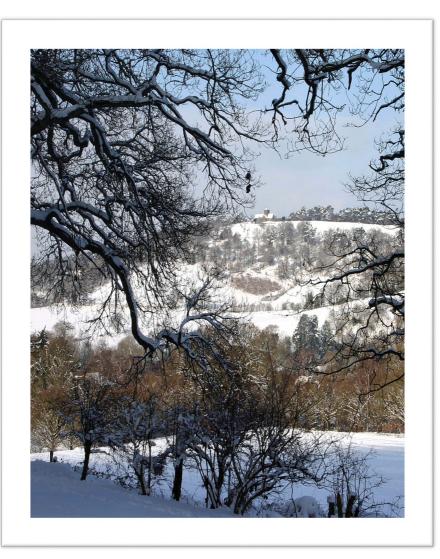
PARKINSON'SUK CHANGE ATTITUDES. FIND A CURE. JOIN US.

The Park

Magazine

JANUARY 2021



PARKINSON'S^{UK}

PARK The magazine, exclusive to members of the Guildford & South Surrey Branch of Parkinson's UK, published three times a year in January, May and September.

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GUILDFORD AREA BRANCH MEETINGS 2021

Meetings are held on the LAST Tuesday of the month

IMPORTANT NOTICE

As we go to press the embargo remains on face to face meetings. In the meantime we will continue with Zoom meetings.

STAY SAFE AT HOME AND CHECK OUR WEBSITE FOR UPDATES

If anyone wants to join these meetings, who is not already on the list, please email our Secretary, Sharyn, on sbullen@guildfordparkinsons.org.uk and your name will be added.

This includes the AGM

January 26th Jacintha Bennett, Community Engagement Officer for NHS Surrey

Heartlands Clinical Commissioning Group, will talk about her work. Part of her role is to ensure that the CCG involves patients and public in a meaningful way to help improve health and care services.

February 23rd AGM

March 30th TBA

April 27th TBA

Cover: St Martha's Chapel in the snow.

The WAGS page

Due to partial Lockdown WAGs have not reinstated our face to face meetings, so for now we are continuing our zoom meetings which are held on the

4th Wednesday each month at 7.30 pm.

Call details are:

Topic: WAG fortnightly catch up Time: This is a recurring meeting

Join Zoom Meeting https://us04web.zoom.us/j/79388903846? pwd=Q0RQSndiYUpPSDEzY2VRZ3REVkdTQT09

Meeting ID: 793 8890 3846

Passcode: wags

Please feel free to join us

Note from the Chair

A very Happy New Year to you all. We are probably all glad to see the back of 2020 and looking forward to a more "normal" year in 2021! As I write, the signs are that a Coronavirus vaccine is on the verge of being rolled out. But it will take time before it will be safe to resume our old way of life. And many people will bear the scars of the pandemic – whether because loved ones were affected, or because social isolation or lack of medical attention has had lasting effects – for some time to come.

Looking back, we will all recall the sense of complete shock in March when everything shut down almost overnight, and all our activities and social contacts were put on hold. But then we gradually realised that this did not have to be a complete hibernation and that there were ways to bring a sense of normality back into our lives. My thanks go wholeheartedly to our wonderful providers of exercise and other activities – Kim, Adam, Sue and Emily – for finding ways of continuing their work with you by imaginative use of technology. And well done to all of you for having embraced – as we all had to – the virtual world which has been our salvation. We are all now Zooming as though we had been born to it!

Looking ahead, we can use some of what we have learned to build a slightly different programme for our Branch in the future. Yes, it will be fantastic to gather together again, as we have all missed those meetings and events which work best in person. But we have also realised that use of technology has been more inclusive for those who do not find it easy to leave the house for different reasons.

The committee will set out its stall in more detail at the AGM on 23rd February, but our priorities for 2021 will be to continue to run our various programmes and activities, virtually and in person, but also to give more support to carers, and to newly diagnosed members to ensure they are getting what they need. You will read more about that elsewhere.

The committee has worked particularly hard during 2020 to keep things going and my thanks go to them. But the Branch needs to replace those who have left us and to help those who have been in post for so long and deserve a break.

Note from the Chair (cont)

Please read my special plea for volunteers elsewhere in this newsletter (P.8)— and I look forward to being overwhelmed by the response!

A very happy New Year, once again.

Níki Tompkinson



Our Branch Finances as we go into 2021

Happy New Year to all, let's hope 2021 is a much better and more normal year than 2020

As I forecast in the September edition of Park, we are entering 2021 in a very sound financial position. Although I have not finalised the 2020 Branch accounts yet (as this article is being written in early December), I am reasonably confident that we should be starting the year with approx. £70,000 in our bank account. I'll present the final 2020 accounts at the Branch AGM in February (will be a Zoom call).

This healthy financial start for 2021 remains due to our great fortune of having received a large 'Legacy' some 6 years ago and our own prudent financial management over the years. The Legacy funds were held for us by Parkinson's UK, and annual amounts paid to the Branch each year for 5 years. The last of these Legacy funds were paid to the Branch in 2020, and from now onwards we need to again rely on our own fundraising to support the various activities we provide. However, having this current healthy financial position will allow us time to transition over this coming year.

Over recent years our Branch expenditure for the provision of our various exercise classes and other social activities has been broadly £60,000 p.a., although for 2020 it will be slightly less due to a lot of activities moving 'online' and others sadly cancelled. By contrast, our local fundraising and donations have been between £20,000 to £25,000 p.a., so we need to significantly increase these if we are to maintain the current activities and our subsidies for these activities. Ideally, we should increase our fundraising to £30,000 or higher this year. Anyone who is interested in helping us fundraise should contact either myself or our Chair, Niki Tompkinson (contact details at the end of this magazine or on our website)

I presented a 2021 Budget to the Committee in late November, which for expenditure is shown below and enables us to maintain the provision of our various existing activities (rounded figures): -SEE NEXT PAGE

Financial Review (cont.)

- £45,000 for subsidies towards the provision of exercise classes (Surrey Hill Rehab, Foundations Physio and Pilates)
- £8,000 towards the costs of providing our Choir
- £4,000 towards providing monthly top up respite care through Surrey Crossroads
- £3,000 towards the costs of any social activities (monthly meetings, Christmas 2021 party, etc)
- £2,000 to cover the cost of producing three printed editions of The Park, including postage
- £1,000 to cover the costs of maintaining our local Branch website, Zoom meeting service, email service, etc

This amounts to a planned expenditure of broadly £63,000 which allowing for inflation is similar to recent years.

As we have the current healthy financial position, the Committee agreed to additionally provide for 2021 only some additional longer periods of respite care (see the separate article in this magazine) and also to potentially sponsor some members to attend a Fighting Fit weekend. A provisional budget of £15,000 for these additional 'one-off' activities has been identified, so our potential expenditure for 2021 could be as high as £78,000.

I am forecasting our available funds to cover this expenditure to be £100,000 made up of our existing £70,000 in our bank, plus hopefully fundraising and donations totalling £30,000. If we do manage to reach this level of fundraising and donations this year, we can potentially start 2022 with around £20,000 in our bank.

I hope the above helps enlighten you to the somewhat dry subject of our Branch finances. I will be more than happy to take any questions on this at our AGM in February.

Steve Heron

Treasurer

Volunteers needed to help run our Branch!

As you all know, local Branches of Parkinson's UK are run entirely by volunteers. The Guildford and South Surrey Branch has an active committee of eight, supported by a number of other volunteers. Each of us takes the lead in a different aspect of the Branch's work, organising and delivering the various activities and meetings. Thanks to the efforts of committee members and to modern technology, we have kept going as much as we can during lockdowns and other restrictions.

But we need more volunteers! Some of the committee have served for many years and have had more birthdays than should be mentioned in polite society! And some jobs are simply not being done because there is no-one to do them.

There are three roles in particular which are currently vacant:

Communications co-ordinator. Keeping members informed is important, especially in these days of COVID-19 when we are not meeting in person. Our regular newsletter, The Park, has an editor (Anne Folkes) but the website

(www.guildfordparkinsons.org.uk) needs an equivalent person to supply up to date content to the technical manager. A communications coordinator would keep themselves informed of the group's various activities (eg by keeping in touch with the committee members and attending our meetings which take place every six weeks), ensuring that relevant information appears promptly on the website. No technical skills are needed, just a few hours to spare each month, a desire to help and a way with words!

Fundraising co-ordinator. During 2021, the last of the Legacy money will be spent. Thereafter, we will need to raise funds if we are to continue to subsidise the many activities which we offer to you, our members. The Fundraising Co-ordinator would work with our Treasurer (Steve Heron) and others to raise the money we will need. This may be by applying for grants, appealing to local businesses or organisations, or organising more traditional fundraising activities (once the pandemic restrictions are lifted.)

Members' meetings and events coordinator. Once we are able to return to meeting in person, our Vice Chair (Hilary Austin) will need some help with booking and setting up Shalford Village Hall each month, doing raffles and teas, and many other behind-the-scene jobs which ensure that these meetings take place smoothly. Plus helping to organise other events like Christmas lunch and the Summer cream tea!

Volunteers needed to help run our Branch

<u>Please consider whether you or a family member or friend could offer the help that we need!</u>

For more information, please contact the Chair, Niki Tompkinson, on ntompkinson@guildfordparkinsons.org.uk

Newly diagnosed?

A diagnosis of Parkinson's often comes as a bolt from the blue. And not a very pleasant one. We try to contact our new members as they join the Branch, to see what support or information might be helpful. But we are aware that many of our activities do not appeal to those of you still trying to come to terms with living with Parkinson's.

We are therefore considering setting up a drop-in group for those newly diagnosed and their partners, to put you in touch with each other and to steer you towards people and information which might help you at this early stage.

The meetings will be held on Zoom in the first instance, with a view to starting after Christmas. These sessions will be very informal – no agenda, and people can drop in or out as they wish. If you are interested, please contact Sharyn Bullen on sbullen@guildfordparkinsons.org.uk.

Please let us know if there is anything else we might do.

GUILDFORD AND SOUTH SURREY BRANCH OF PARKINSON'S UK

ANNUAL GENERAL MEETING

To be held on Tuesday 23 February 2021 at 2 pm

The Meeting to be conducted by Zoom and the Secretary will publish the link a few days before as for the Tuesday meetings

AGENDA

- 1. Welcome by the Chair
- 2. Apologies for absence
- 3. Approval of the Minutes of the Meeting held on 25 February 2020 see The Park May 2020 or website www.guildfordparkinsons.org.uk
- 4. To receive and approve the Report of the Hon. Treasurer for the year ending December $31_{\text{st}}\,2020$
- 5. To receive the Report of the Committee
- 6. To elect a Branch Committee:

Current members of the Committee eligible for re-election are Niki
Tompkinson, Hilary Austin, Steve Heron, Sharyn Bullen, John Oldham,
Anne Folkes, Myra Newnes-Smith and Margaret Westwood.

- 7. To elect Officers to serve until the next AGM as Chair, Vice-Chair,
 Honorary Treasurer, Honorary Membership Secretary, Honorary Secretary
 (Communications), Honorary Minutes Secretary.
- 8. Any other business.

Zoom meeting Tuesday October 27TH Hilary Austin

We welcomed our Parkinson's Nurse Specialist, Amanda Dodson, to this meeting which was well attended by members.



The aim had been to discuss the development of services for patients with Parkinson's disease since the retirement of Dr Patrick Trend but he had not yet been replaced and any change in the service was prevented by the COVID-19 pandemic.

Dr Rachel Davis, consultant Gerontologist, who has a specialist interest in Parkinson's disease, runs a clinic for the

frail elderly on Friday mornings at Milford which is suitable for some of our members.

There are three other consultants at Milford but none of them hold permanent appointments, Dr. Antonus Valavanis, Dr Sarah Miller and Dr Elena Ray-Chaudhuri.

Some of our members see Dr Graham Warner, Consultant Neurologist at RSCH who also sees patients privately.

Amanda aims to see patients every 4 - 8 months between consultant appointments at 6 to 12 month intervals.

These are likely to be telephone consultations at the present time. Amanda is extremely busy seeing 4-6 new patients with PD monthly. To contact her see P 23.



Virtual First Aid

On Tuesday 29th September, our afternoon group was joined by the British Red Cross who gave us a crash course on Basic First Aid Virtual style. 16 of our members joined us and after a short introduction from everyone we were shown a short video on the work of the British Red Cross and how we could help.

We then played **Kim's Game** (which is a memory game) with items from around the house to show us what we could use in case of any emergency, should we need them.

We looked at a photograph of a lady on the floor and discussed what might have happened to her and did we feel capable of helping – our replies were very noncommittal!

We then divided into groups to discuss the management of four common emergency situations – severe bleeding, burns, a suspected fracture and a probable stroke and we will highlight a few important points in their management.

- **Severe bleeding** apply direct pressure to the wound and maintain pressure until help arrives. Elevate the arm or leg if affected.
- Burns -if possible, place under running water until pain relieved, takes at least 10 minutes then cover loosely with cling film
- Fracture support and immobilise if a broken limb, make the casualty as comfortable as possible
- Stroke remember FAST an acronym used as a mnemonic to give rapid help to someone suffering a stroke

F=Facial drooping,

A= Arm weakness.

S=Speech difficulties and

T= Time to call emergency services.

Note the time of the first symptom if possible, the patient should reach hospital within an hour for the best chance of recovery, the so-called **golden hour**.

Nikki showed us the photograph of the lady again and asked if we now felt better equipped to deal with the incident. The answer this time was yes.

It was a very enjoyable and educational session with many of the group feeling a lot more confident should they ever have to deal with a First Aid incident than they had been at the beginning of the training.

Our huge vote of thanks goes to Nikki, James, and Nigel our course trainers from British Red Cross and Myra for organising the session. The afternoon was a great success and was repeated in October for the WAGs.

Basic Rules of First Aid

- Check your surroundings are safe. Do not put yourself or the injured person at risk
- 2. Decide if you or the injured person needs medical aid; ask for advice if not sure
- Do not panic. Stay Calm. Reassure the injured person. If they are severely injured and under shock keep them warm. Stay with the injured person, keep them comfortable and do not move them if you suspect an injury to the back or neck.
 - Call for medical help.
- 4. Tell the medical experts as much information about the accident and symptoms as you can. Also, if you know about allergies or blood group or vaccinations or medical condition of the person (i.e. if they are on medication)
- 5. Wash your hands before you apply first aid and wear disposable gloves if possible, to protect yourself and prevent infection.
- 6. Stem bleeding. Elevate if possible.
- 7. Clean the wound(s) carefully, wiping away any dirt and grit. Use a clean cotton cloth and rinse with cold water, then pat area dry before applying a clean dressing. **DO NOT** attempt to remove embedded objects.
- 8. Keep your first aid supplies up to date. Do not forget to replace any items you use from your first aid kit and check expiry dates regularly.

Sharyn Bullen & Anne Folkes

Zoom meeting November 24th, 2020

It was not possible to hold our immensely popular 'cream tea and bowls' meeting in September this year but instead Shirley Williams, who normally coaches all our members who wish to try their hand. gave us a vey interesting talk on the history of the

club and of bowling.



Shirley's late husband, Leonard was involved in the planning and development of the bowling green and adjacent club house which opened in the late 1990s. It is a popular facility and welcomes members who play all year as well as those

who join for the winter months when they cannot play on grass.

It is the only artificial all- weather green in Surrey, it has a special synthetic surface that was imported from Australia. It is levelled by laser and meets World Bowls Approval Standards. The surface bowls like a grass green and runs at the speed of the best grass greens. It only needs rolling and spraying against fungus once a year, The Club provides coaching for those who wish to learn or improve their game and runs competitions as well as entering national events,

We all hope that Covid-19 will be under control and we can play again next September. Anne Folkes

Christmas in September: Parkinsong Voices tune up!

It's not just supermarkets who are thinking Christmas in September – this year Emily Bollon made all her choirs concentrate on it too! Em wanted to reclaim 2020 as a year that had some positive outcomes and decided to produce a virtual Christmas concert in spite of all rehearsing having to take place through Zoom. This was no mean feat and a very ambitious project! Over 100 people in 5 choirs started by learning "When I Think Upon Christmas" complete with harmonies. Learning it in our Friday sessions was one thing but of course it also had to be recorded and videoed which was an individual choice. Some of us decided that we would give it a go so whilst hearing our part – soprano, alto or tenor – through head phones, we sang along, recording. This ensured that when all recordings were mixed together, they synchronised. Playback was a strange sensation: hearing yourself speak on a recording sounds odd enough but we are even less used to hearing ourselves sing as others hear us!

It took me several attempts but finally decided it was as good as it was going to get, and took comfort in the fact that in the final mix individual voices would not be identifiable! The recording was duly transferred to Emily and her team to blend which was a huge undertaking. All participants were provided with a commemorative T shirt which we wore for the video recording. This time we sang or mimed along to the soundtrack, remembering to smile as we 'sang', whilst videoing ourselves. If this was too daunting, Emily and helpers came to do the recording.

All the choirs also recorded an individual carol. Parkinsong Voices did the accompanying actions to MbM's Gospel Choir's performance of "Noel." This time Parkinson's T shirts and Christmas accessories were the order of the day and we swayed, danced around or waved our hands until the final line of the chorus when the MbM singers offered a token candle to the camera and we reached to the camera to receive it, a technique which worked wonderfully and was very moving. The concert and the individual items and interviews are all available to view on YouTube at https://www.youtube.com/playlist?list=PLXAdf6zaOmrqnZY-aj4zaxnmzgSKQ49jo

In the weeks before the actual concert, Em and the project manager Lucy interviewed representatives from each choir about their choir experiences and how that had been affected by lockdown and virtual meetings. The spokespeople for the two charity choirs, Parkinsong Voices and Topic of Cancer, also promoted their causes as there are just giving pages for both and viewers would be encouraged to donate throughout the concert. Emily's target was to raise £3000 for each cause. As I write this, (December 16th) over £4500 has been raised for our local group and over £2600 for ToC, plus gift aid. The local group had paid towards the production costs but have received a great return on that investment.

All credit and thanks to Emily and her team who did a fantastic job turning all these individual recordings into the professional concert that streamed on December 12th. I think we were all blown away by how good it sounded and how moving it was. It was a challenge to participate but fun – a fitting description for 'Voices' itself as most who join don't think they can sing. If you fall into that category, give it a go. Singing lifts the mood, exercises lungs and vocal chords, and improves breath control. Virtual classes are a good place to start as no one else can hear you so you can sing your heart out and gain confidence in the privacy of your own home! Contact emily@motivationbymusic.com to join.

Valerie Box

Son of a new member of Guildford and South Surrey Parkinson's local group raises over £4000 for Parkinson's UK

When Catherine Cork was diagnosed with Parkinson's and joined the local group, neither she nor anyone else would have believed that within weeks, that diagnosis would have spurred an epic cycle ride that raised over £4000 for Parkinson's UK.

Lockdown and a knee operation had turned Buckinghamshire based Julian Cork, COO of a specialist mortgage lending company, into an inactive person with a growing addiction for chocolate digestives. Weight was going on, so Julian decided to take up cycling, first into the Chilterns and then perhaps to attempt a longer ride. While he was still contemplating tackling a long-distance ride, his mother, who lives in Wonersh, was diagnosed with Parkinson's.



That life changing diagnosis was the stimulus for Julian and 3 companions to cycle from Lands End to John O'Groats, 1,554.69 km (959.8 miles), which they achieved in 67 hours and 40 minutes. Julian set up a just giving page for sponsorship to raise as much as possible for Parkinson's UK.

Parkinson's is the second most common degenerative neurological condition after Alzheimer's. The visible symptoms of tremor, slowness, stiffness, drooped posture, and freezing when walking are easily recognised but there are over 40 different symptoms which people with PD might experience, many of which are not visible. At present there is no cure, nor any treatment that can slow, stop, or reverse the relentless progression

of the condition.

Julian hopes that the money he is raising can support vital research so that better treatments or a cure will be found. His contribution is especially valuable now as lockdown has resulted in the cancellation of most large fund-raising events. The charity's income is seriously reduced whilst demand on its services has increased. Parkinson's can be a very isolating condition even in normal times so the various online activities arranged by the local groups have played a vital role in maintaining mental and physical wellbeing.

Julian's just giving page is still open and gives lots of information about his epic ride. All donations would be gratefully received: https://www.justgiving.com/fundraising/lejog-august-2020.

Alternatively, anyone wishing to contribute directly to the work of Catherine's local group, which subsidises many activities including exercise classes and a singing group, can do so through the group's website

<u>www.guildfordparkinsons.org.uk</u> where there are full instructions including a gift aid declaration form.



Catherine Cork is coming to terms with her diagnosis and is justly proud of her son's achievement. No one should have to face Parkinson's alone. Everyone with PD needs support, be it from family, friends or from Parkinson's UK through its help line and local groups. Catherine certainly has Julian's full support as well as that of the Guildford and South Surrey branch of Parkinson's UK.

Article from the Surrey Advertiser and Haslemere Herald.

A message from Sue Buckland

It seems an exceptionally long time ago that we were doing our weekly classes, at the British Legion in West Clandon. The pandemic has certainly changed the way that we have all been exercising. But as we all know physical activity is a great way to help to maintain your health and well being.

I trust you all have been receiving the weekly PACET online classes and more recently the Christmas themed ones (I will be checking to see if you have completed the 12 days of Christmas) and I hope they have been some solace to you all, in these uncertain times.

If you are not signed up for the PACET classes or would like to know more about the online exercise classes, please feel free to get in touch; sue@pilatesperfection.co.uk

JAMES PARKINSON (1755-1824)

Just over 200 years ago James Parkinson published a short monograph entitled 'An essay on the Shaking Palsy', which contains the first clear technical description of the shaking palsy or *paralysis agitans*, which we now refer to as Parkinson's disease. The value of the essay was not fully recognised during Parkinson's lifetime. His remarkably precise description "involuntary tremulous motion, with lessened muscular power in parts not in action and even when supported; with a propensity to bend the trunk forwards, and to pass through walking to a running pace: the sensors and the Intellect being uninjured" all too familiar to us now, testifies to his keen sense of observation.

The publication was largely ignored until the celebrated French neurologist, Jean--Martin Charcot (1825-1893) rediscovered it some 50 years after its publication. Based on his clinical observations of the disease Charcot proposed the name *La Maladie de Parkinson*.

But who was James Parkinson? Born on April 11th, 1755 he was the son of John Parkinson, a well-known family doctor who practised in Hoxton for many years. James studied at the London Hospital for six months and was then apprenticed as a surgeon and apothecary to his father, qualifying as a surgeon in 1784. During this time, he married Mary Dale, a young Shoreditch lady who was also interested in medicine and geology. Seven children were born of this marriage, three died in infancy, four reached adulthood and the second son, James William Keith Parkinson, joined his father in his medical practice. They both took care of the local poor population as well as wealthy patients from their own comfortable home in what was a poor part of London. Besides his flourishing medical practice, early in his career he developed a wide range of interests from politics to geology. Influenced by the political and social turmoil of the French Revolution, he became a strong advocate for the underprivileged and an outspoken critic of the government of William Pitt the younger.

At the beginning of the 19th century, he turned away from his political career and he put his efforts into medical and social issues. His major concern was the wellbeing of his fellow citizens, especially the poor. He started writing medical booklets that provided general information on measures designed to preserve individual and social

health. James Parkinson also contributed significantly to medical literature including a description of disease of the appendix which is now recognised as the earliest reference to appendicitis in English medical literature

He was very worried by epidemics of typhus fever. In 1815 he and his son, who were both Parish doctors, convinced the Parish Board of Trustees to build two separate fever wards to prevent the spread of the typhus epidemic throughout Shoreditch. It was remarkably effective. In 1824 he summarised his views on this issue in an article published in the London Medical Repository, this was to be his last medical paper.

James Parkinson was one of the most singular figures of his time which spanned the American Revolution, the French Revolution and the Napoleonic Wars. He was successively or concurrently a virulent political activist, a popular medical writer, a scholarly medical contributor, a highly appreciated parish doctor, a prominent amateur chemist, a devoted mad house doctor and a renowned palaeontologist. It was this branch of geology that brought Parkinson fame in his lifetime. He was, like many physicians of the 18th century, an insatiable collector of fossils, minerals, and shells. In 1804 He published his magnum opus – *Organic remains of a former world*. Two more volumes followed, and Parkinson's *Organic Remains* became the standard textbook of palaeontology in England. In 1807 together with 12 other scientists he founded the Geological Society of London.

In 1824 James Parkinson died aged 69 following a stroke, he was buried in the cemetery of St Leonard's Church, Shoreditch, and a plaque to him in the church commemorates his accomplishments. Of greater interest, perhaps, are some of his fossils displayed in the Geology Section of the Natural History Museum including *Parkinsonia parkinsonia*. Parkinsonia is a genus of ammonites belonging to the family Parkinsoniidae. These were actively swimming aquatic organisms alive in the mid-Jurassic period. A fitting memorial to a remarkable man.



Anne Folkes

The church is mentioned in the line "When I grow rich, say the bells of Shoreditch" from the nursery rhyme Oranges and Lemons.

Zoom Meetings for Carers

The Zoom meetings for Carers are monthly and are held on the second Monday of the month at 2pm for one hour. Of course, participants can drop in and out as they wish. It is a small group which is working well and has been well received.

New participants to the group would be very welcome. However, it is most appropriate for the partners of those who are in the mid to later stages of their Parkinson's Journey. As a small number works best for this a second group could be formed if required.

I am aware that some Carers would like the lunches, that I facilitated in the past, to be resumed once we are back to normal times. Friendships made by the Zoom meetings will enable lunches or coffee mornings etc. to take place informally.

If you would like to join or just to discuss, please do email me or give me a ring.

Myra Newnes-Smith

01483 422440

mnsmith@guildfordparkinsons.org.uk

Tips discussed at the Carers Zoom group!

Baby Monitors – if you sleep in separate rooms.

Bed and Chair exit alarms to prevent falls. www.austinmedical.co.uk

Window and door alarms. Widely available and inexpensive.

Going into hospital – Parkinsons UK have an excellent booklet. It includes a double-sided page - one side with headings such as speech, walking, personal care etc for you to fill in your particular issues and the other side is for medication. Pop it into a plastic sleeve for the bedside, see www.parkinsons.org.uk - put 'Going into Hospital when you have Parkinson's Disease' in the search box.

Longer Respite Care Opportunity for 2021!

Your committee is very much aware of the ongoing burden placed on our members' Carers. We had agreed earlier this year to use some of the remaining Legacy money to fund some **longer respite care provision**. We are now ready to launch the scheme which will enable some Carers to have a well-earned break – a few days, perhaps, or even a whole week – during 2021.

The offer is for **up to £1,500** towards an individual's care. A budget, enabling around five or more members to benefit, has been set aside for this and grants will be allocated on a **first come first served** basis. Requests (no more than one per person!) can be put in for a share of the budget from **1 February 2021.** If your application is successful, there is no need to make use of it immediately. For instance, you may already have something planned for later in the year or simply want a break in the warmer weather.

It will be your responsibility to find a suitable respite placement, either with a care home or by a care organisation offering overnight care in your own home. It should be from a recognised home or agency, not an informal arrangement. Before applying, you should have identified a suitable provider and have registered your interest with them. You do not need to have paid a deposit at this stage.

We hope very much that some of you will take up this offer. If you wish to discuss further, with no commitment, then please contact Myra Newnes Smith on 01483 422440 or email mnsmith@guildfordparkinsons.org.uk.

Myra can also send you more details and a simple application form to complete.

Updates: Cobham Brass Band

The Guildford and South Surrey branch of Parkinson's UK received £704.09 from the Cobham Brass Band as a result of being one of their charities for 2019/20. The band was so impressed by our support at their events that they decided to make us their sole charity for 2020/21. Even though Covid restrictions have limited their performances, they have found a way of continuing their support for us. At their open-air Christmas performances in venues ranging from outside the Ivy restaurant to the Cobham service station on the M25, they have set up a Crowdfunder project to enable them to support local charities including our local group.

As soon as they let us know when we can join them again at events, the dates and venues will go on our website: guildfordparkinsons.org.uk

We first met Sharon in 2018 when she won the Aldershot and Underwood Bowls Club Ladies Single Championship Individual trophy. Playing has been difficult this summer under COVID-19 regulations but Sharon and her husband won a pairs trophy. It was the 90th anniversary of their club but no grand celebration was possible. Like many of us Sharon has found solace in her garden.

Our very own Arboretum

By Sharon Blight (Aldershot) 2020

2020 January we could do what we liked.

February it rained morning noon and night,

news of a virus so bad in China

back then we were free nothing could be finer!

March now we get rumbled by Covid nineteen

Should we or shouldn't we, was becoming the theme...

Mid-March now and lock down begins
we must take charge and make sure this virus never wins.

April it's Easter, no egg hunts this year
Instead there is a whopping great virus out there for us to fear.

Nothing is open no restaurants no cafes, no bars,

Technically we must not even make use of our motorcars.

No, no football, not even lawn bowls,

Oh, and did I mention there's been a shortage of loo rolls.

Six weeks of sunshine such a pleasure of mine

I will drink to that day after day with a glass of wine.

We toil in our garden until the end of the day,

where has time gone, we are now in May

Sadly, over this period six people I know have passed one from this coronavirus and five from being poorly with other illnesses to them all, I say God Bless!

I hope it's not long now before our people can come

It would cheer me up I would not be so glum

Even if it's in the garden that we have to meet them,

They too can share in the beauty of our homegrown ARBORETUM



Obituary notice.

Patrick Robson died on October 31st age 85, Patrick and I received the diagnosis of Parkinson's on the same day in 2012. I had known Jean and Patrick for many years as Jean and I were colleagues at RSCH and it was helpful to know someone in the same position as myself and they encouraged me to attend the Tuesday meetings and for

as long as Patrick was able we attended physiotherapy together. The last event Patrick was able to attend was the Christmas lunch in 2019 but even then, his wicked sense of humour still came through. Jean and Patrick moved to Merrow with their daughter and son in the late 1970s and I have many happy memories of charitable events held in their garden and of Patrick's beloved classic car — an Imperial Maroon Jaguar XK 140 In his youth Patrick was a keen hockey player and founded a club



called the Ladykillers and the players wore red, so his coffin bore red roses and carnations

Patrick spent most of his working life in electronic rental in Teddington where he was trustee of Teddington Cottage Hospital. On moving to Merrow Patrick became a very staunch supporter of the Merrow Residents Association and was chairman between 1995 and 1998 retiring from the Executive Committee in 2011.

Patrick dealt with planning matters for the Association for very many years in the most meticulous and methodical manner. He was also a Trustee of Merrow Village hall and involved with the Tennis Club and he is sadly missed in the local community.

Anne Folkes

A SIMPLE WAY to RAISE MONEY for PARKINSON'S

I have started saving ink cartridges for recycling.

Other than raising money for good causes, recycling ink cartridges means less non-biodegradable components being dumped in landfill sites. Any hazardous and precious materials are recovered, and in many instances new jobs are created.

The recycling company operates a 0% landfill policy and any cartridge they cannot recycle or recover, will be turned into energy. Most importantly your cartridges will not end up in landfill.

WANTED LIST—please bring your empty cartridges to the Tuesday afternoon meetings when we restart.





Laser and toner cartridges not accepted.

With many thanks, Anne Folkes

IMPORTANT MESSAGE

NEW way of contacting your Parkinson's Local Adviser

Dial the freephone number for Parkinson's UK 0808 800 0303.

(Monday -Friday 9am-7pm, Saturday 10 am - 1pm) or email hello@parkinsons.org.uk

If you have already met JACKIE WINGRAVE or the PLA for your area mention their name and ask to be referred, If you have not previously met a PLA just ask for a referral.

(The helpline advisers can provide information and support in an emergency)



Stay safe and avoid waiting in A&E - just call 111 first

People in Surrey who need urgent NHS care are being asked to call NHS 111 **before** they decide

to walk into the local Emergency Department (ED), or as many people know it, A&E.

The new approach will ensure that patients can access the clinical service they need, first time. It will help to us to maintain social distancing, reduce the risk of spreading Covid-19 and keep patients and staff as safe as possible. This service went live on December 1st, 2020.

This is specifically for people who are not in serious danger but need urgent attention. The fastest way to get the right care is to contact NHS 111 They will be spoken to by a trained professional and a clinician if needed. If it is decided you need to go to the emergency department then you will be given a suitable time to attend and staff at the hospital will be expecting you. That means less waiting around and faster treatment.

Anyone who attends the emergency department (A&E) without an appointment from NHS 111 will still be seen but could be directed to other services for treatment, but you will have a longer wait.

People with life threatening conditions that need emergency attention should still call 999

Committee Members

Chair

Niki Tompkinson

ntompkinson@guildfordparkinsons.org.uk

Vice-Chair (and Referrals and Activities)

Hilary Austin hillawrie@googlemail.com

Treasurer

Steve Heron sheron@guildfordparkinsons.org.uk

Membership Secretary

John Oldham joldham@guildfordparkinsons.org.uk

Secretary

Sharyn Bullen sbullen@guildfordparkinsons.org.uk

Committee members

Myra Newnes-Smith (Carers' issues)

mnsmith@guildfordparkinsons.org.uk

Margaret Westwood (Minutes secretary)

westwood.m@talktalk.net

Anne Folkes (Editor of The Park)

afolkes@guildfordparkinsons.org.uk

Parkinson's Nurse Specialist

If you wish to speak to **AMANDA DODSON** phone the CCC on **01483 362020** to be booked in.

Do **NOT** use her mobile number.

This will enable an audit of Amanda's excessive workload and help to build a case for extra help.

CCC - This is a hub where all incoming calls to the whole Guildford and Waverley community area can be triaged – it is open 8am -8pm 7 days a week for both professionals and patients/carers. On that number if people are having problems that might require a therapist a district nurse or some care it can be used. The calls are initially taken by admin staff who can access all out diaries and book both clinic and phone calls. There are also clinicians - Nurses and therapists available - who if the problem is complex – such as falls can help sort out a way forward. It is a useful number to have.

Useful Information

Parkinson's Local Advisers see P 22

Guildford, Runnymede, Surrey Heath, Waverley and Woking

Jackie Wingrave 0808 800 0303

Reigate, North Tandridge and East Surrey

Nicky Lawrence-Gravestock 0808 800 0303

Mole Valley, Dorking, Kingston, Spelthorne, Elmbridge, Epsom and Fwell

Vacant

Mid Sussex, Tandridge, Horsham, Crawley and East Grinstead

Carol Coupe 0808 800 0303

Parkinson's Nurse Specialists (NHS)

Milford Hospital Assessment Unit

Amanda Dodson 01483 362020

Email: rsch.gw.ms.parks@nhs.net

North Surrey. Farnham Hospital Outpatients

Rose McKinley 01483 783481

Email: rsch.gw.ms.parks@nhs.net

Parkinson's UK Helpline Service 0808 800 0303

Lines open: Monday to Friday 9.00 am-8.00 pm

National Website

www.parkinsons.org.uk

Local website

www.guildfordparkinsons.org.uk

Don't forget to stay informed of classes, events, meetings and much more on our own Guildford website..