Parkinson's UK Oxford Branch
OUR NEWS

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

Autumn 2018

Here are just a few of this issue's highlights. There is a full list of contents on the next page.

New feature!
*Poetry for Parkinson's - see **page 2***

*Successful performances and successful fundraising at the Edinburgh Fringe: **page 3***

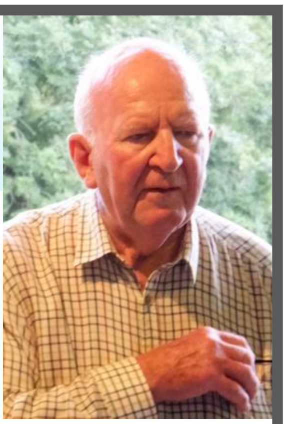
*Great results from our members' fundraising efforts: **page 4***

*Update on Parkinson's therapies currently under development: **page 6***

*Palatial Picnic - see **page 8***

*The Oxford Walk needs you! **back page***

Jem Appleton



As this Newsletter was being finalised, we were saddened to hear of the death of Jem Appleton on 29th August 2018 after a brain haemorrhage.

Jem was a hugely loyal supporter of our Branch. As our Chair we fondly remember his impish wit, kindness, razor-sharp clarity of thought, and the energy and vigour he brought to our activities. After stepping down as Chair he continued to serve as Vice-Chair, providing wisdom, guidance and unwavering support to Sally and the committee. He organised many Branch events with flair and efficiency – lunches, holidays and, most memorably, the Wytham Woods barbecues, ably supported by his wonderful family. Many of us had the pleasure of seeing Jem on fine form at the recent barbecue.

Our sincerest sympathy and warm wishes go to Mais and their family.

In this issue

Autumn 2018

Park's Larks

Wendy Benson

Chapter 1

Mr Park was beginning his life's work.
Until now he had just been alive.
But this morning the postman
      had brought him a letter
and now he had purpose and drive.

The letter was really quite shocking.
It told of a slippery slope
Which he, unawares,
      was already embarked on
and now he could see 'twas no joke.

He felt strongly that Fate was against him,
a poor little victim of sorts,
but then his innate good sense
      rose up and kicked him
and made him determined
      to fight such sad thoughts.

He had put something by for a wet day,
for years he had saved bit by bit,
and now he had nothing to lose
      but his pride
So he took a short lease giving him
      leave to quit.

He needed a name for his business.
It had to be cool, and sound new;
A name that was
      trendy, respectable, friendly,
Unusual, short, and yet meaningful too.

His head was beginning to hurt him.
The kids had lost interest and gone,
When Sparky, his wife,
      voiced a simple idea
That had been in his mind all along.

A name with a certain gravitas,
A name which would ring all the gongs
It would stick like infection,
      and carry conviction,
It just had to be
      "*PDS Park & Sons*".

*Look out for more instalments of **Park's Larks** in future issues of your Newsletter!*

Incurable Optimist

Paul Mayhew-Archer

A reflection on a month of performing at the Edinburgh Fringe

Here’s something to start a conversation.

A couple of months ago I was interviewed for a podcast called "Stories from Science”. You can listen to it at bit.do/pma-surely-joking. The interview ended with the best question I have ever been asked. The interviewer, Mark Thornton, listened to me talking about my appearances at Parkinson’s fundraisers and the excitement of making my documentary *Parkinson’s: The Funny Side*, and then he said “are you glad you have Parkinson’s?” and I found myself saying “Yes.”

I qualified that answer by saying “I’m sure there will come a time when I’m not glad” but it’s the truth. I was glad when Mark asked me and now – after a month of performing at the Edinburgh Fringe – I am more happy than ever.

> *...he said “are you glad you have Parkinson’s?” and I found myself saying “Yes.”*

Why? Am I mad?

You may well think I am mad when I describe what I’ve been doing.

Every day at 5.15pm I stand by a microphone behind a curtain. My introductory music starts playing and I say into the mic “Ladies and gentlemen, my name is Paul Mayhew-Archer and I have an incurable illness. But instead of sitting at home feeling miserable, I’ve come to the Edinburgh Festival so I can make you all feel miserable as well.”

Then I go through the curtain onto a little stage in front of an audience of around one hundred strangers and I talk. For an hour. From memory.

I absolutely adore it.

As I write this, today is Wednesday August 22nd so I have now stepped onto the stage 20 times and I have 5 performances left. People come up to me and say “you must be exhausted” but the opposite is true – I feel invigorated, energised.

> *I talk. For an hour. From memory.*

It is hard to describe, but something remarkable seems to happen in that room every day. I talk about my Parkinson’s and all its indignities – constipation, erectile dysfunction, memory loss – I talk about my mum’s cancer, I talk about depression and death, and people come up afterwards and say they haven’t laughed so much in ages. A man told me he'd just been diagnosed with terminal cancer and then hugged me and thanked me for cheering him up. Another man thanked me because I had actually diagnosed his Parkinson’s (he had seen *Parkinson’s: The Funny Side* and realised that is what he had). I go on Twitter @mayhewarcher and the responses to the show move me beyond words.

It has, in short, been one of the most wonderful, fulfilling months of my life and it would not have been possible without my cruel and incurable illness. So that is why, at this moment in my life, I’m glad I have Parkinson”s.

> ***STOP PRESS:*** *Bucket collections at the end of each show raised a total of £5500, to be shared between Parkinson’s charities and the cancer charity Maggie’s.*

Members’ Fundraising Spring/Summer 2018

☐ EASY ☑ HARD Our supporters take on amazing challenges!

This year has seen a wonderful series of fundraising initiatives by individual members of our Branch. You can find more about these activities and events on our website - follow the headline on the home page, or go directly to oxfordparkinsons.org.uk/sponsorships.

Meanwhile, to celebrate their achievements, here’s a summary of these fine efforts. If you’re inspired by them, it’s time to start planning your 2019 fundraising adventure now!

Already completed

Kathy Greenwood ***Brighton Marathon***

Kathy completed the run and raised over **£2000** for our Branch.

Michael Truby ***London Marathon***

£2700 raised for Cure Parkinson’s Trust.

Paul and Ros Swadling ***Cream Tea***

£470 donations for our Branch.

Richard Hawes ***Cathedral abseil***

£2600 sponsorship for Parkinson’s UK.

Kevin McFarthing ***Vitality London 10k***

Over **£4000** split between Parkinson’s UK and Cure Parkinson’s Trust.

Jonathan Bromley ***Hadrian’s Wall walk***

About **£3000** raised for our Branch.

Richard and Rachel Hawes ***Hot Dog lunch***

This amazing event raised over **£2000**.

Paul Mayhew-Archer ***Edinburgh Fringe***

Bucket collections raised **£5500** for cancer and Parkinson’s charities.

Coming soon

Dee Hembury-Eaton ***BOXCAM***

Don’t forget to support Dee for this 200-mile cycle ride later in September.

Everyone ***Oxford Walk***

Take part, raise money, support friends, help on the day… our biggest fund-raiser of the year takes place on 23rd September.

Reading University public engagement award

Sally Bromley

Dr Patrick Lewis is a Pharmacy lecturer at Reading University and a good friend of our Branch. His efforts in helping to plan and deliver our Parkinson’s 200 Plus conference last year were recognised by his University when he won an award for public engagement at a ceremony in August.

Sally and Patrick at the award ceremony

You can find more about Patrick and his award on the Special Events page of our website.

All this fundraising – but where does the money go?

Sally Bromley

Over the last few years we've received funds left to the branch as legacies. Parkinson's UK check that this money is used wisely, and they will only release it if a good plan has been put forward.

A legacy in 2014 gave us over £100,000 to use over three years. We tried very hard to fund some research into voice changes and loss, but that was not accepted. Instead that money has been used to offer respite care. Further legacies have funded free or subsidised exercise and voice classes and another is funding grants for people to go to the Italian Therapy Centre.

Grants to go to Italy are still available but the other legacies have run out now.

The respite care package was much appreciated by those who used it. Numbers attending exercise and voice classes went up. The committee decided to use any funds raised to continue to offer respite care, though for 20 hours not 30, and to ask for a £2 donation by those who attend exercise classes, with the rest funded by the branch.

This is a mighty commitment. Respite care could cost the branch £12,000 per year, and subsidising the exercise classes will cost about £6,000 per year. Branch members and their families have already thrown themselves into raising funds, and we know the exercise classes can continue. We are some way short of the sum needed to offer respite care, but I am ever hopeful that we'll achieve it by the end of the financial year.

Our biggest fund-raiser, the Oxford Walk in September, is already earmarked to support a research project in Oxford. The classes and respite care must be paid for by other fundraising within the Branch.

So, I guess the question is....who fancies a long zip-slide, or a wing walk, or a sponsored activity, or.... or...?

Your Will and Parkinson's charities

Every one of us should have a Will so that our wishes are properly respected after our death. Many charities, including Parkinson's UK, offer free or subsidised will-writing services. Leaving something to the charity is, of course, a wonderful thing to do – but you can use these services even if you don't make a gift to the charity.

Data Protection and your privacy

Diana Townsend

Membership Secretary

We are busy bringing our membership and mailing lists into line with the new GDPR data protection rules. We now need your written agreement to receive communications from us.

If you are a local member but do not belong to Parkinson's UK, and you have not yet signed a consent form, **you will no longer receive information about our activities**. Please get in touch with me (membership@oxfordparkinsons.org.uk) or our secretary Pen Keyte (secretary@oxfordparkinsons.org.uk) if you need any help with this process.

Research update

Kevin McFarthing

Research on Parkinson's continues to grow rapidly. According to the excellent www.scienceofparkinsons.com there were 645 research articles published in July alone, with 4,751 in the year to date. This website is highly recommended for those of you who would like to follow developments more closely.

LRRK2

The malfunction of the protein LRRK2 (Leucine-rich repeat kinase 2) is strongly associated with Parkinson's. Mutations in the gene that produces LRRK2 are responsible for some genetically-inherited forms of PD. Whilst these may only account for 1-3% of all cases, LRRK2 has been a target for both fundamental research and drug development.

A recent paper has shown that LRRK2 activity is enhanced in patients with idiopathic PD (of unknown cause). This is very important as the therapies under development may now be relevant for all of us, not just a small minority. Two LRRK2 inhibitors are in early clinical development by Denali Therapeutics, with six other projects in research phase.

GLP-1 agonists

GLP-1 (glucagon-like peptide 1) agonists are based on molecules extracted from the skin of the Gila monster. They are used in the treatment of type 2 diabetes, where they stimulate insulin release, but have also demonstrated neuroprotective effects in models of Parkinson's. One of the earliest GLP-1 agonists is exenatide, which has recently been shown to have a beneficial effect on the progression of Parkinson's. Further trials are planned for exenatide, and others are under way for two more GLP-1 agonists, liraglutide and lixisenatide.

Other recent developments have built on this exciting foundation. A new GLP-1 agonist, NLY-01, from Neuraly, again has many positive effects *in vitro*, but works via microglia, the resident immune cells of the brain. Neuraly have raised $36m to develop NLY-01 further.

Finally, Novo Nordisk have published positive Phase 3 clinical results in type 2 diabetes for oral semaglutide (the others are injections). So, an exciting vision is coming together for the future of GLP-1 agonists in fighting Parkinson's, although there will be many steps along the way.

Immunotherapy

Immunotherapy uses either active immunisation (stimulating the body's own antibody production) or passive immunisation (modified antibodies produced *in vitro*) to inactivate specific targets. In Parkinson's, the target is usually α-synuclein. The table at the top of the next page shows the current state of play.

As you can see, there are some large and very capable companies competing in this area, together with the small entrepreneurs. This is an area that holds a lot of promise, but which needs big investment, so it's reassuring to see the financial muscle involved.

COMPANY	PROJECT	STAGE	FINANCIALS
Biogen	BIIB054	Phase 2	$12bn sales
Roche/Prothena	PRX002/RO7046015	Phase 2	$53bn sales
Lundbeck	LuAF82422	Phase 1	$2.6bn sales
Astrazeneca/Takeda	MEDI1341	Phase 1	$22bn/$16bn sales
Affiris	PD01/PD03	Phase 1	€165m invested
Affiris	PD04	Pre-clinical	
BioArctic, partnered with Eisai and Abbvie	BAN0805	Pre-clinical	Eisai sales - $5.4bn Abbvie sales - $28bn
Denali	ATV-a-syn	Pre-clinical	$551m in cash
AC Immune	Anti-a-syn	Discovery	€110m in cash
ProMIS Neurosciences		Discovery programme	$12.5m invested

Table: Immunotherapy studies in progress

Sub-typing Parkinson's

As we all know, each person's Parkinson's is almost unique. It's therefore difficult to apply a "one size fits all" approach to medication and particularly to the assessment of new treatments. For example, in the exenatide trial mentioned above, some people responded very well while others didn't. Combining all the results into averages diminishes the opportunity for the strong responders.

Recent work from our very own Oxford Parkinson's Disease Centre (OPDC) has analysed data from the Discovery and Tracking Parkinson's studies. They found that cases could be clustered into four groups:

1. *fast motor progression* with symmetrical motor disease, poor olfaction, cognition and postural hypotension;
2. *mild motor and non-motor disease* with intermediate motor progression;
3. *severe motor disease*, *poor psychological wellbeing* and *poor sleep* with an intermediate motor progression;
4. *slow motor progression* with tremor-dominant, unilateral disease.

Of course, there will be some of us who don't fit perfectly into these categories, but it is a data-driven attempt to move beyond the catch-all "I have Parkinson's". Progress in this area will undoubtedly be iterative, as we find which therapies have the best effect for different groups.

A Tuesday in July well spent

Nigel Hamilton

For the second year running the Branch held a picnic in the Pleasure Gardens at Blenheim Palace in early July. About 40 people came bringing a wonderful selection of delicious things to share for lunch. If we had had a band, a few elephants and some tame tigers (kept at a reasonable distance away of course) it would have given us a spectacle to make Maharajas mutter darkly that their extraordinary lifestyle in the foothills of the Himalayas was being copied here in the Royal Manor of Woodstock.

But just wait a minute before flights of fancy obscure the reality of a day out for people with Parkinson's and their carers. Here we were enjoying sunshine and having a chance to get to know each other a little better in the enchanting surroundings of Blenheim Palace. The land and the money for building the Palace were given by Queen Anne to the 1st Duke of Marlborough in thanks for his successful defeat of the French in August 1704 at the huge battle at Blenheim, a small village on the banks of the Danube.

Getting to know each other a little better

We had been given an interesting introduction to the history of Blenheim Palace by Mrs Veronica Thorneloe (at one time Head Guide for visitors to the Palace, and friend of the present Duke's family) at our Branch meeting the previous week.

A fascinating story which started with one Churchill (John) and included another (Winston), born here as his mother happened to be staying at the Palace for a ball in 1874.

We were all fascinated by this rich history but when we arranged our picnic we had no idea that the Palace was to form the backdrop for another landmark occasion two days later – a visit by the President of the United States. There was evidence of the high security that was being set up, but the overriding impression was of delightful tranquillity and enjoyment enhanced by the friendly welcome and support from all the staff who helped us.

Blenheim Palace is a beautiful place and we are lucky that it is so easy to visit time and again.

Therapy in Italy

Martin Cowell

I was very pleased to get a place in May at the European Parkinson's Therapy Centre www.terapiaparkinson.it/en at Boario Terme, in northern Italy. I travelled with fellow branch member Nick Wrigley - I would certainly recommend going with a partner or friend as there is an amount of spare time. We also decided to spend a few days 'Italianising' ourselves beforehand on nearby Lago d'Iseo (smaller and much less touristy than its large neighbours).


Lake Iseo

Our Boario stay (after a last-minute switch on arrival) was at the excellent Hotel Diana, right in the middle of the small town. There are several good restaurants nearby, although the fully-inclusive full-board hotel deal is incredibly reasonable, and the restaurant fine.

There are several good restaurants nearby...


Hills above Boario Terme

Of course the programme is what we went for: it was a good mixture of physical activity and presentations from the wonderful founder and Director, Alex Reed, and his team. We (just five Brits, with a similar number of Italians and Dutch making up the week's intake) gathered on a Sunday evening, had an introductory briefing from Alex, then on Monday morning had our initial assessment with our own dedicated neurophysiotherapist (they are all young Italians, speaking excellent English). This created our personal programme of 90 minutes daily exercise, including working on a treadmill, static bike, learning 'power steps', shadow boxing, walking properly – all designed to give us an activity regime to continue on our return home. There were also one-to-one sessions with a neuropsychologist to assess and discuss the non-physical side. Challenging, stimulating, inspiring, enabling – thoroughly recommended, and I would be very pleased to answer any questions at any time.

Summer teas and barbecues

This has been quite the year for outdoor feasting, with fabulous events organised by members of our Branch providing not only valuable fundraising but also fine social events with ample opportunities for shameless gluttony.

Cream Tea

Cream Tea at Longworth

In late June our traditional Cream Tea was brilliantly hosted by Ros and Paul Swadling at their home in Longworth. Once again the Cream Tea Society provided free jam and cream, and our members baked scones and cakes. The delightful event raised £470 for Branch funds.

Very Hot Dogs and Puddings

What a setting!

In early August Richard and Rachel Hawes staged a Hot Dogs and Puddings outdoor lunch on an epic scale, with over 100 neighbours, friends and a few Branch members attending. Their rural garden in Horton-cum-Studley makes a stunning setting, the catering was magnificent and the array of puddings nothing short of awesome. On one of the hottest days of a hot year, the village’s water supply completely failed – but Rachel, Richard and their team coped as if nothing had gone wrong, and donations from their guests totalled well over £2000.

Hot dogs under construction

Did we mention the puddings?

Wytham Barbecue

We rounded off the summer with our much-anticipated barbecue at the barn in Wytham Woods. The setting is idyllic and, breaking with rainy tradition, the weather was fine and sunny.

Grills in safe hands

Welcome to new members

We welcome everyone who has joined us recently:

Derek and Susan Taylor
David and Mary Bagnall
Rosemary Phillimore
Denis de Berger
Alastair Muir
Alice Godfrey

It's our birthday!

Sally Bromley

As we said in our previous Newsletter, 2019 will see us celebrating 20 years as a Parkinson's UK Branch. We'd like your ideas for places to go, things to do and exciting fundraising events to take part in. Please let your imagination run riot!

Our members raise their concerns

Sally Bromley

August's discussion meeting

At our August meeting, alongside our annual shared discussion, we held sessions giving us a chance to air our views on the services available to Parkinson's patients. We have already used the results to decide activities for an action-packed September meeting, with talks and hands-on taster sessions for various activities. Don't worry if you missed either or both of these meetings – the findings and results will soon be published on our website.

Farewells

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

Pamela Tumbridge
Terence Bishop
Peter Mackett
Jem Appleton

The Oxford Walk on 23rd September

Sally Bromley

There are some who can and some who can't, some who will and some who won't, some who take part and some who help on the day BUT we can all sponsor someone!

Those who can walk – please come, as there's a route within everyone's capability. Those who can't walk can get a lift to the city centre in a minibus and can be pushed or use a walker to see the sites.

Those who will – we look forward to seeing you. Those who won't could support someone who will.

Paul Mayhew-Archer will start the walk from Cherwell School at 10am.

Choose to walk 1½ miles, 4½ miles or 8 miles. Registration is £10 and £5 for children. If you register on the day it will be £15 and £7.50 for children. Dogs are free!! Visit parkinsons.org.uk/walkoxford for details and registration.

If you think you could help on the day, please contact Malcolm Benson (email 200club@oxfordparkinsons.org.uk) and plan to be there from 9am to set up refreshments or help with registration. If you could bring a cake the walkers would be very happy.

So… make your choice.

We hope to see you on the day.