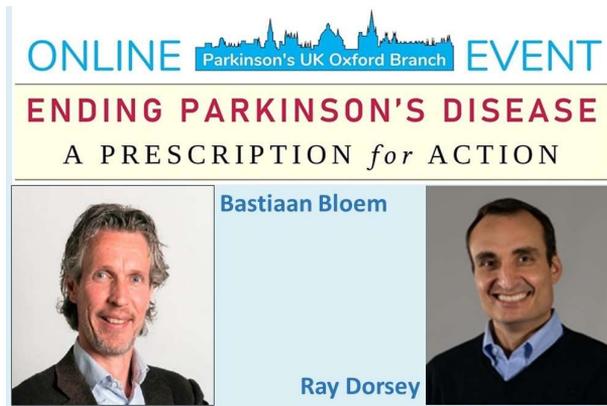
Finally I don't think I mentioned the cost of the classes, the training and the walks. That's because there isn't a cost. They're free.

And finally, finally, if Nordic pole-walking doesn't appeal at all, then get in touch with me and I'll give you Birgitte's details.

# The Secretary's Year: 2021 highlights

## Pen Keyte

For me, the year kicked off with what I called the Baz and Ray Roadshow.



Bastiaan Bloem and Ray Dorsey are two of the writers of *Ending Parkinson's Disease: A Prescription for Action*. Thanks to the power of Zoom, Ray joined us from the US, and Bas from the Netherlands: an amazing achievement thanks to the hard work and inspiration of Sally, Nigel and Jonathan. The speakers explained their PACT mission, where P stands for Prevent, A for advocate, C for Care, and T for Treatment. It was great to hear them give really practical advice, such as how to get the best out of your neurologist. As the ever-gracious Jane Asher, President of PUK, said in her closing remarks, she could think of nothing better than to be cared for by Bas and Ray, and to have them as advocates on behalf of Parkinson's.

Zoom also enabled us to benefit from the Design Thinking Team, over half of whom are based in the States, as we worked on the problem of how to contact newly diagnosed patients, and how to broaden the reach of the Branch. We know that some people who are recently diagnosed feel overwhelmed and lost, and we are still thinking of ways in which we can reach out to them. Ideas, anyone?

So it was a year where everything that could go online did, from exercise classes, coffee and chats, to pantomime performances and singing classes, Christmas parties, Committee meetings and Branch meetings. Arguably one of the benefits of lockdown – and lord knows there aren't many – is that Zoom opened up opportunities for people who might otherwise have had difficulty in coming to meetings or classes in person. The few meetings we did have in person were all the more exciting; the barbeque at Wytham, the lunch at The Greyhound, the visit to Batsford Arboretum, the Winchester Christmas market, the Oxford Walk, were all great fun and hugely enjoyable. Who can resist a garden centre? Well, it appears that some Branch members definitely can't!

Lockdown also gave us the chance to review how we run Branch meetings. As membership of the Branch grew, so also did a feeling that we had outgrown the space at the WI hall in Botley. The Committee contacted the letting manager at Cherwell School and found her to be immensely helpful in meeting our needs. The new venue is wheelchair accessible, has plenty of parking, a good ventilated indoor space, and a separate café area. We have had three meetings there so far, and look forward to many more.

Zoom has also given us a chance to broaden contacts with other branches and to benefit from their programmes. So we are able to access Jane Rideout's webinars on *Living Well with Parkinson's*, and the *No Silver Bullet* webinars with experts Simon Stott and Roger Barker, all of which are available on YouTube. On a local level, huge credit to Becs in Witney, owner of the Eden Café; when her father found it difficult to access Branch meetings, she brought the Branch to him! On two occasions she has opened her café specifically for Oxford Branch members, and hopes to be able to offer more in the future.

As you can see, it's very exciting working with and for such a dynamic group of people; thank you all! Without you I would never have met my husband (first anniversary last December!) nor would I have received a golden brain from Parkinson's UK!

# Activities, events and visits

Martin Cowell

## Batsford Arboretum

In June we had our first activity since the Covid pandemic had hit. Around 25 Branch members and partners had a lovely afternoon at delightful Batsford Arboretum, near Moreton-in-Marsh. After everyone had explored at their own pace, we gathered in the café for tea and cake, and reflected on how lucky we were to have chosen such a fine warm day!



## Branch Lunch at the Greyhound

It was a pleasure to be able to make a return visit at last to The Greyhound at Besselsleigh for our Autumn Branch Lunch. Almost 30 members and partners enjoyed a splendid two-course meal (the cost partly subsidised by the branch) and we were extremely well looked after. On Tuesday March 22nd we will have our Spring Lunch at The Evenlode, Eynsham – a new location chosen for the benefit of our many members in Witney and around!

## Walk for Parkinson's in Wytham Woods



I was very pleased to be part of the planning for this, working with our fundraiser Kit and Parkinson's UK Regional Fundraiser Katy Slade. Moving location to Wytham Woods was made very straightforward with the ready and able support of Wytham Conservator Nigel Fisher, and we had an excellent walk on Sunday 19 September. I was pleased

to be joined by Simon Coates from Wantage, who had walked a total of 2000 miles during the summer, raising funds for our Branch and a host of other local charities.

## Cricket St Thomas holiday

In October I was delighted to be able to lead our Branch group on another most enjoyable four-day break to a Warners Leisure Hotel: this time to Cricket St Thomas in Somerset. Once again the weather was kind, not least on the day that my wife Anne and I, with Chair Mark, went to Lyme Regis.

Early evening drinks were enhanced by some clever 'icebreakers' devised by Mark: it is always amazing to learn of our PwPs' life experiences!

We will be heading to Bembridge in the Isle of Wight this coming October.

## Winchester Christmas Market

We made a return visit by Heyfordian coach to the best such event in southern England in late November. Winchester is a lovely place to visit at any time, with lunch at the Wykeham Arms a most enjoyable addition. A good time was had by all, with fortunately not too much advantage taken of the preponderance of varieties of craft alcohol that were on offer in the Market!

## Eden Café, Witney

Courtesy of Beccs, the owner, whose father is a PwP, we had two well-attended coffee mornings here, in early October and late November. It was a great opportunity to meet up informally with other members and partners. We were very pleased to be joined by Abi White, Parkinson's UK Senior Area Development Manager.

## FUNdraising

Sally Bromley

Just because we were confined to our homes due to the pandemic doesn't mean we could forget that funds are always needed by charities to continue the research and practical support many of us need. This called for a different kind of fundraising.

Our imaginative fundraiser, Kit, came up with the idea of home hairdressing. With hair salons closed we had to do it ourselves – cutting, crimping and colouring. So Kit thought to introduce the 'Lockdown Locks down.' Donate £10 to the branch in exchange for help with cutting your hair yourself or asking your partner to help.



Coming out of the Covid restrictions now, let's think of something to lighten our spirits, brighten our smiles and look to the year ahead with renewed vigour. As I write, Debbie Carpenter is striding up Mount Kilimanjaro. But we don't need to go that far! I'm planning to go to north Wales to ride the longest, fastest zip wire ride in Europe. Care to join me, anyone? What will you do to raise FUNds with FUN?

# gaitQ – a promising startup

Tristan Collins

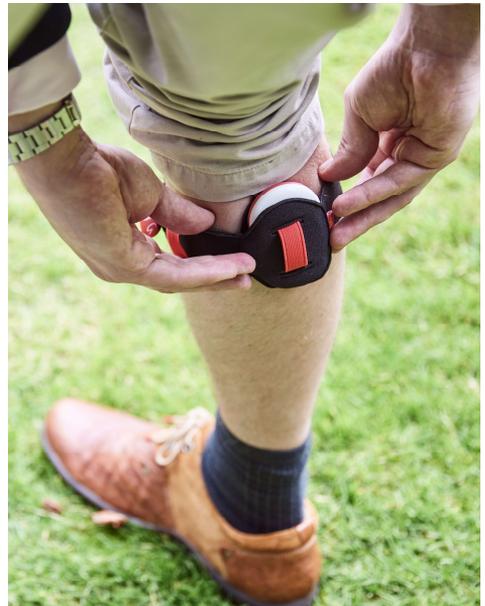


Several Branch members have been involved in early trials of the gaitQ wearable device, which promises to help relieve gait freezing for people with Parkinson's. Tristan Collins, CEO of gaitQ, reports:

I'm pleased to report that there has been great progress made over the last year on company and product development. Firstly, we were able to conduct some product evaluations at our test site in Chalgrove over the summer months. Many thanks to the volunteers who helped in this. We received much valuable feedback and the team enjoyed showing off the prototype to many of the Botley members who attended. Secondly, we were able to complete an additional funding round in December to allow us to develop a further product iteration, aiming for production by the end of the year.

As a company we have grown, bringing our engineering and software development in-house. This means we will be able to start testing "in-home" and be able to demonstrate our "user portal" in the very near future. Watch out for another call for volunteers to give feedback!

Whilst we can't deny that COVID has slowed things down, the green shoots of springs are beginning to show. It will be an exciting 2022 for gaitQ and I hope we can continue to involve the Oxford Branch along the way.



# Messy Futures

## The In Control By Design team

A group of us from Oxford Branch and a couple from Banbury Branch worked together alongside researchers, designers and those with lived experience of Parkinson's, to see if our needs are met in everyday living. The pandemic halted progress, but fortunately we had enough material to put together a photographic exhibition at The Pitt Rivers Museum, Oxford.



Working with museum curators who introduced us to many unusual examples from the museum's collections, we recognised the similarities, as well as differences between everyday objects from another era and another part of the world, and those today. The samples were priceless and we couldn't handle them but we studied each one. Every visit introduced us to some new objects, each

linked with objects in daily use in our lives today: pill holders, walking aids, cutlery, communication and many others.

Surely combining a stylish design, function, practicality and – dare I say 'fun' – would raise the spirits of those of us having to use aids. We found a colourful front-fastening bra. Susan Diab, our artist in residence, added some lipsticks because I love lipsticks, yet they remind you of bullets. And



my second object is yet to materialise: a walking aid with a built in fridge for inviting friends to join you in a gin and tonic!

The exhibition 'Messy Futures' is on now at The Pitt Rivers Museum, until April 4<sup>th</sup> 2022.

# Fancy having a go...?

Sally Bromley

Having a go at ... what? I hear you say.

Alexander Technique! It teaches you to be

- more aware of your body
- it improves posture
- and helps you move more efficiently

Many living with Parkinson's need help to ...

- manage our symptoms
- carry out everyday tasks effectively
- live independently

... and to do it all pain free.



Loretta Manson writes in the recent Parkinson magazine that Alexander Technique (AT) lessons can be tailored to fit your needs. So, if you need help standing up from a chair AT can help you to achieve this, though you may have smaller goals such as lifting a kettle, tying shoe laces or writing.

It is no surprise that the NICE guidelines recommend Alexander Technique to relieve symptoms of Parkinson's such as tremor, speech and balance. Recent research indicates that it can improve mood and back pain.

Simon Fenn teaches Alexander Technique and would like to help a small group of people with Parkinson's (PwP). He is fully qualified and trained alongside Loretta to support PwP. He will do it at no cost to you and the branch will fund the hall hire. If you are interested in being part of this group please contact Sally or email [alextech@oxfordparkinsons.org.uk](mailto:alextech@oxfordparkinsons.org.uk)

# Research Update

Kevin McFarthing

For this newsletter, rather than describe the current state of research, I thought it would be best to update you about some of the resources already available online. You can find clickable links to all the resources mentioned in this article by visiting the research page of our Branch website

[oxfordparkinsons.org.uk/research](https://oxfordparkinsons.org.uk/research)

Starting with the basics, what causes Parkinson's? Here are some links to the Parkinson's UK (PUK) and the Michael J Fox Foundation (MJFF) websites:

- [parkinsons.org.uk/information-and-support/what-causes-parkinsons](https://parkinsons.org.uk/information-and-support/what-causes-parkinsons)
- [michaeljfox.org/parkinsons-101](https://michaeljfox.org/parkinsons-101)

For an overview of clinical trials in progress, there is a review that was published in the Journal of Parkinson's Disease in 2021.

*[Editor's note: Kevin is too modest to say so, but he is Clinical Trials Highlights editor for this journal.]*



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## Clinical Trials Review

### Parkinson's Disease Drug Therapies in the Clinical Trial Pipeline: 2021 Update

Kevin McFarthing<sup>a</sup>, Gary Rafaloff<sup>b</sup>, Marco A.S. Baptista<sup>c</sup>, Richard K. Wyse<sup>d</sup> and Simon R.W. Stott<sup>d,\*</sup>

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<sup>d</sup>Cure Parkinson's, London, UK

A link to the paper is here:

[content.iospress.com/articles/journal-of-parkinsons-disease/jpd219006](https://content.iospress.com/articles/journal-of-parkinsons-disease/jpd219006)

A wider database covering projects at all stages of the research and development pathway, for the more scientifically trained, is the regularly-updated Parkinson's Hope List, which you can find at [drive.google.com/file/d/1NeSyFA37b9IbUzryRRP-EqrgScjCRL-3](https://drive.google.com/file/d/1NeSyFA37b9IbUzryRRP-EqrgScjCRL-3) [... and which is also written and maintained by Kevin – Ed.]

Michael J Fox Foundation holds a webinar on the third Thursday of each month covering a range of topics, often including research updates. More details at [michaeljfox.org/webinars](https://michaeljfox.org/webinars).

Simon Stott of Cure Parkinson's runs the Science of Parkinson's website – [scienceofparkinsons.com](https://scienceofparkinsons.com) – that covers a wide range of topics and news, and while it's science focused, it's also accessible to the non-scientist.

The Research page on the branch website contains not just clickable links to all the resources mentioned here, but also links with information on participating in a clinical trial and other interesting information. Please take a look and let us know if there are other things you would like to see. From any page on the Branch website,

**Parkinson's** pick **Research** from the **What we do** menu near the top of the page.



# BBB is Back, Bigger and Better!

Jonathan Bromley

Just in time for this Newsletter to go to press, we held our first in-person Friday morning Big Bold and Balance class for two years. In our bright airy new venue at Seacourt Hall there was plenty of space for Sarah to put everyone through their paces. You can now choose between the sociable delight of exercising together in the same room, or the convenience of joining online from your home. For this first class we welcomed 30 participants with a roughly even split between in-person and online.



We are deeply grateful to Sarah and the whole Generation Games team for keeping these sessions going throughout Covid times and returning them to live meetings now that we can safely do so. Your correspondent confesses to a bit of a lump in his throat at the sight of everyone working so happily together and renewing face-to-face friendship after two very difficult years.

These sessions are designed to help with balance, strength and flexibility, combining chair-based and optional standing exercises. If you would like to join in, either on Fridays at Seacourt Hall in Botley or on Wednesdays in Didcot, please contact Generation Games on **01235 849403** or via our Secretary.



# Getting in touch

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

# 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:

Peter Allen	Iona Lennon	Stephen Pitson
Charles Baker	Barbara Levick	Fred Probyn
Petula Carter	Lorna Logan	Ian Sainsbury
Francis Fedorowicz	Sharon Maplethorpe	Cathy Stasz
Victoria Howley	John Maxted	Allan Taylor
Derek Jones	Janet McCrae	Peter Thompson
Joan Jones	Michael McKinley	Adriane Thompson
Marcus Laphorn	Sally Oakey	Julian White

# Farewell

We note with sadness the death of several Branch members over the past two years, including:

Antony Brown	Andrew Leach	Peter Snook
David Byrne	Elaine Mifflin	Martin Tims
Jenny Devaney	Michael Payne	Annemarie Walsh
Alex Flynn	Ian Pearson	Gill Westbury
Valerie Horsfield	George Philip	Peter Wood

**Cover photo:** Supporters taking part in our  
Walk for Parkinson's at Wytham Woods, 19 September 2021

Photo credit: Parkinson's UK