# Parkinson's UK Cirencester & Stroud Branch Minutes of Committee Meeting 5<sup>th</sup> February Siddington Park - Cirencester

#### Attendees:

Kevin Young (KDY) - Chair
Jenny Hoffman (JH) — Treasurer
Steven Goldblatt (SG) — Vice Chair
Kath Clements (KC) — Vice Chair
Karen Young (KY) — Secretary & Membership Sec
Angie Fenton (AF) — Committee Volunteer

#### 1. Welcome & Apologies:

KDY opened the meeting at 6.15pm and welcomed everyone.

Apologies received from Diane Shelley

Also, It is with regret that we have accepted Barry Thornicroft's resignation from the committee due to ill health (see Chairs Report). It was agreed by the Committee to send a note and small gift to thank Barry for his input:

Action: KLY to arrange

#### 2. Minutes from last meeting

The minutes from the last meeting dated 4<sup>th</sup> December were accepted.

#### 3. Matters Arising - Status as of 5<sup>th</sup> Feb 2024 - Updates in red

Original Meeting date	Agenda item no.	Follow up Action required	Resp.	Date:
4th April 2022	4h	Local Business contacts: Review if we want to join Stroud Chamber of Commerce Review in June 23 05/06/23 – need someone local to engage with SCoC, we do not have the capacity at the moment – so defer until Jun '24	AII	Review Jun - 24
25 <sup>th</sup> July 2022	12.4	In Memoriam donations Funeral Director contacts in the branch area to be reviewed. 04/12/23 – update – Details received from BT's son who works as a funeral director in Stroud 05/02/24 – We have added Philip Ford & Sons in Stroud to our contact list	All	Closed
6 <sup>th</sup> Feb	14.4	Joining Pack New Action: Joining pack to be established 2/10/23 KC/SG have met and drafted out a list of what should be in the pack along with an agreed introduction letter. To be finalised and agreed as part of Nov Committee Meeting  04/12/23 – Final drafts of letters will be available for review and approval by the committee for the Jan committee meeting 05/02/24 - Kath still to share with committee before next meeting.  KLY to use same text on welcome email when request come via the website	KC/SG	ASAP
3 <sup>rd</sup> May	9.5	GDPR Training - Diane Shelley - expired on 17/05/2023 KC to assist DS in completing training 04/12/23 – DS struggling with the training website. KC will assist.	KC/DS	Closed

		05/02/24 – Di has now completed the training		
		Note to be issued to Jane with regards to struggles that		
		members may have accessing the Training modules online		
		29/01/24 – see response below: Currently, all volunteer training modules are online only, with the exception of the Advanced Data Protection module (a required module only for certain volunteer roles). Where required, copies of this training can be printed locally by staff contacts. We haven't		
		done a print run for this centrally because we've been informed by our Data Protection Officer that there is going to be another update to the guidance in the coming months.  We're aware that there are volunteers who are unable to complete training online and are taking this into consideration for future planning.		
5 <sup>th</sup> June	7	Programme 23/24 Sue Mills (PUK) was unable to attend the May meeting, so will need to rebook for later in the year. 05/02/24 – Sue booked for Cirencester (19 <sup>th</sup> Aug) & Stroud (9 <sup>th</sup> July)		
		KC to check with DS to ascertain if Sue is to be invited to attend Cam meeting	KC	End Feb
3 <sup>rd</sup> July		Focus Group Meeting KDY to facilitate - suggested date 23 <sup>rd</sup> August & location, Siddington Village 05/02/24 – Need for focus group was discussed, and it was agreed to put on hold for the time being	KDY	Review July 24
		PUK have launched their new strategy for 2023-26: Four priorities:  1. Pushing for excellent health and care. 2. Building your community of support. 3. Getting your treatment faster. 4. Fit for the future.  KDY/SG/KC to look at Branch strategy to ensure it aligns to PUK's 2/10/23 – to be added to Agenda for Nov Meeting 4/12/23 – Reviewed as part of Chair/vice chair meeting and agreed that we could map our activities to the PUK strategy – To be reviewed in 6 months 05/02/24 – See note in Chairs report	KDY	Review in June Chair/vice Chair meeting
2 <sup>nd</sup> Oct	4	It was agreed that the Willow Trust Boat Trip was enjoyed by all and is to be booked for next year:  05/02/24 – Booked for 11 <sup>th</sup> Sept	KLY	Closed
	6	Cam's Report (DS/KC) 3 new members. KC to provide information to add new members to the membership database. 05/02/24 - Received	KC	Closed
	12	Carers Group – JH/SG has suggested that we organise a regular carers group/meeting.	All	Next Meeting

		JH/SG to contact other groups who run this to find a model that would work for our Branch and report back to next full committee meeting.  04/12/23 – JH in contact with other groups/organisations to ascertain what the most successful model is. This is still work in progress. KLY to provide JH with Longfield's Contact details (Louise Wilson)		
		05/02/24 – It has been agreed that a Carers meeting would be held. Meetings will be:  • held every two months,  • alternate timings: Weekday/Sunday afternoon		
		<ul> <li>in a venue where there are two rooms so that Carers/PwP can be in two separate spaces to hold 15- 20 people</li> </ul>		
		<ul> <li>Nice location with reasonably priced beverages</li> <li>Action: All to assist in sourcing a venue –</li> <li>suggestions:</li> <li>Siddington Park – the Pavilion</li> </ul>		
		Minchinhampton Golf club RAU		
	12	Website hits – A question was raised about the number of hits on our website. Post Meeting Note: There is a cost to acquiring the data from the website company – Action: KDY to ascertain costs  04/12/23 – still working with website designers – WIP  05/02/24 – This facility could be made available to us via an upgrade on the website, the upgrade would also give us additional functionality for booking events/activities and direct payment. However, this will increase the annual cost of the website  Action: KDY to put together a case for justification for the upgrade – for discussion at next meeting		Next meeting
4 <sup>th</sup> Dec	8.4	Kingshill School Tutor Group - AF reported that her daughters Tutor Group at school has chosen Parkinson's as a charity to support. It was suggested that someone from the Branch spoke to the tutor group to give them an understanding of Parkinson's  Action: AF to find out if this is feasible  05/02/24 - The school is voting on the overall charity they want to support. AF will advise if the school want a presentation about Parkinson's / Charity/Branch	AF	As required

#### 4. Chairman's Report (KDY) - (See Paper 1 attached dtd 5<sup>th</sup> Feb 2024)

KDY's report was circulated prior to the meeting and content reviewed & accepted

## 5. Treasurers Report (JH) - (See Paper 2 attached) Account Summary:

 Starting Balance (01/01/23)
 £13163.60

 Total Income:
 £18155.09

 Total Expenditure:
 £11,302.63

 Final Balance:
 £20,016.06

The grant from Cam Parish Council has been received and is now in the account.

SG checked with CDC, but no funding is available, however, it was suggested that we approach St Lawrences & Cainscross to see if there is anything available.

Action: KLY agreed to investigate

#### 5.1 The Budget proposal for 2024

The 2024 budget was discussed, and a few amendments were agreed.

Action: JH to make necessary changes and circulate for review before submitting to PUK

It was proposed that £5000 would be made available from Branch funds to donate to PUK, and to whether the donation should be to help support another branch, or a research project and, if a research project, which one? It was noted that there is an increase in the Branch running costs due to extra activities and the meeting in Stroud, so it was suggested that we offer £3500 now and £1500 in 6 months dependant on how successful any fundraising events are.

A final proposal is to be prepared for review and acceptance at the AGM.

Action: KDY/SG/KC/JH

#### **5.2 Expenditure Authorisation Policy**

A draft policy was circulated and discussed. Again, a number of amendments were suggested, and further work is required to finalise the policy including a clear definition of what activities/events are subsidise

Action: JH to make necessary amendments and circulate for review before next meeting

#### 6. Local reports

#### 6.1. Cam's Report (DS/KC)

Rather than our usual meeting in December members decided they would prefer to go out for a Christmas meal. Twelve of us enjoyed a very pleasant meal at the Tudor Arms in Slimbridge with all attendees receiving a small Christmas raffle gift. A number also attended the branch Christmas meal at Minchinhampton. Unfortunately, several members were unable to attend at the last minute due to illness.

Our January meeting welcomed another new member with seventeen of us struggling to work out answers to a general knowledge quiz. Culminating in a nail-biting decider to finally crown Mike and Marion overall winners.

Caroline Robson is going to be running seated exercise classes on the 2nd and 4th Fridays in the month at 10:30. Classes commence on February 9th at Cam council office room at a cost of £5 per session.

### ACTION: KC to add information to the website (https://www.cirenstroudpuk.co.uk/parkinsons-exercise-classes)

Members are asked to bring along an item they would like valued to our February meeting as we have a visiting speaker from Wooton auction rooms.

A successful application to Cam Parish Council has resulted in £300 being paid into branch funds to cover Cam room hire, speakers and refreshments.

#### **Finances**

Opening balance £266.61 Income (coffee morning and donation) £49.00 Expenditure (Christmas raffle prizes) £41.33

Closing balance £263.28

#### 6.2. Cirencester (KLY)

Members Meeting: 15<sup>th</sup> Jan

Speakers – Exercise Class with Tim Bird/ Scams with Bill Cowley

Attendees: 20 people

Numbers have dwindled slightly due to some people now attending the Stroud Meeting, we may need to learn lessons from Stroud and advertise the Group locally to drum up some membership

#### **Petty Cash:**

#### 2023 Year end:

Starting balance: £100
Income: £777.73
Expenditure: £435.04
Year End Balance: £442.69

Starting Balance 1st Jan 2024	£442.69	_	
Details	Money In	Money Out	
£150 moved to Stroud Meeting Petty Cash Fund		£150.00	
Refreshments for Ciren members meeting		£9.60	
Walking Football fees collected	£32.00		
Total	£32.00	£159.60	
		Year to date Total	£315.09

#### 6.3. Stroud Branch Report: (KLY)

1<sup>st</sup> Members meeting held 9<sup>th</sup> Jan

Speakers: Introduction from KDY, Exercise Class with Tim Bird, & chat with Ruth Wright PUK

The meeting was busy with over 30 people attending, some of whom were existing members who live in the area, plus a number of additional people who heard about us through the advertising campaign at Doctors Surgeries/libraries and via word of mouth

(Thanks to BT & Janie Bates for all their hard work and passing the word around).

We have had a number of new members register with us via our website. Note that there was also a mention about the Group on Gloucestershire Radio, which has also drummed up some interest, so it is anticipated that there will be an increase in numbers in Feb.

#### **Petty Cash:**

£150 has been allocated to Stroud for refreshments/Consumables – This is currently being held by KLY and expenses will be managed with the Cirencester Petty Cash for the time being.

Note that due to BT health, he was unable to attend the first meeting of Stroud.

Janie Bates has agreed to join the committee and assist in the running of the Stroud Branch.

Action: KLY to send details to Jane Henderson to enrol Janie as a volunteer.

#### 7. Review of 2024 Programme (All)

A number of bookings have already been made - see schedule below.

KC/DS are meeting next week to discuss speakers programme for Cam, and we also need to work with members in Stroud to find out what they would be interested in listening too.

		2024	Dates		
	3rd Mon	3rd Thurs	2nd Tues	2nd Thurs	last Wed
Month	Members Meeting	Cam Meeting	Stroud	Tetbury Coffee	Cuppa Chat
	15th Tim Bird - Exercise Bill Cowley - Scams		9th		
Jan Feb	19th Denise Nethcotte - Exercise Alan Fisher - Mindsong	18th  15th  Wooton Auction Rooms	13th Caroline Peyton Nutirtionist	11th 8th	31st 28th
Mar	18th (AGM) PUK - Campaigns Team Jack Grant	21st	12th	14th	27th
	15th Mary Burton - Physio Phil Collins - The two Ronnies History		9th Sarah Live well & Dance - Taster Session		
Apr	20th Kate Holland - Chair exercise	18th		11th	24th
May	WWT - Peter Cranswick Flight of swans  17th	16th	14th	9th	29th
Jun	Kate Holland - Chair Execise Medical Detection Dogs	20th	11th	13th	26th
Jul	15th Caroline Peyton Nutirtionist	18th	9th  Sue Mills - Living  Aids  (1 hour  presentation)	11th	31st
Aug	19th Sue Mills - Living Aids (1 hour presentation)	15th	13th	8th	28th
	16th Phil Collins - Gloucestershire	19th	10th	12th	25th
Sep	Unventions  21st  William Cooper				
Oct	History of Cirencester  18th Red Arrows Pilot - Andy Wyatt	17th	8th 12th	10th 14th	30th 27th
Dec	Tba - Christmas lunch				

### Other Suggested speakers for 2024:

Speaker	Actions
Neil Russell - London to Barcelona for Parkinson's – Note	4/12/23 – NR agreed to speak to us – date to be
that Neil is speaking at the RAU on 12 <sup>th</sup> Oct	confirmed
	05/02/24 – KLY to chase
Medical Detection Dogs	Booked for Cam/Ciren
	5/02/24 Action: KC to check if they can also visit
	Stroud
	Exact times are to be advised
Speech Therapist	SG to provide KLY with contact details
	05/02/24 - SG to chase up
Painting/Crafting	AF may know someone who could run a crafting
	session for us
	05/02/24 – AF to chase
Aerobility – Flying access for those with disabilities	Not practical – But JH may know someone who may
	want to come and talk to us about this subject
	05/02/24 – JH to chase up
Longfields – Louise Wilson	KDY to Contact

Acupuncturist	BT has contact with an Acupuncturist – will see if		
	available for a talk in ~Ciren/Stroud		
	05/02/24 – KDY to catch up with BT for details		
Trip to Brain Bank in 2024	KLY to arrange! - ongoing		

#### 7.1. Trips/Events

- Willow Trust Boat trip booked for 11<sup>th</sup> September we have booked 30 places (whole boat)
- Nature in Art looking at alternative art activities and dates
- Brain Bank Trip to be arrange for June/July numbers will be limited
- Theatre Trip Offered Sherlock Holmes at Barn Theatre No takers to date

#### 8. Fundraising (All)

- **8.1. Clubbing Together** 17<sup>th</sup> May We are manning the halfway house and the branch will benefit from any donations received there. We will need volunteers to help run on the day as well as donations of cakes and savouries
- **8.2. World Parkinson's Day** 11<sup>th</sup> April we are looking to run a few Cream Tea events (Siddington Park/Tetbury Goods shed/Cam?/Stroud?/golf club) details are still required from PUK KLY will keep Committee posted of any developments
- **8.3.** Murder Mystery event May? Themed evening run by Phil Collins Work in Progress
- **8.4. PPU7** Planned for Oct 2024
- **8.5. Cirencester Golf Club** See progress on website : <a href="https://www.cirenstroudpuk.co.uk/cirencester-golf-club-captains-charity-fund/">https://www.cirenstroudpuk.co.uk/cirencester-golf-club-captains-charity-fund/</a>

#### 9. Welcome Pack/Information Booklet

See Matters Arising

#### 10. Group Membership (KY)

Our membership numbers have risen, mainly because of the opening of the Stroud Meeting. We currently have 194 registered members. However, a number of our members who would normally attend Cirencester are now attending the Stroud meeting, so numbers are down slightly.

KDY requested that all groups keep a register of attendees to meetings.

It was suggested that we have name badges at meetings and events, we do have some historical ones, but there has been a lot of new members recently and this is quite an administrative task to maintain and manage. It was agreed that this was a good idea, but would be put on hold until we have more volunteers to help.

We need to run a new members campaign to let people know who we are. We have new leaflets and posters advertising our meetings, so need to distribute around each of our areas.

We also need to advertise for more volunteers!

Action: KDY to draft some posters for Cam & Cirencester: All to share suggestions as to the establishments organisations and locations where we can put up posters - ongoing

We unfortunately lost one member since our last report: Harry Reeve

#### 11. Up-date From Dec PUK Network & Volunteer Call (AF)

#### Big thank you from Caroline Rassell.

Volunteers have been delivering the ambitions of PUK to improve life for PWP, using the Every Parkinson's journey strategy, starting with Health and Care – many volunteers supporting campaigning for this. Volunteers who educate clinicians to understand needs. Support for

community branches and the difference they make to PWP, carers and supporters. Fantastic activities, tea, cake and smiles! Impressed by the range of physical activities on offer.

## <u>PUK latest research. Dr Becky Jones – Research Communications Manager PUK. Accelerating</u> Breakthroughs Together.

Currently funding over 50 research projects across the UK and beyond.

- New ways to diagnose Parkinson's
- Understanding Parkinson's progression
- Non-drug treatments
- Parkinson's Brainbank
- The Parkinson's Virtual biotech trying to FastTrack treatments

Ways to get involved...

- Take part in research 162 clinical research trials ongoing across the world. Need 17,000 participants!
- Have your say.
- Join the research support network. Sign up at <a href="www.parkinsons.org.uk/rsn">www.parkinsons.org.uk/rsn</a> to get invites to research projects.

Where can the results of PUK research projects be found?

- Join the research support network
- PUK website Research pages
- PUK research blog

#### Dr Shiva Kompella, Research associate at UK Dementia Research Institute, Cardiff University.

Parkinson's over time from Neuron health to behaviour. He explained very scientifically how the changes occur, based on the percentage of Dopamine lost over time.

Finished with a video of the year in review of all the volunteer achievements.

#### 12. AOB

- 12.1. Recumbent Bikes Some costs have been drafted for initial trials Further discussion on going Action: KDY/KLY will keep Committee posted of any developments
- 12.2. **Drumming for therapy** This is work in progress,

  Action: KDY/KLY will keep Committee posted of any developments
- **12.3. Strolll** –Post Meeting note: PUK have confirmed that they are working with Strolll on a trial. **Action: SG will keep committee informed of any developments**
- 12.4. **Walking Football** –Beginning to gain momentum with a regular core of people attending, need to remind people to Pre register to play
- 12.5. **Nordic walking** Now running every Thursday and proving to be popular, could become over prescribed, so need to again encourage people to Pre -register. The Trainer will be visiting the Stroud meeting to talk to members about the activity. There may be a need to put on additional sessions to be monitored.
- 12.6. **Business Cards** KDY has produced some business cards with Branch contact details. We now have a template if anyone else wants some.
- 12.7. **Push for new Members.** See action above (item 10)
- **12.8. Spring Newsletter** KDY will be working on Newsletter and will share draft. For distribution end of Feb.

- **12.9. First Aid Training** The need to have our members First Aid Trained was discussed. The Walking Football Group are arranging some training, and KDY will get some training. JH to look into other sources of training via her running group.
- **12.10.** Longfields Gloucester event KDY/SG attended the event on 31<sup>st</sup> Jan a few good contacts were made which may result in some good speakers or access to information:
  - Lisa Carr "Orange folder" Wants to come to one of our meetings Action KLY to arrange
  - Your Circle Information about local services Need to review to see if there are
    any additional things that could be useful for our members i.e. transport which is a
    big issue for our members. We need to investigate what is on offer. Action: KLY to
    investigate
  - A&E consultant Dr Tanya De Weymarn -May be available to speak at one of the meetings. Action KLY to arrange
- **12.11.Grey Matters** SG met with Peter Skinner to discuss the services they offer (at a cost) and to talk about the issue we had with one of our members. SG believes that with a different approach, other members may benefit from talking to Grey Matters, but we need to ensure that it is clear that we do not endorse them. We need to look at potential alternatives who may not charge. Suggest that we speak to the Carers Hub to see if they can help –

Action: SG to investigate & KDY to speak to the members involved to see how they feel about it.

**Meeting Closed: 20.15** 

**Next Meeting: 4th March (to prepare for AGM)** 

Time: TBA Venue: TBa

Action: KDY to confirm date/venue

#### Suggested 2024 meeting dates:

Meeting Type
<b>Full Committee</b>
Chair/Vice Chair