

Our Branch Area

**PARKINSON'S<sup>UK</sup>**  
**CHANGE ATTITUDES.**  
**FIND A CURE.**  
**JOIN US.**

## Cirencester & Stroud Branch

# Newsletter – September 2022

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## [News from the Chair](#)

### Listening, Talking and Helping Together

Hello and welcome to our first monthly Newsletter. In this, my first (and very busy) general communication to everyone since becoming Chair a few weeks ago, I want to use the subject of 'communication' as my main theme. I also send my thanks to the previous administration in guiding the Branch through incredibly difficult times due to the un-precedented Covid situation.

In my wide and varied career, clear and regular communication was always used to share positive and negative updates, progress on activities, latest details, and other useful information. This gave teams and individuals the kind of information they needed to help them achieve their goals, hence the same for our Branch members.

We are very much missing regulars at Branch Meetings and Activities. We want to see you again, catch up with your news, new members can get to know you and you them and get back to socialising with each other. We want to provide a nice social relaxed experience to encourage everyone to share their own Parkinson's story. Yours might be just the one that offers much needed reassurance to a new member. A friendly ear awaits. See some of the useful information links on page 9 that may help you.

I can report that your committee have been busy in the background working out how to structure the Branch to best meet your needs. I have personally met a few of you, attended a conference at Gloucester, some members meetings, a couple of committee meetings, and some pre-arranged activities. In every one of these I have met genuinely lovely people all trying to live with and cope with Parkinson's in the most appropriate way for them and their families / carers.

I quickly concluded that as a committee, we should focus on meeting the needs of our members in as many ways as we can (resources permitting) and increasing communication with each other. By that I

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mean people newly diagnosed and people living with Parkinson's as well as carers, family, support etc. Each group in my view, have slightly different needs. We will cater for these needs as much as we can.

In the next few months, I aim to lead your committee to review, create and implement an action plan that can deliver varied activities and support information for ALL Branch members, family, and carers. Also, to keep you informed of supportive services available in our stretched out rural area. We held our first Focus Group meeting on 12<sup>th</sup> Aug, where over 100 ideas were raised, we will funnel these into actions over the coming weeks. Updates will be published here.

Look out for more regular information on how we are doing with fundraising – an important measure; fun & interesting activities aimed at as many as possible; as well as any updates from the medical fraternity. We are quite rural but can be together.

Along with my wife Karen (Branch Secretary), I went to the Cirencester Chamber of Commerce Business and Community Awards at St John Baptist Church in Cirencester on Friday 22<sup>nd</sup> July on behalf of the Branch to explore networking opportunities. A podcast was made where I was interviewed by Corinium Radio. If you can bear it, it can be found at the following link – it is at 21:00 minutes into the recording. We will be joining this organisation to explore networking opportunities for fundraising.

Go to <https://coriniumradio.com/2022/08/11/the-brains-behind-the-business-special-business-and-community-awards/>

May I point you to the interesting article on Longfield's Wellbeing Centre which has a lot to offer - not only for people living with Parkinson's but also the caring support and family members too. All free of charge and excellent help.

And finally, after seven years as Branch Treasurer, Stuart Keay has decided to step down, a replacement is being recruited. That is a lot of service to give to a charity. I am sure that as well as the committee, you all wish to thank Stuart for his studious efforts and support over that time. His last task will be as part of the AGM on 19<sup>th</sup> September, all members are invited.

Thank you for reading,

KEVIN YOUNG

Chair

## Fundraising / Donations

The Branch is self-funded, we receive personal as well as In Memoriam and legacy donations, and we generate just enough from raffles and sales of Parkinson's goods to cover the years planned activities. We also try to raise more through Fundraising events however, Covid has impacted this, and returning to normal has been very slow.

Up to the end of August this year we have raised a total of £690.21 in monies coming in. The cost of hosting our efforts has been £552.07 so far, the account balance is at £7008.07. This leaves some to send to Parkinson's UK for medical research funding opportunities and some to fund the Branch next year. More income is required. A number of different fundraising approaches are now being considered by your committee. Here are a few of them that have in the past been successful but were outside of the Branch with donations going direct to P-UK.

- PPU 1-4 (see next section for current event) – raised £28,000 over last four fundraising events
- Parkinson's Golf raised around £8,000
- Other fundraising events - £2,000
- Charity Poker night at Cirencester Rugby Club shared with relay 4 life cancer charity is currently aiming to raise approx. £150 per month when it starts in the next few months

The branch aims to consolidate all charitable fundraising efforts so that a consistent level of support and communication is available and for the total raised in the year to be distributed to chosen research and also to cover branch support costs effectively.

## Events / Activities

Here's an update on some of the events we have recently had followed by the remaining planned events of the year. If you want to attend, please contact your committee.

### **Marjorie's Tea Party 8<sup>th</sup> Aug.**



A well-attended event on a hot August day with lots of tea / coffee and many varieties of cakes and biscuits kindly made and brought collectively.

On Monday 15<sup>th</sup> August at the members meeting St. Lawrences, Cirencester we heard from

Dr Matthew Smith  
Clinical Research Fellow/Specialist Registrar in Neurology  
Aging and Movement Research Group  
Population Health Sciences  
University of Bristol

He gave us a talk on what research is and the trials that are on-going at the moment. Here is a copy of his synopsis for those that could not make it.

*“STRIPE – a study looking at a wearable ankle stimulator device to improve bladder symptoms in Parkinson’s*

Contact details: [stripe-trial@bristol.ac.uk](mailto:stripe-trial@bristol.ac.uk), telephone: [07940 220966](tel:07940220966)

*CHIEF-PD – a study using the patch medicine rivastigmine to help with walking, balance and falls in Parkinson’s*

Contact details: [chief-pd@bristol.ac.uk](mailto:chief-pd@bristol.ac.uk), telephone: [0117 42 83113](tel:01174283113)

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TOP-HAT – a study looking at the use of the tablet ondansetron to help with hallucinations people can experience

Contact myself at: [matthew.smith@bristol.ac.uk](mailto:matthew.smith@bristol.ac.uk), telephone: [07940 220966](tel:07940220966)

OCEAN – a study looking at the use of the tablet opicapone to help with pain in Parkinson's

Contact myself at: [matthew.smith@bristol.ac.uk](mailto:matthew.smith@bristol.ac.uk), telephone: [07940 220966](tel:07940220966)

A further aside is in the next year or two we will have a project named "Digimap" running which will look at the mobility and activity levels of people with Parkinson's using wearable monitoring devices (with the hope of developing more meaningful markers of success for clinical trials and Parkinson's services) – if anyone wants to register their interest please do email me at: [matthew.smith@bristol.ac.uk](mailto:matthew.smith@bristol.ac.uk),

Thanks again for having me and thank you in advance to any of your members who are able to take part in research."

### Willow Trust Canal Boat Trip 17<sup>th</sup> Aug.



Another well attended event, everyone enjoying the trip from Saul Junction to Sharpness and back with a picnic and a good social catch-up.

### Up-coming activities booked by the Branch for Members and carers / supporters:

If you wish to attend any of these events, please contact a member of the committee.

- Steam Train trip 6<sup>th</sup> September – from Cheltenham racecourse to Broadway via Toddington for lunch, the cost is £11 (subsidised by the branch)
- Cobalt Health 17<sup>th</sup> October St. Lawrences Hall, Cirencester
- Phil Collins Ukulele Workshop – 21<sup>st</sup> November St. Lawrences Hall
- Xmas Lunch at Minchinhampton Golf Club, 12<sup>th</sup> December

### Other events in our area to be aware of:

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- **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-parkinsons-and-their-carers>


- **Summer Fete** – Sunday 28<sup>th</sup> August 1pm – 4pm at Longfield's, Burleigh Lane, Minchinhampton
- **Walking Group** – we are trying to re-establish this, contact Richard and Lyn Alcock at [richard.alcock@randl.clara.co.uk](mailto:richard.alcock@randl.clara.co.uk)
- **Parkinson's Living Aids** - Sue Mills, Parkinson's UK Trading Manager – date to be confirmed – to advise on all products that PUK sell on **living aids** for people with Parkinson's
- **Dance For Parkinson's** – this is held at Forest Green Rovers football stadium **but is now called Choose2Move**. Contact Sarah Hartley at [dancebesocial@gmail.com](mailto:dancebesocial@gmail.com) to book a slot (closed during school holidays).
- PPU 5 – See poster below – anyone who wants to go should contact Dave Trinder.


**PPU 5**

**Saturday 24<sup>th</sup> Sept 2022 at Bingham Hall 7.30 PM – 12.00**

For just **£5**, join us for a great night of music, entertainment and fundraising for **Parkinson's UK**; here's the line up :

New Rules  Acoustic Covers


THEN Plucking Different  electric ukulele rock band

Ending with The Human Jukebox 


We are offering 75 members of staff at Cirencester Hospital from cleaners to specialists a free ticket, along with a partner to say a big **THANK YOU** for all you did and continue to do under difficult circumstances.

With everything that has happened in the last few years, we all know the **NHS have been amazing.**

There will be an auction, conducted by professional auctioneer Joe Trinder plus a raffle.



Tickets £5 from Dave Trinder 0789 4868242 and if you or you know of anyone who could donate prizes for this great Parkinson's fundraising event Please let me know

Sponsored By: 

# Remaining Program for 2022

	September	October	November	December
<b>WK1</b>	5th <b>Committee Mtg</b> Frampton Village Hall (2:30-4:30pm)	3rd <b>Committee Mtg</b> Frampton Village Hall (2:30-4:30pm)	1st <b>Committee Mtg</b> Frampton Village Hall (2:30-4:30pm)	
<b>WK2</b>	6th Steam Train trip Cheltenham racecourse to Broadway via Toddington for lunch £11 (subsidised)			5th <b>Committee Mtg</b> Frampton Village Hall (2:30-4:30pm)
<b>WK3</b>	19th <b>Branch Mtg</b> St. Lawrences Church Hall, Cirencester (14:00 - 16:00) <b>Branch AGM</b>	17th <b>Branch Mtg</b> St. Lawrences Church Hall, Cirencester (14:00 - 16:00) <b>A talk from Cobalt Health</b>	21st <b>Branch Mtg</b> St. Lawrences Church Hall, Cirencester (14:00 - 16:00) <b>Phil Collins Ukuele Workshop</b>	12th Xmas Lunch Minchinhampton Golf Club 1-3pm
	15th <b>Cam &amp; Dursely Local Group Mtg</b> Cam Parish Council Rooms (10:00 - 13:00) Social Quiz & Bingo	20th <b>Cam &amp; Dursely Local Group Mtg</b> Cam Parish Council Rooms (10:00 - 13:00) Claire Greenwood (comedian)	17th <b>Cam &amp; Dursely Local Group Mtg</b> Cam Parish Council Rooms (10:00 - 13:00) Cotswold Dogs & Cats Charity	
<b>WK4</b>	27th Members' Pub Lunch The Ram, Bussage (12-2pm)	25th Members' Pub Lunch The Ram, Bussage (12-2pm)	22nd Members' Pub Lunch The Ram, Bussage (12-2pm)	

We are currently working on a comprehensive, fun, interactive and interesting program for 2023 – watch this space!

## Membership

This section provides an update on membership.

Welcome to Peter and Barbara from Cirencester who joined us for their first meeting on 15<sup>th</sup> August to listen to Dr Matthew Smith explain about clinical trials on-going at the University of Bristol (see his synopsis above).

## Networking

In terms of networking, we are currently looking within the local community as well as the wider community, businesses, and the Parkinson's network to locate all opportunities for our members to

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engage in a plethora of activities. There are several free activities and therapies in our area that you may or may not know about. We are now beginning to establish connections with the more organisations that we think will generate interest with our membership. The first organisation to mention and to promote here is **Longfield Wellbeing Centre Minchinhampton**. They are offering a very wide range of activities and therapies from ‘just diagnosed’ onwards and are all completely free of charge. Here’s a statement from Louise Wilson, their Community Engagement Officer –

“I was invited to come along to the Cam group in August and was made to feel very welcome, a lot of people were surprised by everything we do here at Longfield and did not realise we are here for people from diagnosis onwards, or the range of services we provide, so Kevin asked me to provide a bit more information about our Wellbeing Centre.”

The many services on offer from Longfield’s are explained in the summary table below:

Being in Nature	Carers Café	Complimentary Therapies	Counselling Service	Living with Fatigue & Breathlessness	Living Well Program	Mindsong Music Therapy	Move More Program
Expect nature-based activities including ecology, art and craft and meditative ‘time with nature’.	Go along for a friendly chat, an opportunity to receive peer support, make new friends and relax in a welcome space. Social Prescribers will be coming along to share what they offer to carers, families and patients in Gloucestershire.	for people with a life limiting illness and those close to them. The therapies promote relaxation and wellbeing through massage, Aromatherapy, Reiki and Reflexology.	this is available to anyone experiencing emotional distress as a result of their own life-limiting condition or the illness of someone significant to them.	to help find ways to cope with your symptoms and enjoy a better quality of life.	Explore how to manage common issues such as poor sleep, anxiety, fatigue, nutrition, future planning, emotional support and more. Look at prioritising your own goals and developing an action plan if required.	An opportunity to go along and play in a group, exploring making music together, expressing yourself without the need for words. A range of instruments are available to play, no musical skill or experience is necessary – just a willingness to have a go!	Exercise in a safe and supportive environment, the exercise is fun and tailored to your needs.
Nordic Walking	Patient and Carers’ Support Group	Relaxation Program	Tai Chi Movements for Wellbeing	Therapeutic Art	Walk and Talk (once a month)	Wellbeing Centre	Writing Through Grief
This is a walking technique using poles, it’s a fun way to improve fitness, enjoy outside spaces, learn a new skill and find out whether Nordic Walking suits you.	Connect with others in a similar situation and focus on what is important to you. Explore how to prioritise your goals, relaxing techniques, self-care activities and how to get the most out of your clinical appointments.	Relax using elements of Tai Chi Movements for Wellbeing, guided relaxation, essential oils, hand massage and reflexology.	to help find a sense of tranquillity, with standing or seated Tai Chi. Guided by trained facilitators, move your body mindfully.	The creative Assistant will provide a safe and private space in which the art materials are used in any manner desired. There are no ‘rules’ to this as long as the materials are used safely.	Walk and Talk is a monthly group aimed at bringing people together. It is an opportunity to be alongside others of similar experience, to benefit from tranquil surroundings and to connect with new people.	there is a drop in morning on Friday’s 10am – 12pm, go for a coffee and a chat (no appointment necessary)	Facilitated by local published author, psychologist, and grief counsellor Patsy Freeman. On offer is a safe, gentle space to explore the benefits of writing / journaling.

**A note regarding Thames Water – Water Restrictions coming into force 24<sup>th</sup> August.** Go to this website [www.thameswater.co.uk/help/water-restrictions](http://www.thameswater.co.uk/help/water-restrictions) to the ‘Mobility issues’ section dealing with people with Blue Badges. Sign up for their “Priority Services Register”, this may help any of the Thames Water users in our area to still use a hose for watering your garden; cleaning vehicles / windows / paths / filling a pond. It is only available to Blue Badge holders or people on their register of Vulnerable Consumers.

Cotswold Friends

## Useful Information

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](mailto:cirenstroudpuk@yahoo.com)

Chair – Kevin Young [cirenstroudpuk@yahoo.com](mailto:cirenstroudpuk@yahoo.com)

Treasurer – Stuart Keay [cirenstroudpuk@yahoo.com](mailto:cirenstroudpuk@yahoo.com) (**POSITION AVAILABLE** after AGM)

Secretary – Karen Young [cirenstroudpuk@yahoo.com](mailto:cirenstroudpuk@yahoo.com)

Local Group Coordinator (Cam) – Diane Shelley [dianeshelley@btinternet.com](mailto:dianeshelley@btinternet.com)

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

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

Committee Volunteers – Steven Goldblatt, Karen Brookes, Angie Fenton

**Cirencester and Stroud Branch Website** – this is in construction, but we aim to have one similar to this one at Parkinson's Newbury – check theirs out at this address [www.newburyparkinsons.org.uk](http://www.newburyparkinsons.org.uk) please feedback any comments to your committee.

### **Branch Meetings** (at the moment)

Committee meetings – 4<sup>th</sup> Monday each month (Frampton Mansell Village Hall)

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

Pub Lunch @ The Ram, Bussage – 4<sup>th</sup> Tuesday each month

Cam Coffee Mornings – 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](mailto:jhenderson@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](mailto:hello@parkinsons.org.uk))

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

**Parkinson's Nurse Specialist Service:** 0300 422 6610 or ([ggh-tr.parkinsonsteam@nhs.net](mailto:ggh-tr.parkinsonsteam@nhs.net))

**Cheltenham Branch:** [www.cheltenhamparkinsons.org.uk/](http://www.cheltenhamparkinsons.org.uk/)

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

- **Parkinson's Living Aids** – 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 – [www.parkinsons.org.uk/dla](http://www.parkinsons.org.uk/dla) (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](http://www.longfield.org.uk)

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- **Carers Hub** – offering: *support for carers to meet others in a safe place* can be contacted here – Bond Mills, Stonehouse GL10 3RF Tel: 0300 111 9000 [www.gloucestershirecarershub.co.uk](http://www.gloucestershirecarershub.co.uk)
- **Charcot Therapy Centre** – 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 [www.thecharcot.org.uk](http://www.thecharcot.org.uk)
- **The Churn Project** – 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 [www.churnproject.org.uk](http://www.churnproject.org.uk)
- **Cotswold Friends** – 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 [www.cotswoldfriends.org](http://www.cotswoldfriends.org)
- **Megan Baker House** – 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 [www.meganbakerhouse.org.uk](http://www.meganbakerhouse.org.uk)
- **Walking Football** – 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: [stuartlangworthy@thewfa.co.uk](mailto:stuartlangworthy@thewfa.co.uk)