Parkinson's UK
Guildford and South Surrey

The Park

May 2025

The magazine of the Guildford and South Surrey Branch of Parkinson's UK

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* Cover is of swan on LLangorse Lake April 2025

The Committee of The Guildford and South Surrey Branch would like to thank Oakleaf Enterprises for their efforts in printing and distributing this Magazine

TUESDAY AFTERNOON SOCIAL MEETINGS (2pm)

Venue: Shalford Village Hall, King's Road, Shalford, Guildford, GU4 3JU

All Members (and non members) and their partners, carers, and family members are welcome to attend these monthly social meetings. These meetings are free of charge to attend. They allow you to meet new friends, learn from each other's experiences and often hear a guest speaker while having light refreshments.

Date	Event
28 January, 2025	Drumhead
25 February, 2025	AGM
25 March, 2025	My life as a personal protection officer Lee Johnson
29 April, 2025	Three Peaks Challenge Peter Clutterbuck
27 May, 2025	'A is for Arsenic -The poisons of Agatha Christie', Dr Kathryn Harkup
24 June, 2025	Volunteer Lead PDUK Zoe Sole
20 July, 2025 (SUNDAY)	Summer Picnic (Clare's)
August, 2025	NO MEETING
30 September, 2025	Chair Exercise Lucy Wyndham-Read
28 October, 2025	Halloween Silliness
25 November, 2025	Parkinsons update/Q&A Amanda or Dawn, PD Nurses
9 December, 2025	Christmas Lunch Godalming Rugby Club

Introduction from the Chair

Welcome to the May edition of *The Park*, the membership magazine for the Guildford and South Surrey Branch of Parkinson's UK.

This magazine is here to keep you informed about the activities supported by the Branch, especially event dates and start times, so you can plan your diaries for the months ahead. You will also find a range of engaging articles – some previewing upcoming events, others reflecting on those we've enjoyed recently.

In this issue is a full write-up of the AGM held in February. You will notice that my speech focused on the theme of *community*. While I may not be the most eloquent communicator on the subject, I hope I managed to get people thinking about what community really means to them – particularly the joy of positively impacting someone else's life.

April (the month that the magazine gets produced) marks twelve months since I first took part in a clinical trial for the University of Exeter, held at Hammersmith Hospital. As the trial involves two sets of scans, a year apart, I have been called back for three days of repeat testing and scanning. As the three days were consecutive I stayed in a hotel nearby during that time. There's a more detailed write-up on the trial on page 18 but one key takeaway for me was how well my medication masks many of my Parkinsonian symptoms and consequentially impacts my interactions with others. In other words, when I am medicated and 'on', my life and interactions with others is fairly normal, when unmedicated and 'off' then it's a whole different ballgame.

The first realisation, I suppose, was one of apathy—though I'm not entirely sure that's the right word. It was more a sense of, "Is it worth it?"

Most mornings, I found myself facing that question head-on: Am I really prepared to put in all the effort required today to have buffet breakfast? The idea of a lovely buffet spread seemed appealing in theory but the reality of actually getting up, assembling a plate, and eating it all felt like far too much hassle.

At the heart of it were two competing thoughts. On one hand, I didn't want to give this dreadful illness a single inch—I wanted to fight back, not give in to weakness or inertia. On the other hand, skipping breakfast might help me keep my weight down, which wouldn't be the worst thing.

In the end, I decided it just wasn't worth the effort. I'm still not sure that was the right answer—but it's the one I arrived at. What would you have done?

The second revelation was the unexpected kindness of others – it changed my perspective in ways I hadn't anticipated. Let me share two brief examples.

The first involves my taxi driver, John. As part of the clinical trial, transport was arranged between my hotel and the hospital. These days, taxis no longer wait in ranks as they used to – instead, rides are managed through an electronic system called 'Gett', which allocates jobs via the Internet. On Monday, I was collected by John, a friendly chap with 20 years of taxi-driving experience. I shared a bit about my Parkinson's and the purpose of my trip, and he was genuinely interested. The journey lasted just 10 minutes, but I was astonished the next day to find that John had again been assigned to me – despite being 15 minutes away. He'd made a point of taking the job so he could check in on how my second day had gone. That small act of kindness meant the world to me.

The second moment took place in a local pub. After deciding to venture out for food, I ended up in a packed pub full of families on school holidays, after-work drinkers, and a few of the regulars enjoying their evening in various states of intoxication. With limited seating, I found myself in 'sad, old man siting alone, drinking a pint since opening time' corner. When I attempted to leave, my walking – not at its best – meant I struggled with shuffling. What amazed me was how, in that moment, this man who had previously seemed lost in his own alcoholic world suddenly became calm, attentive, and genuinely concerned. He asked if I was alright and whether there was anything he could do to help. It was an unexpected moment of care from someone society might often overlook.

It's hard to capture the emotional weight of those interactions in writing, but both left a deep impression on me. They reminded me that people, by and large, *are* decent – that community spirit still exists, and many will go out of their way for a stranger.

David Lowther

GUILDFORD AND SOUTH SURREY BRANCH
ANNUAL GENERAL MEETING
Tuesday 25 February 2025
in Shalford Village Hall

Present: Mr David Lowther, Chair; Mr Steve Heron, Treasurer; Mr Keith Black, Membership Secretary; Ms Debbie Gaskell, Communications; Mrs Myra Newnes -Smith, Carers Support; Mrs Clare Price, Fundraising; Mrs Margaret Westwood, Minutes & Meetings Secretary; and Mrs Hilary Austin.

Apologies: Mrs Sharyn Grenville, Branch Secretary.

1. The Chair, David Lowther, welcomed the Members' of the Committee, Mrs Sarah Bowdage Spencer (Parkinson's UK) and some 40 Branch members and friends to the Annual General Meeting 2025. The Minutes of the AGM on 27 February 2024, which were published in *The Park*, were formally approved.

2. The Treasurer, Steve Heron, spoke to his **Financial Report** for the year ending 2024 which was tabled. The Branch was currently in good financial health, thanks largely to the substantial donation from the Richard Ely Charitable Trust.

However these annual donations will come to an end in 2025. The Branch faces the challenge of raising sufficient income to maintain the current level of Branch subsidies (listed on the reverse of the Agenda) as costs continue to rise.

Steve Heron presented his Budget for 2025. He set out the expectations for income and outgoings;, to meet the proposed expenditure of approximately £80,000, mostly on subsiding Branch activities, serious fundraising must be a priority. Unless some £20,000 comes in, there will inevitably be a reduction in subsidies (or fewer Branch activities supported).

The Meeting accepted the challenge

3. **The Chair's Report**. David prefaced his presentation by stressing that the AGM was intended to give members a snapshot of the Branch and its management and also provide an opportunity for members to feedback their opinions. In a traditional setting, the Chair would make a formal speech, reviewing the year past and looking forward to the next.

David favoured a different approach; he presented his as a "school report" with sections to be "graded". The text was tabled – but with significant *blanks.* The members (provided with pencils) were invited to fill in the missing words or phrases as *answers* to the questions he fired out. This unusual way of holding members' attention worked extremely well, with good-humoured participation. He concluded by urging the members to continue engaging in Branch activities and supporting each other whilst he, as Chair, pledged to continue developing a culture that nurtures community. The AGM "report" was marked A and received with applause.

4. The Members endorsed the strategic direction proposed and approved the Budget for 2025 by show of hands.

5. Members were invited to *add or reject* nominations for the Committee. The Minutes Secretary confirmed that none had been received. The Chair, the Lead Volunteers and Committee members were declared re-elected. David then nominated Mrs Hilary Austin (formerly Vice- Chair) for the role of Honorary Counsel to the Chair, to which she would bring compassion, wisdom and many years of experience. The Treasurer, Steve, presented her with a bouquet which she graciously accepted.

6. The Meeting was open for Members contributions. Clare Price drew attention to Friday 11 April – *Parkinson's Awareness Day,* and welcomed any suggestions for marking the occasion. Ron and Maureen Wride have been preparing teas for Branch meetings in Shalford for 27 years but it was no longer possible for them to continue. He was hanging up his apron, but hoped that someone would come forward to take over – with the help of his loyal "assistants". The meeting applauded the selfless commitment to the Branch that both Ron and Maureen had shown, despite the progression of age (and Parkinson's). Ron responded saying they had many happy memories and made many friends over the years. They would continue to attend meetings whenever possible.

Sarah Bowdage Spencer was invited to saw a few words; she was fulsome in her praise for all the Branch achievements and the efficiency with which the Branch operated – all thanks to the leadership of the volunteer Committee. In answer to a question she explained the move of Parkinson's UK London office from Victoria to a better location in 50 Broadway, St James's SW1

7. The Chair declared the Business Meeting closed and it was time for tea and cakes.

Margaret Westwood (Minutes Secretary) 1.03.2025

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Full Text of Chair's Report

The AGM is the opportunity for key members of the Branch Committee to give you an annual snap shot of the Branch health, good or bad. It is also an opportunity for you, the membership to give us feedback on our leadership, with the ultimate feedback being your power to dismiss us!

I hope you find the AGM informative. Please also note that the year runs from AGM to AGM (February to February)

Now is the traditional time on the agenda where a 'normal' Chair would explain the progress the Branch has made over the last year and the ambitions going forward. Typically, this might be a long list of activities that the Chair and the Branch have started, maintained, or completed over the year.

I am however not 'normal' and believe we need not measure ourselves against defined principles. Accordingly, I propose to write this as if it were our school report :-)

I am a big believer in transparency – non-sensitive information should be shared with the members close to the time it is released to the Lead Volunteers and not held back to be first disclosed at the AGM. I score us an A this year as we have had an exceptional year with:

- 3 '*The Park*' magazines (May, September & January) totalling 80 pages
- 11 Monthly Newsletters now known as '*The Park Bench*'
- Production and distribution of 'Useful Aids and Other Suggestions for those with Parkinson's'

My second principle is inclusivity. Everyone of our 390 members should feel they are important and valued. As we know Parkinson's is a cruel disease that effects each individual in unique ways. Accordingly, we need tailor our offerings to a broad range of member types. With this in mind we introduced the paper dissemination of *The Park Bench* this year. I score us an A-

My third measure of success is compassion. I believe many volunteers. incorrectly measure Branch success based on finance or by a project delivery plan. For example, I may hear volunteers from Other Branch's say "we're a great Branch as we offer three types of exercise classes”. While this is not a bad thing I assert success is something much more spiritual – “what’s the enthusiasm level of the Committee and Members to give their unconditional love to others? “. We have this spirit in abundance, so this is a cert, scoring an A.

I hope all of you agree with me that every single person has their part to play in creating the supportive culture described above. Although we are currently on top form, I don’t think this is something we should take for granted.

So the challenge for each of us is to determine what role we can play and how we can do our own little bit to help others. This is not easy with Parkinson’s, as we have to really push ourselves to give to others, when we struggle to find energy to look after ourselves.

My choice is to act as Chair. Certainly, I see my principal role is to develop the culture that nurtures community. Let’s continue to support each other, show loyalty to one another, and ensure that the values we’ve built over time remain strong.

Going forward, I implore you all to be kind to yourselves, be considerate to others, and continue to build a culture where new members feel supported and valued. I will aim to do my bit, alongside the following tactical activities:

- Complete the membership census so that we have a high degree of confidence in the membership list.
- Continue to be open and actively seek any new activities that may benefit our members lives and wellness.
- Ensure, as a Committee, that we have no knowledge silos regarding the technical tools we use.
- Improve the website.

Thank you and feel free to ask me any questions.

David Lowther

Chair

Bright Ideas for the summer!

The summer is coming so we have put together a number of good or not so good) ideas

Unsure what to wear to the Shalford Afternoon Meeting? Why not purchase the Parkinson's Aware shorts. The only downside is that I can only find them in the US. Get them ordered before retaliatory import tariffs are put in place

Summer is coming and let us hope we can all benefit from some sunshine!

The National Trust now uses a scheme run by Outdoor Mobility to lend out mobility scooters. The trust does not gain financially, the cost is to cover Outdoor Mobility insurance.

Prices are as follows: Single use £3. Taster for 2 weeks £5. Annual £15.

The following list is where they are available in Surrey, Sussex and Kent. It appears there are none in Hampshire.

Surrey: Hatchlands GU4 7RT

West Sussex: Nymans RH17 6EB. Wakehurst RH17 6TN

East Sussex: Sheffield Park TN22 3QX

Kent: Ightham Mote TN15 0NU. Knole TN13 1HX. Scotney Castle TN3 8JN

National Trust Accessible Holiday Properties.

Are you planning a holiday this summer in England or Wales?

The National Trust has thirteen properties that are accessible to wheelchairs. The properties are mostly on one level or include ground floor accommodation and thus also suitable for non-wheelchair users with mobility issues. At some of the cottages specialist equipment such as hoists can be hired, and they may offer a percentage of the holiday cost back to help pay for it.

The Trust is working with AccessAble which makes guides to help guests get a fuller picture of what to expect before they book. This enables you to check on facilities such as wet rooms and accessible showers etc.

For those of you who find navigating websites a little tricky (including me) follow below!

Go to wwwnationaltrust.org.uk.

Press the menu button to the right of Donate.

Press Holidays

Press Explore all the places you can go on holiday

Scroll right down to and press Book your holiday.

What could be more summery than an ice-cream. Walking down a beach with cornet in hand but what flavour to choose. Should it be the reliable vanilla or should you think out the box. Great news, Baked Bean ice-Cream is now available in the UK

Meeting Katy Slade, Area Development Manager

Hello there! My name is Katy Slade, and Area Development Manager (ADM) at Parkinson's UK, I cover Buckinghamshire, Oxfordshire, Berkshire, and Surrey (BOBS). I have been at Parkinson's UK for 17 years and have done a number of roles… I started off as an Education Officer working just 11 hours a week delivering education sessions at Nursing Homes, Home Care agencies, GP surgeries and Hospital wards. I loved this role as it was great to see how keen people were to learn about Parkinson's. Now much of this learning is done online and we have a wealth of materials available at parkinsons.org.uk/professionals/learning-hub, do have a look… I moved onto managing the local Information and support team for 5 years and then onto the fundraising team - where I may have met some of you before at Guildford Cathedral abseil or a walk for Parkinson's, and of course at this time I worked with the amazing Valerie Box who as a Community Speaker educated and raised awareness locally to 1000's of local people.

Now working as an ADM my role is to work locally across BOBS to develop opportunities such as exercise and cafes and also maintain and build the service provision - such as Nurses and other professionals. I work closely with the branch committees, Zoe the Volunteer Co-ordinator and the Local Adviser - Jill Beaumont to agree local priorities. At Guildford you are very lucky to have a strong committee, and you may not have seen me that regularly… but I look forward to meeting you again soon.

Outside of work I play the Trombone in a local brassband, where my fellow bass trombonist has Parkinson's - you may have seen a feature about him in The Parkinson's last year. I also enjoy playing netball and horse riding. I regularly join my local Parkrun, knowing the importance of exercise I try to do at least 3 hours weekly. My most embarrassing moment whilst playing the trombone involves me marching and whilst playing a vigorous march losing my slide along the local high street… luckily the instrument was not damaged in the process, although I did fall out of step.....

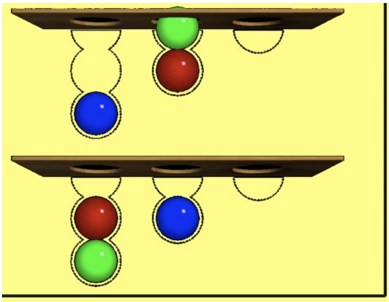
My favourite part of working at Parkinson's UK is working with the local groups and I have come to feel that many members are friends and do regularly join my local group in Milton Keynes at their events, recently I was at a bucket collection at MK Dons football stadium and their community stand at the city centre for World Parkinson's Day. The most challenging part is working with the NHS, due to the pressures they are under and the multiple layers of managers and constant changing of staff, it can be slow in effecting change with them and this frustrates me.

Something that has been constant over the 17 years I have worked at Parkinson's UK is the great friendships I have made and the amazing dedication of the volunteers at the branches, without the work they do the local network would not exist and the number opportunities for people living with Parkinson's to meet, exercise or support each other would be hugely diminished. Thank you to each and every one of you.

Katy

kslade@parkinsons.org.uk

Example Cognitive Test



This is an example of the Cognitive Tests I undertook.

The question is "what is the smallest number of ball moves that need be applied to the bottom layout to make it match the top arrangement?"

What Happens When the Carer Needs Care?

Finding Help That Truly Fits

I'd put off having my hip replaced for far too long. Not because I feared the surgery itself, but because of what came after. How could I care for Robin during my recovery, when I'd barely be able to care for myself?

My consultant was clear: for at least ten weeks post-op, I'd need significant help —not just for Robin, but for me. Any attempt to power through it could jeopardise my healing.

That left us with only one real option: finding a live-in carer.

The plan was simple - at least in theory. The carer would support both of us initially, and as I regained strength, I'd gradually take back responsibility for my own care and they would focus just on Robin. In practice, however, nothing about inviting someone to live in your home feels straightforward, especially when you're at your most vulnerable.

It's not just about handing over practical tasks, it's about allowing someone into your routines, your space, your life - during a time that already feels uncertain and overwhelming. I'd already been using a care agency for occasional hourly visits, so I turned to them for help. Let's just say I was surprised by how limited the process was. I'd receive a short profile of the candidate, followed by a quick phone interview—and then it was decision time. That was it.

The first two carers didn't work out and, by mutual consent, didn't stay long. All of this was unfolding while I was recovering from major surgery and trying to make sure Robin was okay. The whole process was physically exhausting and emotionally draining. With each mismatch, I grew more frustrated, more worn down, and more unsure of how to get it right.

Then something clicked.

Maybe it wasn't that I was incompatible with live-in care, maybe the issue was in the questions I was *(or wasn't)* asking. I needed to go beyond their work history. I had to really understand who they were - their personality, their values, how they approached care, and how they might fit into our daily rhythm.

Up to that point my questions had been fairly standard:

- How long have you worked in care?
- What kinds of clients have you supported before?

Important, yes – but not enough. So, I began to ask more meaningful, practical questions:

- What do you find most challenging in this kind of role?
- Are you comfortable with other family members visiting or helping out?
- How do you see your role—more clinical and task-focused, or integrated into the household?
- How do you like to handle meals—do you prefer to cook for yourself, or would you rather we eat together?
- Can you share an example of a placement that didn't go well, and why?

These types of questions might feel a little awkward at first, but they make a world of difference. After all, you're not just hiring a professional, you're inviting someone to live in your home and become part of your life during a deeply personal and challenging time. Thankfully, the third time was the charm. With those more thoughtful questions, I found someone who was amazing and truly fit. Their presence transformed the experience - easing the pressure, creating a sense of partnership, and allowing me to focus on recovery without concern for Robin's wellbeing. If you're facing a similar situation, I hope sharing this helps you feel a little more prepared, and perhaps a little less alone. The right support *is* out there. Sometimes, the key is just asking the right questions to find it.

Rona Lester

Resilience Personified—An event with Nina Schumann

A Conservatoire Concert—Godalming Baptist Church

March 2025

Nina Schumann is a distinguished South African pianist renowned for her profound impact on classical music both nationally and internationally. She was born into a musical family in Stellonbosch and is now head of piano at the Department of Music at Stellonbosch University. Her first appearance with an orchestra was at the age of 15 and since then she has won every major South African music competition and scholarship.

In 2012 Nina was diagnosed with Focal Dystonia which is a Neurological Condition causing muscle spasms, fingers curling and sticking in a position. Musicians who have intensely practiced their instruments over several years are most affected by this condition.

Then in 2017 she was diagnosed with Parkinsons. One can imagine that any pianist facing a future with such a double diagnosis would retire from performing. But Nina has battled on and with the help of Botulinum injections to her hands has managed to continue at a very high standard. To do so she must move her body into various positions to play the keys. Her resilience is incredible and watching her play is an inspiration. Nina recently toured Europe and her final stop was at Godalming Baptist Church on March 21st.

The church regularly holds concerts often for young musicians early in their career. They are free with a retiring collection towards the musician's fees. Their next concert on Saturday May 3rd at 7pm features the young flautist Daniel Shao winner of the Overseas League Wind Prize 2024. He is accompanied by Pianist Simon Callaghan. They have chosen a programme of delightful music to suit a variety of musical tastes.

Myra Newnes-Smith

In Memoriam Gifts

None of us like to think ahead to our own funerals, although it will happen to us all. Often we will give a vague message to our loved ones that *" … whenever my time comes, I would like…….",* and not much more than that.

However at least two of our members who died in recent years had asked that their spouses set up 'In Memoriam' donations pages on the internet, asking friends and family to donate money to the Branch through websites such as "Much Loved", "Just Giving", and "Memory Giving" rather than sending flowers. There are probably more 'In Memoriam' sites.

These websites allow donations and enable friends and family to share memories to honour the loved one. A Funeral Director can help you set up a suitable In Memoriam site.

The passing of those two members raised several thousand pounds of much needed funds to enable the Branch to continue its support of you all.

Like other charities we can signpost you to free Will Writing services—see https://www.guildfordparkinsons.org.uk/donations/ for more details.

Just a thought to consider when you are pondering your future.

Steve Heron

Treasurer

Research

We’re chasing down a cure. Investing in pioneering projects that could slow, stop or reverse Parkinson’s. Discovering life-changing new treatments. And we aim to deliver the next new treatment in years not decades.

THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON’S RESEARCH

Research—FOX 2

As referenced in the Chair’s Introduction I have taken part in a Clinical Study. I thought I’d give you some insight.

The first thing to note is Study Team’s like complexity—why use one term when you can use three. For example this Study is

- funded by the Michael J Fox foundation,
- Managed by the University of Exeter and
- Executed using some of the advanced scanning facilities at Hammersmith Hospital..

The Study has itself three titles:

- Full Title—“Longitudinal Investigation of Imidazoline-2 Binding Site as a Novel Marker of Disease Progression in Parkinson’s Disease: An [11C]BU99008 PET Study
- Short title—Longitudinal Investigation of I2BS in PD
- Easy Name—Fox 2

What is the purpose of the study?

The purpose of this study is to find a biomarker for Parkinson’s disease (PD). A biomarker is an indicator of the presence of a disease, that can be measured, and that is able to give information about the progression, or severity, of it. PD is a chronic neurological disease that progresses over time and causes a variety of symptoms, such as slowness of movement, stiffness and shaking. The symptoms of PD are caused by the malfunction and death of vital nerve cells in the brain. We do not know what causes PD and we do not have a biomarker for it. Generally, PD occurs without a known cause, and is called sporadic PD. In a few cases, however, PD occurs because of a genetic mutation, and it is called genetic PD. Patients with genetic PD share features to sporadic PD patients. It is believed that studying people who carry mutations for genetic PD mutations would provide precious information on what are the causes of PD and help to devise successful treatments for both diseases.

In this study, we aim to find a biomarker of PD. To do so, we will use imaging scans called Positron Emission tomography (PET), Single Photon Emission Computed Tomography (SPECT), and Magnetic Resonance Imaging (MRI). The PET and SPECT scans use small amounts of radiation and specific compounds called tracers, to study chemical changes in the brain in a way not possible with any other procedure. The MRI uses magnetic fields to generate images of brain structure and function. We will also use a blood and urine collection

Our findings will provide a deeper understanding of the brain changes in PD. More importantly, this study will help with the discovery and development of new medications aiming to delay progression of PD symptoms.

David Lowther

New research and CBD trial

The Reigate Parkinson's Support Group organised a presentation in April focussing on research updates.

Parkinson's UK Research Communications Officer, Emma Rodgers, gave an overview of the latest research, how Parkinson's UK is driving forward new and better treatments and how the Parkinson's community can get involved through the organisation's Research Support Network. With 10 million people worldwide and 153,000 in the UK diagnosed with Parkinson's, finding what causes Parkinson's and what causes its progression, is vital. As is finding new treatments for the condition.

Emma highlighted a few of the research projects that PUK is funding, including studies into

- links with gut bacteria. Studies have shown that the gut bacteria in some people with Parkinson's differs from the gut bacteria in those without Parkinson's. Further studies are underway to identify if the gut bacteria can be rebalanced.
- Differences in Mitochondrial structures between those with and without Parkinson's (Mitochondria are the 'battery-like' cells that power the brain)

Emma added how valuable the ICL Brain bank is to researchers in helping our understanding of what happens in the cells and may help us predict Parkinson's. Did you know that you can pledge your brain to the ICL Brain bank? And there are in vivo studies too. If you don't have Parkinson's but are 60-80 years old, you can take part in this research now. If you go on to develop Parkinson's in the future, this will enable researchers to see if there are patterns eg digestive problems.

For more information on Parkinson's UK research visit https://www.parkinsons.org.uk/research

Professor Sagnik Bhattacharyya from King's College London spoke about his research team's ongoing clinical trial called CAN-PDP. This aims to understand whether cannabidiol (CBD), part of the cannabis plant, might be useful for treating hallucinations and delusions in people with Parkinson's. The research is funded by Parkinson's UK and is sponsored by Kings College London and South London & Maudsley NHS Foundation Trust.

Currently, the drugs that are used to treat hallucinations experienced by people with Parkinson's Disease Psychosis (PDP) make their symptoms of Parkinson's worse. And the drugs used to treat their Parkinson's symptoms makes the hallucinations worse.

So this trial is using CBD - with the THC extracted, hence no risk of causing psychosis - and is seeking to find a well tolerated CBD treatment. The trial is in its second stage and the team is looking to recruit more participants. In order to be eligible you must have a Parkinson's diagnosis, be aged 40 years or older and be experiencing symptoms of psychosis (such as delusions or hallucinations).

The researchers have already recruited over 70 people out of the 120 aimed at. Half of the participants will get the drug and half will get a placebo. Treatment duration is 12 weeks, with dosage starting at 400mg a day for the first 6 weeks then 800mg a day for final 6 weeks. There are various stages to the trial if you take part, including visits, assessments and follow-up.

If you think you might be interested in getting involved in the trial email canpdp.trialoffice@kcl.ac.uk or call 07936 545178

For more information about the trial visit www.kcl.ac.uk/research/cannabidiol-for-parkinsons-disease-psychosis-can-pdp-trial

Our thanks to Hazel Dawson and her fellow volunteers at the Reigate Parkinson's Support Group for organising this fascinating talk.

Debbie Gaskell

How the Branch Subsidises activities

I often mention the need to raise funds to support the Branch in my articles as we receive no funding from Parkinson's UK. However to balance these articles, I thought it useful to explain how we spend these funds.

We are currently spending over £70,000 each year to support members in a whole range of activities. The majority is spent on subsidised physiotherapy exercise classes (over £40,000), as we all believe regular exercise helps slow the progression of Parkinson's. Our approach is to subsidise <u>one</u> physiotherapy based exercise class per member per week, and if a member decides to have more such classes each week, then they pay the full cost for such additional classes directly to the provider.

The Branch 'subsidy' for a member attending physiotherapy exercise classes is approximately 50% of the real cost of each class as follows:

Provider	Class Full Cost per member per week	Member pays	Branch Subsidy	Subsidy %
Surrey Hills Re-hab	£20.00	£10.00	£10.00	50%
Foundations Physio	£16.50	£7.50	£9.00	55%

We also pay most of the members initial assessment cost when they first consider attending these exercise classes, (£90.00 per member).

Members who miss an exercise class may be charged by the Provider, depending on the reason for missing the class. The provider may also charge the Branch the subsidy element of their fee. In 2024, such missed class subsidy fees cost the Branch almost £2,000, a significant amount of 'loss' to the Branch and something we are seeking to reduce. (Note: £2,000 is approx. the amount fundraised at our annual Summer Picnic)

We subsidise members who attend Pilates classes and Dance classes (other ways to staying fit) as follows:

Provider	Class Full Cost per member per week	Member pays	Branch Subsidy	Subsidy %
Pilates Perfection	£13.00	£6.00	£7.00	54%
Dance for Parkinson's	£7.30	£4.00	£3.30	45%

Our Speech Therapy and Parkinsong Voices classes are subsidised:

These two classes assume 'full membership' (capacity) for the subsidy %, as the providers fee is fixed irrespective of attendees. When the classes are at lower attendee numbers, the subsidy % per attendee obviously increases.

Provider	Class Full Cost per member	Member pays	Branch Subsidy	Subsidy %
Loud & Clear (monthly)	£8.50	£4.00	£3.50	41%
Parkinsong (weekly)	£9.48	£5.00	£4.48	47%

Our recently introduced Oxygen Therapy is subsidised: Members can, and often do, attend more than one type of subsidised activity each week, and that is OK. Our only restriction on 'subsidy' is that as mentioned earlier, we only subsidise one physiotherapy based exercise class per week.

Provider	Full Cost per member	Member pays	Branch Subsidy	Subsidy %
Samson Centre	£20.00	£12.00	£8.00	40%

The hire of Shalford Village Hall each month is £73.00, and some of the guest speakers, or activities on offer, charge a fee typically £150.00 or £200.00. Some are very generous and often agree to no fee.

We subsidise the Christmas Lunch by approx. 50% per attendee, and this last year subsidised the Newly Diagnosed Group's evening Christmas

Dinner by a similar %.

The Park Magazine costs approx. £3.50 (print and postage) per edition for each member, and the printed monthly Park Bench newsletters are now costing a similar amount per recipient. Where possible we are seeking to reduce our expenditure on 'printing', moving communications online although we fully appreciate many members prefer 'paper'.

We also produce various leaflets and guides for use by the Parkinson's nurses and GP surgeries to ensure anyone with Parkinson's is aware of the Branch and our activities. The costs of our Branch website is minimal as are our Committee expenses.

I hope the above helps you understand more how we spend the money we fundraise to support you all.

Steve Heron

Treasurer

MIND GAMES by Peter Taylor

Light and life both sapped away,
dark winter's day, I long for
bright, bold artist spring to splash
crocus colours over grey.

Strong hearts strip the light from dark:
let eyelids drop, rouse sleepy thought;
to find the good, despite the hurt,
in every word the song of larks.

Faint hearts miss the majesty
of winter's sun, warming cold,
the hush, the calm of fallen snow
the blue, streaked silver, canopy.

No arrow less than iron bolt
may lodge in flesh, fester long,
if we quietly forgive and
do without the search for fault.

So may gloom be swept aside,
frozen winter smell of spring;
love will steer sweet souls serene
if within love doth abide.

Staying Intellectually Active

As you know, keeping your mind in shape is as important as any of the other mantra values.

I try to help by posing the occasional teaser… here are the answers:

In the January edition of *The Park*, I asked where you would find this sign.

The answer is: near Farnborough, as *AAIB* stands for the **Air Accidents Investigation Branch**, and *RAIB* for the **Rail Accident Investigation Branch**

The Air Accidents Investigation Branch investigates civil aircraft accidents and serious incidents within the UK, its overseas territories, and Crown dependencies.

Are You an April Fool?

In the recent edition of *The Park Bench*, the following applied:

- **Richard Longthorpe**, 71, a pig farmer from East Yorkshire, did indeed do 1,000 press-ups a day for a month – although his Yorkshire explanation and the PDUK spokesperson's response were complete fabrications. (BBC article)
- **Richard Lee**, CEO of *Sakuto Knives*, did indeed send me an email – but it was clearly spam.

- **Martin Lynch** does indeed spend his mornings in his wheelie bin filled with cold water. (BBC article) I should caveat this by suggesting you seek medical (perhaps psychological) advice before attempting to copy him.

- Finally, while producing *The Park Bench*, I received an email from **Margaret Westwood**, who said she was reminded of an April Fools' joke in *The Guardian* many years ago, about the island of *San Serriffe*.
  I felt compelled to keep the story alive for the next generation. (Wikipedia article)

Branch 100 Club

Our 100 Club will 'celebrate' its 4th anniversary on 1st July, and over these years we have made many members millionaires *(albeit it in some random foreign currency!!).*

If you are not already a member why not give it a try! The 100 Club is drawn each month, usually at the Shalford Village Hall social meeting, and the amazing 1st Prize is £60, with 2nd £20 and 3rd £10. It costs £1.00 per number per month, and majority of existing members have multiple numbers and pay their subscription annually in advance.

To join visit our website (https://www.guildfordparkinsons.org.uk/fundraising/) or contact either

- Nick Hetherington nhetherington@guildfordparkinsons.org.uk OR
- Steve Heron heron@guildfordparkinsons.org.uk

Steve will be contacting existing original members soon to collect their annual subscriptions. Recent winners are:

2025	**1st Prize £60**		**2nd Prize £20**		**3rd Prize £10**	
	Name	**Number**	**Name**	**Number**	**Name**	**Number**
January	Joan Peacock	189	Barry Butcher	70	John & Joan Mayers	210
February	Janet Oldham	102	Gaber Burnick	123	Olivia Ames-Lewis	93
March	Valerie Tanner	105	Peter Witter	75	Di Keir	82
April	Richard Abbott	141	Rodney Brown	26	Lin Ballington	117

Thanks for all the Tea!

Ron and Maureen Wride are retiring from making the tea at the Shalford Afternoon Meeting after 27 years. Over this time they have missed only about 3 meetings.

The Committee express their sincere Thanks

Branch Activities

Activity	Where	When	Comments	Contact
Carer's Group	Inn on the Lake	2nd Monday of Month	Share with others Carers	Carers@GuildfordParkinsons.org.uk
Committee Meeting	Church House	6 weekly 10:00 - 12:00	volunteers always welcome	Chair@GuildfordParkinsons.org.uk
Friendship Group Meeting	White Hart, Godalimning	3rd Wednesday of Month @19:00	All welcome Option to eat or not	Membership@GuildfordParkinsons.org.uk
Loud and Clear Speech Therapy	Online	1st Monday and Wednesday	Improve your speech in fun format	Treasurer@GuildfordParkinsons.org.uk
Newly Diagnosed Social Meeting	**Grantley Arms Wonersh**	2nd Tuesday of Month @ **19:00**	All welcome Option to eat or not	Secretary@GuildfordParkinsons.org.uk
Tuesday Social Meeting	Shalford Village Hall	Last Tuesday of Month @14:00	Guest Speaker, Refreshments and Camaraderie	Secretary@GuildfordParkinsons.org.uk
Dance for Parkinsons	Godalmin United Church, Godalming	Weekly on Wednesday		Treasurer@GuildfordParkinsons.org.uk
Parkinsong Voice Classes	Busbridge Village Hall (and Online)	Tuesdays 11.45 - 12.45	Work on breathing	Treasurer@GuildfordParkinsons.org.uk
PD Warrior type Exercise Class	Whitley	Weekly	Multiple sessions on different days	Foundation Physio
PD Warrior type Exercise Class	West Clandon	Weekly	Multiple sessions on different days	Foundation Physio
PD Warrior type Exercise Class	Cranleigh Youth Centre, Snoxall	Weekly	Multiple sessions on different days	Surrey Hills Rehab
Pilates	West Clandon	Weekly on Wednesday		Treasurer@GuildfordParkinsons.org.uk

Key Email Addresses for Branch

Chair	David Lowther	Chair@GuildfordParkinsons.org.uk
Treasurer	Steve Heron	Treasurer@GuildfordParkinsons.org.uk
Communications Manager	Deborah Gaskell	Comms@GuildfordParkinsons.org.uk
Membership Secretary	Keith Black	Membership@GuildfordParkinsons.org.uk
Carers Support	Myra Newnes-Smith	Carers@GuildfordParkinsons.org.uk
Support Groups	Sharyn Grenville	SupportGroups@GuildfordParkinsons.org.uk

National Website www.parkinsons.org.uk

Local website www.guildfordparkinsons.org.uk

Parkinson's Nurse Specialists (NHS)

Amanda Dodson Dawn Rowson	Rose McKinley Jenny Honey
Milford Hospital	*Farnham Hospital*
01483 362020	*01483 908183*
rsch.gw.ms.parks@nhs.net	**vcl.parkinsonnurses@nhs.net**