Parkinson's UK Oxford Branch

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

OUR NEWS

Spring 2018

Welcome to our new-look Newsletter!

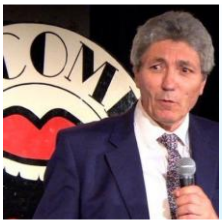
Don't forget you can find the latest information on our website oxfordparkinsons.org.uk. Here are some of this issue's highlights. You can find the full contents on the next page. If you're reading this on a computer, clicking a picture takes you straight to the item.

News of our members challenging themselves for fundraising – see page 9.

First Steps programme – two members describe their participation and involvement

Forthcoming Events – our roundup of Branch activities for the coming months

Recollections of Sir Roger Bannister



Paul, our resident scriptwriter, is developing a new career

Our chair Sally looks rather pleased with herself. Find out why on page 3.

Learn about the latest opportunities to volunteer for research projects

A creative new fundraising idea, and news of all our fundraising activities

Keep up to date with research news

What do LSD, Parkinson's and cream tea have in common? All is revealed on page 8!

In this issue

Spring 2018

A special request: please don't lose touch!

Jonathan Bromley

Data protection laws are changing and we need your help

It's now only a matter of days before new data protection law, known as *GDPR*, comes into effect.

We should all welcome these new rules, which will make everyone's personal information more secure and better protected. For our Branch, though, there are additional responsibilities that we must meet to stay within the law.

You will soon hear from the Committee asking you to confirm your preferences about how we contact you, so that we have your choices properly recorded.

It's really important for you to respond, so that we can continue to keep you informed about Branch activity while respecting your preferences.

If you have any questions about the new rules and how we're planning to meet our responsibilities, don't hesitate to contact me and I'll do my best to answer or to find someone who can.

admin@oxfordparkinsons.org.uk

Thank you!

Honoured by the Open University

Sally Bromley

On April 14th, our Chair was at the Lighthouse Arts Centre in Poole to receive an honorary degree of Master of the University from the Open University. You can find all the details on our website at oxfordparkinsons.org.uk/special_events, but here is her own description of the day.

We had to be at the venue for 9.15. It was a chilly day and the mist hung low.

From walking through the door to walking out at the end I couldn't have been better treated. I was welcomed along with my family and friends and shown to the Green Room where drinks were available. I was then whisked off to see the theatre and have a run through. I asked if the circle would be full too but no-one knew.


Presentation of the degree

Then once we'd done that I was ushered to be dressed in the special gown and photographed. I was with people from Open University, Jonathan and my daughter, Katie, then the local dignitaries. Before very long it was time to get in line fo rthe parade into the theatre and on to the stage. I had the seat next to the Vice Dean who presided over the day. I looked up to see the auditorium full with over 1000 people, and yes, the circle was used too.


Acceptance speech

The day was formally opened and graduates received their certificates. Then it was my turn. A citation was read out and then I received my certificate and I was led across the stage to sign the book of honorary degree recipients (including Jane Asher our PUK President). Throughout this there was rapturous applause and I commented that it was all for me. I read my response of acceptance and I returned to my place, again with applause.

An odd thing happened in the middle of the final degree presentations. As one of the graduates was collecting his certificate He requested a moment to speak to me. He was emotional as he said that what he had was a piece of paper, that's all, but I had made a difference to people's lives, which he regarded as far more important. He asked and received a hug from me. I later tried to seek him out but was unlucky. It was but a moment but it will remain with me always.

After celebratory drinks and meeting Julia Gracey, Chair of Poole Branch, we went to lunch and I was on the table with the worthies.

The day closed. I turned to see my daughter carrying two floral table decorations which we were given. They are lovely and colourful. My special day ended with a meal out with our friends. A day I shall never forget.


With Julia Gracey, chair of Poole Branch

First Steps

Ian Sargent

Martin Cowell

This item is condensed from two longer pieces written by Ian and Martin describing their experiences of the First Steps course for newly-diagnosed people with Parkinson's. You can read their descriptions in full on our website at oxfordparkinsons.org.uk/documents/first-steps-reviews.

I was diagnosed with Parkinson's in April 2015. Like many, I was shocked and uncertain about what the future would hold. However, my Parkinson's nurse recommended a two-day course for newly-diagnosed people being piloted in Oxford. It was called First Steps.

We were soon put at ease by the friendly welcome

My wife Ruth and I were invited to the first session, held at the end of July 2015. We went with some trepidation but were soon put at ease by the friendly welcome. The course, devised by Oxford's Sally Bromley and Peter Harling, is held at Witney Lakes Resort rather than a hospital, because the focus is not on medical issues but on well-being. The first morning covers a wide range of topics, including the importance of managing one's life and taking control, current Parkinson's research, and details of the multi-disciplinary team of health care professionals who are there to help us. The afternoon session stresses the importance of exercise, followed by our local advisor, Delia Wells, who describes the support provided by PUK. The final session discusses six key ways in which we can take control of our lives, namely: thinking positively; getting informed; staying connected; doing things; making plans; and getting involved.

The second day of the course, which normally follows about six weeks later, gives the opportunity for group discussions and sharing of experiences. The highlight of the day is a taster PD Warrior exercise session which is always very popular. The message from both days is clear – there is life after diagnosis and that life depends on you!

A key principle of the course is that it is presented by people with Parkinson's, who have empathy for those attending. This allows them to share anecdotes about their own experiences and give tips and hints on how to get round problems, in a way which people who do not have Parkinson's could not. My course was led by Jason Batup and Richard Tyner, two very different characters united by their desire to help people with Parkinson's – and their passion for golf!

A key principle of the course is that it is presented by people with Parkinson's

At the end of the course we were asked to identify the things we intended to do as a result of having attended. Ruth and I made some immediate decisions. I took ill health retirement from work, and Ruth decided to retire too. I joined the PD Warrior exercise programme, Parkinson's UK, and the Oxford Branch, and we booked the African Safari holiday we had always promised ourselves. A pretty good outcome for two days that changed my life!

Moreover, that was not the end of it. In September 2016 Jason asked if I would like to help present the course. I was a bit uncertain as to how I would fit in – especially as I don't play golf! But after a couple of sessions watching the masters at work I was up and running and have been helping ever since. The whole experience has been immensely rewarding and we have received great feedback. We have seen many changes in people's attitudes as they relax and gain confidence, also making new friendships in the process. To date there have been around 200 people who have benefited from First Steps, so it's thanks to Sally and Peter for a great idea, and to Jason and Richard for turning it into a reality.

I was a bit uncertain how I would fit in (especially as I don't play golf!)

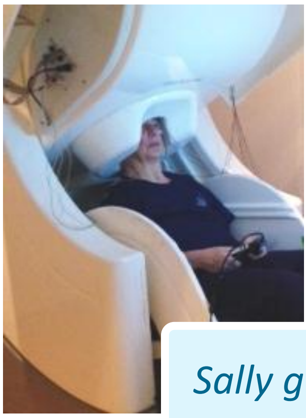
Volunteering for research

Nahid Zokaei

A key priority in Parkinson's research is to identify the disease at its earliest stages. In order to do this, we need to identify markers, either behaviourally or through neuroimaging techniques that can aid diagnosis as well as treatment monitoring.

Cognitive impairments are an important feature of Parkinson's and are apparent at very early stages of the disease. These impairments include deficits in short-term memory and attention and can potentially provide a means for early detection.

Recent studies have highlighted that patients with Parkinson's, even in the early stages, have distinct patterns of brain activity observed at rest compared to healthy participants. Most of these studies have focused on neural activity measured by magnetic resonance imaging (MRI). We use this technique but also apply another method of measuring brain activity known as magnetoencephalography (MEG). It records magnetic fields produced by the brain with resolution of milliseconds. This will allow us to examine the pattern of brain activity and its changes with higher resolution and link to behavioural functions that rely on this fast changing activity, namely short-term memory and attention. Both MRI and MEG are non-invasive and safe techniques.



Sally has taken part in this research and reports that she values taking part in research generally but that this one was interesting as "she got to go into machines!"

If you'd like to get involved in research projects, please contact nahid.zokaei@psy.ox.ac.uk

Remember, some projects need controls – people without a condition – so a fair comparison can be made.

Sally got to go into machines!

Forthcoming events

May to August 2018

May

May 2nd, 7:30pm *Branch Meeting*

Becky Bell of Oxford City Council talks about support with home improvements and repairs.

May 8th, 10:30-12:00 *OxPAL*

Meet at Sally's home in Summertown for coffee and chat.

May 12th *Richard Hawes' Abseil*

Richard climbs 249 steps to the top of Guildford Cathedral tower, only to leap off it to raise funds for the Branch.

May 17th, 10:30-12:00 *OxPAL*

Coffee and chat at Erdington House, Yarnton by invitation of Alison Pegrum

May 28th *Kevin McFarthing's 10k Run*

Kevin tackles the Vitality London 10k to raise money for Parkinson's UK and Cure Parkinson's Trust.

June

June 6th, 5:30-6:30pm *OxPAL*

Meet before our Branch meeting at The Fishes, North Hinksey, OX2 0NA.

June 6th, 7:30pm *Branch Meeting*

Penny Thewlis from Age UK discusses how to stay independent and live a full life.

June 11th-15th *Jonathan's Wall Walk*

Armed with nothing but hiking boots and a Latin phrase book, Jonathan Bromley walks the 84-mile Hadrian's Wall National Trail to raise funds for the Branch.

June 18th *Lab visit*

This chance to experience the fascinating work of the MRC Brain Dynamics Network Unit is already fully booked.

June 24th, 3.00-5.30pm *Cream Tea*

Our ever-popular social and fundraising event takes place this year by kind invitation of Paul and Ros Swadling. For details or to offer help, contact Pen Keyte.

July

July 4th, 7:30pm *Branch Meeting*

Veronica Thorneloe of Blenheim Palace tells us about 300 years of history on our doorstep, and sets the scene for our visit the following week.

July 10th, lunchtime *Blenheim Picnic*

Picnic in the grounds of Blenheim Palace – contact Nigel Hamilton for details. Bring some picnic food. Drinks are available from the Palace garden café. More information on page 11.

August

August 1st, 7:30pm *Branch Meeting*

Our annual discussion and open forum where you can raise your concerns. This year's theme is **Coping with Parkinson's: The Real Issues**. Join us to share your challenges and experiences in an open, supportive and friendly environment.

August 5th, lunchtime *Hot Dogs and Puddings*

Richard and Rachel Hawes host an all-new social and fundraising event in their garden.

August 18th, evening *Barbecue in Wytham Woods*

A great end to the summer in a fabulous location, with plenty of shelter in case it's showery. Contact Jem Appleton to register your interest.

Forthcoming events

September 2018

September

September 5th, 7:30pm ***Branch Meeting***

Solutions and Self-Help: Health professionals respond to the concerns you aired in August, and share their ideas on how to address them.

September 22nd-23rd ***BOXCAM***

Parkinson's UK stages this 200 mile Bristol-Oxford-Cambridge sponsored cycle. Riders will stay in Oxford overnight. On her fundraising page Dee Hembury-Eaton explains why she's taking part and why you should support her: justgiving.com/dee-hembury-eaton

September 23rd, morning ***Oxford Walk***

The year's biggest fund-raiser, the Oxford Walk, sees our members, friends, academic researchers, clinicians, dogs and children all enjoying short or long sponsored walks around our beautiful city. Get involved as a marshal, helper, or walker!

Branch Holiday

Autumn 2018

We are planning a Branch Holiday, probably on the South Coast in the early autumn with four days' full board. These have been very successful in the past. The cost is likely to be around £250 per person. Please get in touch with Sally Bromley if you might be interested.

Living alone with Parkinson's?

Our OxPAL group

has been set up to offer comfort and support to those living with, or affected by Parkinson's and living alone. Times and venues for our May and June meetings are on the previous page.

Contact David Salisbury for details: oxpal@oxfordparkinsons.org.uk

A special celebration

January 2019

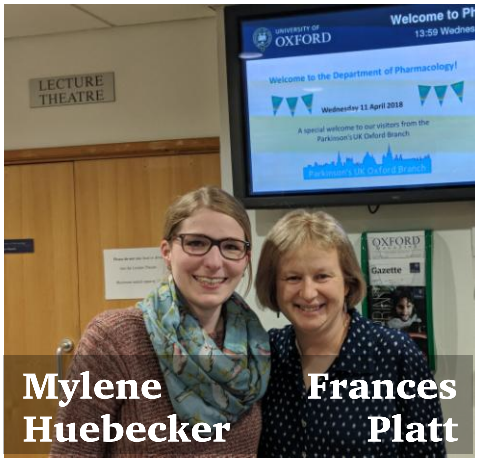
Our Oxford Branch will be 20 years old
in the New Year. We're busy working on plans for a celebration to mark the occasion, some time in early January. We will be on the lookout for interesting photos, anecdotes and reminiscences from the Branch's history, so dig around in your archives over the next few months!

Lab visit on LSD provides new insights into Parkinson's!

Ian Sargent

No – not that kind of LSD!

The LSD in question are Lysosomal Storage Disorders, as a group of us learnt from Professor Frances Platt and her Research Team when we visited their laboratory in the Department of Pharmacology, University of Oxford, on 11th April to mark World Parkinson's Day. So what are Lysosomal Storage Disorders and why might they be important for Parkinson's?



Lysosomes are the waste disposal and recycling centres of our cells, containing enzymes that break down large molecules into smaller ones. When cells are unable to get rid of waste material because the enzymes in the lysosomes don't work properly, it builds up. In time, this "storage" causes cells to go wrong and eventually die.

> *Lysosomes are the waste disposal and recycling centres of the cells in our body*

Frances' student Mylene Huebecker told us how recently it has been found that there is a link between Parkinson's disease and the most common lysosomal storage disease (Gaucher Disease), which affects babies and young children. The Oxford team now want to understand how changes in the function of the lysosome may cause brain cells to die in Parkinson's disease. This is important as they have developed therapies for Gaucher disease that may be unexpectedly useful in treating Parkinson's patients in the future.

Mylene is making great progress. Her work, supported by Parkinson's UK, has shown that there is an accumulation of glucosylceramide (a fatty molecule) in the brains of normal mice as they age, with a corresponding decrease in the lysosomal enzyme glucocerebrosidase which normally breaks it down. A similar pattern is found in the brains of normal individuals but is far more pronounced in people with Parkinson's. Interestingly similar changes can be found in skin cells of people with Parkinson's and this may prove to be a useful diagnostic test. More information can be found at: http://plattlab.nsms.ox.ac.uk/

There then followed a fascinating tour of the laboratory where we met other members of the team, David Priestman, Nick Platt and Gokhan Yilmaz, who introduced us to the dark arts of High Pressure Liquid Chromatography, Flow Cytometry and Confocal Microscopy. The afternoon concluded with a delicious cream tea courtesy of our hosts.

We would like to thank Frances and her team for a highly entertaining and informative afternoon and look forward to hearing how this exciting new work develops in the future. I would also like to thank Mylene for her help in writing this report.

Members' fundraising challenges

Our supporters are throwing themselves into fundraising by taking on a range of challenges – running, walking, cycling, and even leaping off tall religious buildings. Our website's sponsorship page oxfordparkinsons.org.uk/sponsorships has all the details and updates. Please give them your support, both financially and by cheering them on in whatever they do.

Kathy Greenwood

Kathy ran the Brighton Marathon on 15th April, successfully finishing in under 4¾ hours (a personal best) and raising nearly £2000. Congratulations, Kathy!

Michael Truby

Michael took part in the London Marathon on 22nd April to raise money for Cure Parkinson's Trust. We don't yet know his finishing time, but he's raised well over £3000, a brilliant effort.

Richard Hawes

Richard is a familiar face at Branch meetings, and seems to us to be far too sensible to throw himself off a cathedral tower with only a rope keeping him from a very un-cathedral-like spiritual experience. Nevertheless he's going to do the Guildford Cathedral Abseil on 12th May. Contact him directly to sponsor, persuade him not to be so crazy, offer to hold a trampoline at the bottom, or anything – but mostly to sponsor.

Kevin McFarthing

Kevin has Parkinson's himself, and is our Research Officer, so he should know a thing or two about the value of exercise in Parkinson's. Running more than six miles of London streets may perhaps be taking things a little far, but that's what he will do in the Vitality London 10k on 28th May. He's committed his sponsorship to Parkinson's UK and Cure Parkinson's Trust, and you can support him online: uk.virginmoneygiving.com/KevinMcFarthing

Jonathan Bromley

Your Chair's husband hasn't done a long-distance hike for about thirty years, so this may hurt a little. He's walking the 84-mile Hadrian's Wall National Trail over five days in early June, racking up nearly 100 miles including detours to archaeological sites and overnight stops. He's raising money for Branch funds at his Virgin Money Giving site uk.virginmoneygiving.com/JonathanBromley and he'll be keeping us updated with his progress on our website.

Dee Hembury-Eaton

Dee takes part in September's BOXCAM 200-mile 2-day cycle ride in aid of Parkinson's UK. Please read her story at justgiving.com/dee-hembury-eaton.

Donkey's Delight folk concert

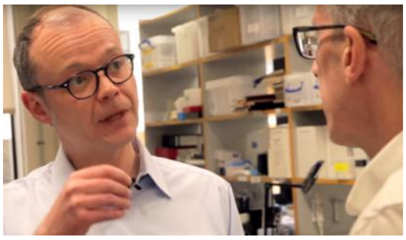
Sally Bromley

Our annual concert with the Donkey House Players was just as enjoyable as always. The theme this time was of favourite folk music and the audience was encouraged to join in a few songs too. The packed tiny Church of St Laurence was surrounded by daffodils and primroses, which was most welcoming. The church ladies had baked delicious cakes for the audience to enjoy with wine in the break. A fun evening that raised over £800 in ticket sales, donations and raffle takings.

Keeping up with research progress

Our Research Officer, Dr Kevin McFarthing, has been busy adding material and links to our website to help us stay abreast of the latest in Parkinson's research.

Lewy Bodies appeal video



Kevin also features in the latest appeal video from Parkinson's UK, where he interviews Prof. Peter Magill about his research into the significance of Lewy bodies. You can see it at bit.do/magill-lewy-bodies

What goes wrong in cells?

There is a tremendous amount of research into the causes, progress and potential treatment of Parkinson's. Indeed, much of this happens in Oxford and we hear about this regularly through local researchers presenting at our branch meetings. It's quite difficult to retain an overview, so Kevin has written a short summary intended to summarise what goes wrong inside our nerve cells. You can find it on our website: oxfordparkinsons.org.uk/research

Following current research

We've said this before but we don't apologise for saying it again: if you are interested in staying up to date, follow these two blogs. They are an excellent resource, and readily accessible to non-scientists.

Science of Parkinson's (SoPD)

Cambridge researcher Dr Simon Stott's SoPD blog is amazing. He adds new items several times a week, and although some are quite detailed they are always well-written and easy to understand: scienceofparkinsons.com

Parkinson's UK research blog

Dr Beckie Port, Claire Bale and Annie Amjad are part of our parent charity's research communications team. They maintain a thoughtful and very readable review of interesting aspects of current research: medium.com/parkinsons-uk

Blenheim Palace Picnic
Tuesday 10th July 2018

Nigel Hamilton

Following on from last year's afternoon tea-time event we have been able to arrange another ....

FANTASTIC SUMMER PICNIC

This will give everyone who comes a chance to tour the Palace, explore the magnificent grounds, visit the Butterfly House, get lost in the Maze, travel on the Blenheim Palace Train and spend a little time in the shop. All this after enjoying a leisurely bring-and-share picnic with friends from the Oxford Branch of Parkinson's UK in beautiful surroundings.

All you need to do in advance is decide who is going to come (PwP plus one carer), let us have names and your car registration for us to give to the Palace and plan the food you will bring to share. Contact Nigel at programme@oxfordparkinsons.org.uk.

Highlights:

- Free entry to the Palace grounds (normally £13 or more)
- Tour of the Palace State Rooms, including the Churchill Exhibition, at a special rate of £10 (normally £23-26)
- Hot drinks to go with your picnic (provided by the Blenheim Palace café and paid for by the Branch)

News from the OxWAGs

Pen Keyte

OxWAG is our group for all working-age people with Parkinson's

Under the galvanic and stimulating leadership of husband and wife team Laura Tilt and Ashley Lisle, OxWAGs continue to run a busy schedule of social activities and informative talks/seminars while getting on with their equally busy working lives. At the end of April, Dr Tom Barber gave a talk to the group about his research into the connections between REM sleep behaviour disorder and Parkinson's. His team's long term aim is to be able to offer trials of new treatments aimed at delaying the onset of symptomatic Parkinson's, and their article can be found at https://doi.org/10.1093/sleep/zsx071

About the group

OxWAG is our group for all working-age people with Parkinson's. It arranges social events and informative meetings, and provides an opportunity to share ideas and concerns in a supportive environment. Contact Laura for more details: wag@oxfordparkinsons.org.uk

Branch Lunch, April 2018

Pen Keyte

More than forty of us in the Dog House!

On 26 April we enjoyed a three course lunch at The Dog House in Frilford Heath, organised by the indefatigable Jem Appleton. It was lovely to spend time over chats in the Spring sunshine, and catch up with friends. Jem had arranged a varied menu to suit all tastes, at a very reasonable price. Thanks Jem! A good way to welcome Spring.

Welcome to new members

We welcome everyone who has joined us recently:

Elisabeth Colkin
Alan & Vivienne Cripps
Jill & John Grain
Clive Hallett
Nabeel & Rachel Hamdi
Paul Hyatt
Brenda & John Kemp
Janet & David Robertson
Geof & Sally Wade
Gill & Brian Westbury
Duncan & Caroline Whitehead

Parky Pocket Money

Martin Tims

Each night I empty my pockets of loose change, and the 10p and 20p's ended up in PUK collection boxes. It has amazed me how quickly it mounts up, and yet how little I notice in the overall cash flow. Bring this change to the next meeting where there'll be a bucket to throw your money in!

Thanks to Martin for this excellent and simple scheme. You can pick up a box at any Branch meeting. Many of us are using the boxes and we've collected about £100 already. Join us and give your unwanted loose change a good home!

Funny with a Fringe on top

Our resident scriptwriter and humorist Paul Mayhew-Archer is taking his hour-long show ***Incurable Optimist*** to the Edinburgh Fringe this August. Find more at the Fringe website:

http://bit.do/edfringe-optimist

Paul writes:

They say one of the side effects of Parkinson's drugs can be a tendency to gamble.

The only time I've gambled in the traditional sense is when we went to Las Vegas some years back and I squandered an entire dollar in a fruit machine.

But in a wider sense I suppose gambling can mean risk-taking or deciding to "go for it" without much thought as to what "it" is or whether I can "pull it off".

The "it" I've decided to "go for" this year is to put on a One Man comedy show at the Edinburgh fringe. With me as the one man. "Why not?" I thought to myself. "I did ten minutes of stand up comedy at the Comedy Store last year and I loved doing that. So why not do a whole hour? And why not do it every day for a month?"

Why not indeed? As I write this I can think of loads of reasons why not. Indeed, whenever I tell people what I am planning they give me pitying looks and clearly think that Lewy Body dementia has set in.

But I can think of two compelling reasons why I really want to do my show.

One reason is that behind the jokes and the laughs there is something I want to say about my illness. I want to say that a diagnosis of Parkinson's is not the end of the world. It's more like landing on a new world and making it habitable.

The other reason is that I recently performed my first "try-out" shows for Edinburgh at a little theatre in Abingdon and before I went on I was full of terror thinking this was a reckless gamble far too far. But as soon as I started and heard the audience laugh it was as if my brain was being filled with a lifetime supply of Dopamine and Sinemet and Ropinirole and, above all, joy.

We all have our different ways of coping with our condition and all I can say is that comedy is helping me more than I could have hoped. In a very real way comedy is my carer.

So now all I need is an audience. I am appearing every day from Aug 1st to Aug 26th with just the 13th off. My show is at 5.15 in the afternoon, and it is at the Underbelly Friesian which seats 115 people. By my calculation I have to sell around 2750 tickets.

That's a lot.

So if you know anyone who lives in or near Edinburgh please urge them to come.

Here are a few of the comments I received after my first two shows in Abingdon.

"My friend and I needed a good laugh and boy did we get one."

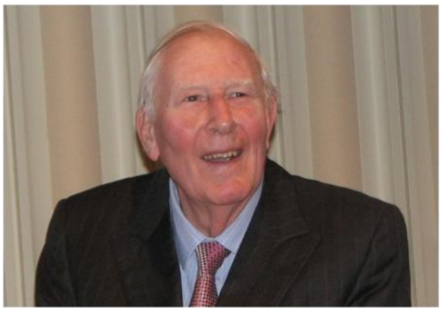
"I haven't laughed so much in a very long time."

"We laughed 'til we cried! Not only the humour, but the message."

"It was funny- of course it was- but it really did leave us thinking about the importance of humour, particularly when facing big challenges like Parkinson's."

Remembering Sir Roger Bannister

Jenyth Worsley



I came to know Sir Roger Bannister slightly after he retired as Master of Pembroke College. When his daughter Charlotte Bannister-Parker was serving her curacy at the University Church of St Mary the Virgin we occasionally found ourselves walking together across Radcliffe Square after a service. He often said 'How's the BBC?' which I had long left but enjoyed being asked, as it implied that I had insider knowledge.

During the years that Sir Roger developed Parkinson's, I learned from Charlotte that he was studying philosophy with a professor in the congregation in order to exercise his mind. After I was diagnosed with PD this was a reminder to follow suit. (She later told me that he no longer drank alcohol, which is harder to follow)

When Charlotte returned to St Mary's as an associate priest, Sir Roger was wheelchair-bound and needed to be pushed up the aisle with his family. But when the service ended he was always surrounded by people queuing up to talk to him. I shall remember Roger Bannister as a man who despite his eminence treated me and everyone as equals with interest and courtesy.

Sally adds...

I invited Sir Roger to come to the branch, to start our Oxford Walk and to join in our conference but he felt too weak to come. Each time I wrote a letter and delivered it by hand to his front door. Each time I received a phone call, politely saying he could not oblige us. He was gentle spoken, was clearly caring of what we do, yet unable to support. He was so gracious and I felt he'd have been a good friend and colleague.

Farewells

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

Michael Longford

Eric and Jeanne Richens

Stella Wood

Pam Silver