

Main updates from your committee:

- AGM 17th October Chair, Secretary, voted in, Treasurer stepped down, position to be filled urgently, all other committee members re-elected
- PPU5 Fundraiser 24th September impressive total raised, £5,689
- Walking Group recommenced
- Focus Group continuing to progress activities and events program for 2023
- Branch website work on hold from HQ

At the AGM, Stuart Keay stepped down after 7 years in the post. All of the Committee wish to thank Stuart very much for his long service and guidance looking after the Branch accounts which are a solid platform for future planning. Past Chairman, Mike Steven's, a constant guide to my tenure as Chair was also present. Neil Smart, Southwest Area Development Manager officiated. To bring us back into sync following impact of the pandemic, the AGM will once again be in the first quarter of the year, it is booked for 20th March 2023.

PPU5 was the big event of last month raising almost £5,700. My thanks go to Dave Trinder and friends for all of their hard work. See Fundraising section for more details.

The Walking Group was able to get the going again, thanks go to Richard and Lyn Alcock for their organising work, a couple of pictures are available in the Events section for your interest. Please attend when you can, they are very good meet ups, enjoyed by all.

The Focus Group met again in September to discuss and review options and considerations on how to encourage us all to meet up more often socially. It means a lot to meet friends and chat about whatever our life issues are; good, bad, and indifferent and to share them with likeminded people, to consider our own and other people's ways of dealing with things. To relax and to laugh, looking at life in a good positive way – to enjoy every day.

Branch Website News - HQ has asked us not to proceed just yet with our plans for a branch website. Parkinson's UK General Counsel is working on an ethical issue related to volunteers (and / or service providers) undertaking a role for branches but also paying a professional (Parkinson's) to undertake the same role. Our Branch have funding and a solution in waiting for our own website, but we cannot proceed until advised. This is very unfortunate as we are desperate for our own website to enable much greater degree of communication and information flow for all our members. No timescales have been advised on a way forward as yet.

Your committee aim to encourage people to meet up socially, and for these social gatherings to grow organically, so that they become informal, regular, enjoyable social get togethers.

There's lots more to read in this edition, we spoke with Tim Bird about PD Warrior and how exercise is a very important part of life (more details in the Living Well section). Also, we spoke with Deb Thurman, a Parkinson's Nurse Practitioner, she is booked to come and speak to us next year. Deb also informed us about other similar work that is going on for other charities such as the MSA Trust (Multiple System Atrophy) and PSP (Progressive Supranuclear Palsy). Working with similar local charities is yet to be explored to see if we can share experience from work that they do.

I continue to hold networking meetings with members of the Cirencester Chamber of Commerce, in the hope of soliciting some fundraising, support and possible volunteer opportunities. Some companies, as part of their Corporate Social Responsibility policies, support local charities by providing volunteers. It is useful to make them aware of us, and hopefully, get a little extra horsepower in organising events, or providing venues / facilities or activities.

It is important for the Branch that we fill the following Committee roles as soon as possible:

- Treasurer
- Social / Fundraising Volunteer
- Membership Secretary

Thank you for reading and enjoy every day!

Kevin Young,

Branch Chairman

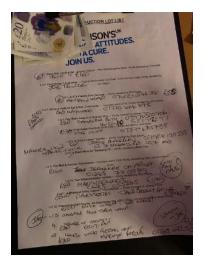
Fundraising

The main fundraising update this month is due to the outstanding efforts of Dave Trinder and his friends in organising the PPU5 fundraiser event 24th September in Cirencester, sponsored by Greg Power. The event included entertainment from three local bands, a raffle, and an auction of donated prizes, including holidays in Spain & Devon, a golf day at Cirencester Golf club, a piece of art from a local artist, plus many others.

The total raised at the event was **£5,689**. Our thanks go to Dave and his team who organise these events annually.



One of the 3 bands who performed



Auction bids



Andrew Heap (left) was MC on the night and is pictured here along with Dave Trinder (2nd left) the organiser of PPU5. Dave, however, could not attend the event due to a mobility problem. A huge thank you too to the Sponsor Greg Power and Kelly-Ann Bradley along with Jim Vincent (missing from the photograph above) who were instrumental in the planning and success of the whole PPU5 event.

Eve Clements, Lady Captain of Minchinhampton Old Course Golf Club very kindly donated £300 which was given to support members in our area. This was raised at the Ladies 'Drive in' and a Military Whist event held at the golf club. Our thanks go to Eve for her generous work.

Note: We have established a process for In-Memoriam donations through three other Funeral Directors from Stroud, Nailsworth and Cirencester to cater for bereaved family requests to support Parkinson's.

All monies raised for our branch from fundraising, or donations is consolidated into a Parkinson's Charitable account (Barclay's bank). The Committee have the responsibility for managing the funds in a transparent way. The funds are used to support the branch activities and costs, as well as donations to research projects. The accounts are open for review by any member at any time and were reviewed and approved at the AGM (17th October).

Events / Activities

This section is an update on some of our recent events and activities, and a summary of the remaining planned events for the rest of the year and a look ahead at what's being planned. If you want to attend any activity, please contact your committee.

WALKING GROUP

The walking group restarted on the 1st October, with a walk around Minchinhampton Common, thanks to the help and support given by Richard and Lyn Alcock (<u>richard.alcock@randl.clara.co.uk</u>), we all enjoyed the sunshine followed by lunch at the Old Lodge. The feedback received was very encouraging, another walk will be coordinated sometime soon. If you wish to take part, please let us know.



A couple of pictures of the lovely views from Minchinhampton Common

The Cobalt Health talk on 17th October from Jenny and Irene on the latest diagnostic technology to enable earlier and more accurate diagnosis was very interesting. Mainly used on Cancer and Dementia patients and some Parkinson's patients too. They explained that their state-of-the-art technology and equipment plus the research they are able to contribute to from their work is helping to understand how patients can be treated / helped at the earliest possible stage in their condition.

Last of the 2022 pre-booked events for members / care supporters:

Next Members meeting 21st November 2pm-4pm

St. Lawrences Church Hall, Cirencester

We have 2 activities:

- Dr Tina Smith PGCE(PCET), FHEA a Senior Lecturer in Biomechanics from Wolverhampton University Health & Wellbeing Faculty will be talking to us about her newly funded research project on 'monitoring symptoms of Parkinson's disease to improve quality of life'. She is looking for direct involvement in a Patient and Public Involvement (PPIE) session, <u>you may wish to take part in</u> <u>this!</u>
- Phil Collins Ukulele Workshop an amusing event called "Fun with a G string"

Xmas Lunch 12th December at Minchinhampton Golf Club

Menu has been circulated, please contact Karen Young (<u>cirenstroudpuk@yahoo.com</u>) to book a place and confirm selection. This event has been subsidised by the Branch for all members. Non-members can also attend but at the non-subsidised price.

Cam & Dursley

Only two meetings left this year, 17th November – the Dogs and Cats Charity are bringing a rescue dog

1st December there will be a mince pie and coffee morning, also a Tombola stall where you can pick up some Xmas presents, all welcome. Contact Diane Shelley.

A few planned events are still to take place before new activities and events for 2023 commence.



Details for the 2023 program are beginning to take shape, here's a few of the confirmed bookings

January 16th – a talk from Louise Wilson about the benefits of utilising Longfield's Health & Wellbeing Centre (all services offered are free of charge)

February 20th – Tim Bird a talk and demonstrations around PD Warrior / Tai Chi / boxing / wellness & physical activities

March 20th – Branch AGM plus Mary Burton – a talk / demonstration on benefits of physio and exercise

April 17th – a talk from Ann Henderson (Glos. Parkinson's Advisory Service) + Deb Thurman (Parkinson's Specialist Practitioner)

May 15th – Sue Mills, Parkinson's UK – a demonstration of the latest Parkinson's living aids

June to October - yet to be confirmed

November 20th – Mark Cummings from BBC Radio Gloucestershire

December 18th – Xmas Lunch

Other interesting bookings will be here very soon, but here's a flavour of what's being considered by your Focus Group, venues for these are to be spread around the branch area – coming closer to you, our members: -

- Wednesday coffee Mornings and a bacon roll at Cirencester Baptist Church (starts 26th Oct)
- PD Warrior exercise classes from Tim Bird
- Physio from Mary Burton (Dursley area)
- Parkinson's Dance (currently looking for a new venue for this)
- More walking groups
- Table Tennis group activities
- Carer drink and a chat night out
- Longfield House wellbeing events
- A tour of Corinium Museum with wine and nibbles afterwards
- Stroud Brewery tour followed by lunch and a chat
- Potentially, a tour of Renishaw to understand the technology behind the Deep Brain Stimulation probe

- Dr Fletcher / Parkinson's Nurse talks
- Future collaborations with the PSP charity and with Jill Lyons from the MSA Trust

TRANSPORTATION

It is a key aim of the Committee to increase attendance at all events and activities, to that end, we are working on options to support our members in getting to/from events. We are working with local firms to check what support and costs are available to make it work. More on this in the next edition.

BRANCH WEBSITE

Work is underway to develop a website that eventually will be the hub of the Branch communications, replacing this newsletter. We are working with a member organisation from the Cirencester Chamber of Commerce, who can develop and maintain a website for us. This item is a key discussion point on the next Committee meeting Agenda. We will keep you posted as things develop.

CLUBBING TOGETHER

This is an annual Parkinson's golf day held at Cirencester Golf Club, the next event is Friday 19th May 2023. The Branch are now assisting the Clubbing Together committee with this fundraising event. Money raised will mainly go direct to Parkinson's HQ for research, other donated or collected funds on the day will be donated to the Branch to help with supporting planned events and activities. There will be further updates on this as planning develops ahead of the golf day.

Keep watching this space for bookings of activities to attend and get involved with – if you have ideas or wish to help on the Focus Group, please let your committee know.

Membership

This section provides an update on our membership.

We have 121 members listed including 40 members who are partners / care & support but there are many more people living with Parkinson's in our Branch area who are unaware of the Branch and support activities. The branch details will be given to all Parkinson's Nurses and consultant surgeries as well as medical practices for distribution to newly diagnosed patients.

Living Well

This section is dedicated to stories, people or organisations that may interest you relating to living well with Parkinson's.

A couple of interesting topics here, firstly **Helping Old Friends** is a local organisation who provide personal assistants and companionship services to anyone who would like to remain independent in their own homes. They can provide a tailor-made service to suit your individual needs and budget. Find them at this link: <u>Helping Old Friends Helping Old Friends</u> they can setup regular visits to suit your requirements with well-matched companions who will listen, help do the odd jobs or just be there for you. Through our advanced scheduling software, we can ensure that you will get the visit when and where you want them with a Companion best suited to your character. Call them on 01793 550895.

Here's an overview of **Tim Bird** for your information. We are working with Tim to introduce a taster session and hopefully on-going physical activity sessions for small groups. He will be with us 20th Feb.

"I'm an exercise specialist based in Cirenceste, first became involved with working with clients with Parkinson's through running falls prevention classes in the community in 2013. Several of my class members had Parkinson's. At around the same time I took on a one-to-one client for cardiac rehabilitation who also had Parkinson's and I worked with him up until his death earlier this year. In June 2018, to increase my knowledge and Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. A charity registered in England and Wales (258197) and in Scotland (SC037554)

understanding of Parkinson's, I attended the inaugural Parkinson's Exercise Professionals Study day (The Exercise Hub) from which the Exercise Framework for PD was developed (see <u>parkinsons.org.uk</u> The Exercise Framework). At this study day I was introduced to PD Warrior and since then have completed the Level 2 PD Warrior instructor training and for the last 2 years have been running a weekly exercise class for clients with mild to moderate Parkinson's. I also provide one to one training for clients with PD. In addition, as a postural stability instructor, recognised by the NHS falls prevention service, I run 3 community strength and balance classes for clients at risk of falling or with a fear of falling.

Some background on PD Warrior.

PD warrior is specifically for people with mild to moderate PD. It is a PD specific neuroplasticity-principled exercise programme that shows promise to slow disease progression, improve symptoms, restore function, and increase longevity and quality of life. The 7 core principles of PD warrior are: specificity, salience (meaningful), high effort, powerful, fun, complex and frequency. To maximise the potential benefits of PD warrior and similar programmes (PWR, Power for Parkinson's) participants need to be motivated, able to work hard and be prepared to commit to regular exercise forever! It's not a cure or a quick fix, it's a lifestyle choice.

For full details of PD Warrior see their website - pdwarrior.com

The principles of PD warrior are similar to several other PD-specific exercise programs, eg Parkinson's Wellness and Recovery (PWR) and Power for Parkinson's.

Other background

For details of Parkinson's Wellness and Recovery (PWR) see <u>https://www.pwr4life.org</u>. At last week's Parkinson's UK Exercise Network event that I attended in London we had a very worthwhile presentation from Dr Becky Farley, who runs PWR.

During lockdown, I was one of a number of physiotherapists and exercise instructors who were asked by Parkinson's UK to produce a video to enable PWP to follow along at home. Search YouTube - 'Parkinson's UK| Vigorous Intensity Aerobics - Tim Bird' and hopefully you can find it!

I am also a Tai Chi instructor (I am currently running a Tai Chi course for beginners and hope to run a second course next year) and a Boxercise instructor (boxing for exercise) - boxing has been shown to be effective exercise for PWP (for example see Rock Steady Boxing)

My current availability to offer additional Parkinson's specific exercise programmes is limited as I only work Tue, Wed and Thu (I am 64 and semi-retired, but expect to continue working for a few more years!). I would welcome new members to my existing group which meets at Stratton Village Hall, Stratton, Cirencester on Wednesdays 1215 to 1pm. I do have some availability at other times in the week, but I try and restrict my working day to between 9am and 5pm (sadly not ideal for those wanting to exercise after work)

Finally, I can confirm that I would be happy to come and chat to your members about exercise for people with mild to moderate PD and maybe demonstrate some elements of PD warrior or Tai Chi or boxing!"

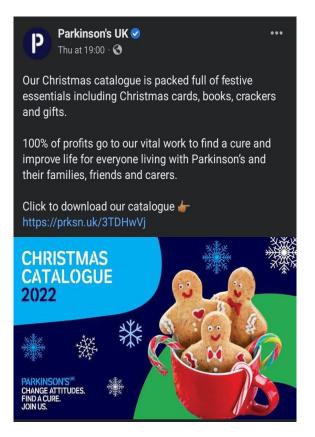
A link to Live Well with Parkinson's

Web pages full of information on booking onto online sessions of different speaker sessions: -

https://www.livewellwithparkinsons.uk/

And a story worth reading relating to Probiotic Supplements Found to Ease Parkinson's Constipation in Trial can be found at this link <u>https://parkinsonsnewstoday.com/news/probiotic-supplements-ease-parkinsons-constipation-small-trial/</u>

CHRISTMAS 2022



Christmas cards for sale, available for order from the PUK shop - see link below:



Christmas cards

It costs just £1 to play and each ticket you buy will help improve the lives of people living with Parkinson's.

Buy your tickets today ∠ <u>https://prksn.uk/3ekDIcC</u>

<u>Useful Information (keep for your reference)</u>

This final section will be dedicated to contact details of people and organisation that you may wish to use for help, support, activities, or information. We will keep adding to this list as information becomes known and keep up to date when things change.

Branch Contacts

Branch email - cirenstroudpuk@yahoo.com

Chair – Kevin Young cirenstroudpuk@yahoo.com

Treasurer - POSITION AVAILABLE - please contact Branch Chair if anyone can help

Secretary – Karen Young cirenstroudpuk@yahoo.com

Local Group Coordinator (Cam) – Diane Shelley <u>dianeshelley@btinternet.com</u>

Membership Secretary – **POSITION AVAILABLE** – please contact Branch Chair if anyone can help

Social / Fundraising Secretary – **POSITION AVAILABLE** – please contact Branch Chair if anyone can help

Committee Volunteers – Steven Goldblatt, Karen Brookes, Angie Fenton

<u>**Cirencester and Stroud Branch Website**</u> – this is in construction, but we aim to have one similar to this one at Parkinson's Newbury – check theirs at this address <u>www.newburyparkinsons.org.uk</u> please feedback any comments to your committee.

Branch Meetings (at the moment)

Committee meetings – 4th Monday each month (Frampton Mansell Village Hall)

Member's meetings – 3rd Monday each month (St. Lawrences, Cirencester)

Pub Lunch @ The Ram, Bussage – 4th Tuesday each month (contact Stuart Keay)

Cam Coffee Mornings – 4th Thursday each month (Cam Parish Council Rooms 4 Noel Lee Way Cam GL11 5PS)

Parkinson's Charity Contacts

Parkinson's UK Southwest Region - Jane Henderson 0344 225 3694 (jhenderson@parkinsons.org.uk)

Parkinson's Fundraising: Aaron Coleman (acoleman@parkinsons.org.uk)

Parkinson's UK Website: http://www.parkinsons.org.uk

Parkinson's UK Helpline: (phone free) 0808 800 0303 or email (hello@parkinsons.org.uk)

Parkinson's Local Advisor Service: contact our helpline on 0808 800 0303 or email hello@parkinsons.org.uk to be put in touch with a local adviser

Parkinson's Nurse Specialist Service: 0300 422 6610 or (<u>ghn-tr.parkinsonsteam@nhs.net</u>)

Cheltenham Branch: www.cheltenhamparkinsons.org.uk/

Organisations and activities that may be what you are looking for in our area

 Everyone Active – An excellent opportunity to join Cirencester Leisure Centre free of charge for anyone with Parkinson's

https://www.parkinsons.org.uk/news/everyone-active-offers-free-membership-people-parkinsonsand-their-carers

- <u>Parkinson's Living Aids</u> offering: a chance to purchase quality everyday living aid products to make life just that little bit easier for people with Parkinson's can be contacted here – <u>www.parkinsons.org.uk/dla</u> (this is the catalogue ordering page, Sue Mills, PUK Trading Manager will be booked to give a talk to us in 2023)
- Longfield's Well-being Centre offering: a very wide range of activities and therapies from 'just diagnosed' onwards and are all completely free of charge can be contacted here Burleigh Lane, Minchinhampton GL5 2PQ, 01453 886868 www.longfield.org.uk
- <u>Carers Hub</u> offering: *support for carers to meet others in a safe place* can be contacted here Bond Mills, Stonehouse GL10 3RF Tel: 0300 111 9000 <u>www.gloucestershirecarershub.co.uk</u>
- <u>Charcot Therapy Centre</u> offering guidance, support, information and therapies to anyone living with or supporting someone who has a neurological or long term condition can be contacted here - 71-75 Frampton Road Gloucester GL1 5QB 01452 419 246 <u>www.thecharcot.org.uk</u>
- <u>The Churn Project</u> offering: people of the Cirencester community free (or at very low cost) support and wellbeing through difficult times when needed including Friendship Café; Family Matters; Memory Club (for anyone with memory problems) can be contacted here 14-16 The Waterloo, Cirencester GL7 2PY Tel: 01285 380038 <u>www.churnproject.org.uk</u>
- <u>Cotswold Friends</u> offering: support to people who do not have access to transport, helping with journey's for medical, social and practical need can be contacted here High Street Moreton-on-Marsh, GL56 0AZ Tel: 01608 651115 for transport bookings <u>www.cotswoldfriends.org</u>
- <u>Megan Baker House</u> offering: sessional services for adults and children with neurological motor disorders using methods of conductive education can be contacted here Orchard Lane, Ledbury, Herefordshire HR8 1BY 01531 633840 <u>www.meganbakerhouse.org.uk</u>
- <u>Walking Football</u> offering: a chance to play football at a slower, safer pace in a fun way regardless of age, proven to improve confidence, coordination and mobility and to make friends can be contacted here Abbeydale Sports and Community Centre GL4 4BL Tel: 0777 989 5832 Email: <u>stuartlangworthy@thewfa.co.uk</u>
- <u>National Trust</u> Discounted and free entry
 <u>https://www.nationaltrust.org.uk/features/access-for-everyone</u>

Essential Companion card - The Essential Companion card makes it simple to bring one or two carers or companions with you, free of charge. Just show the card when you arrive, and your carer(s) or companion(s) won't need to pay an entry fee.

It's in your name so you can bring whomever you like, but even if you don't have an Essential Companion card, you can still bring carers or companions free – the card just makes it quicker and simpler for you.

If you're not a National Trust member, you will still need to pay for your own entry.

- <u>The Young Ones</u> offering: an informal network of working age people living with Parkinson's, playing sports, walking, socialising, 1:1 support when needed contact Alison Anderson on 07775 525 053 to join WhatsApp group550895
- <u>Helping Old Friends</u> offering: *personal assistants and companionship services tailored for you* contact number 01793 <u>www.helpingoldfriends.co.uk</u>