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News from the Chair

Living Well with Parkinson's

It was a nation in mourning in September following the death of HM The Queen, the end of an era of exemplary service and now the start of many things new. In this month's communication I write about the people I've met and things I've read that have made me think and learn more about Parkinson's. In life I'm always learning, I have learnt to improve when perhaps things didn't go quite as expected by seeking to understand exactly why expectations were not met! Now, I am listening to, and learning from people living with Parkinson's, how it affects them and their loved ones, but also how they are managing to live well, and enjoy life. I aim to understand what is needed to be in place to offer help, support, and interest for our members.

I met a very interesting lady by the name of Alison Anderson in Cheltenham recently, some of you may already know her. She was diagnosed at 46 with Young Onset Parkinson's. A very active person all her life, cycling, walking, playing tennis and socialising with her friends and family. She realised that keeping active was important and has continued to do all the above and does "live well with Parkinson's". A very positive lady! I learnt a lot from her. Alison writes a regular blog called "The Ramblings of a Cyclopath". For more details about my discussion with Alison, her story and link to her **blog**, go to page 6 for a new section called **Living Well**. This will be where this Newsletter will capture stories and share experiences of living well with Parkinson's.

In other news, the new Focus Group, as reported last month, are continuing to work on a program of events for 2023, next review is 27th Sept, it all looks very good. They are working on producing a full and varied program of events and activities in different locations around our very rural area, at different times of the day / rotational basis to ease travel and allow more people to attend. The main objective is to offer you all a "**Menu of Choice**" aimed at all groups within our membership, reaching different geographic areas and at varying times of the week. Sharing activities from different PUK Branches is also being considered, as are those activities that have been done previously that we want to do again. If there are any particular activities that you would like your committee to organise, then please let us know and we will look into it.

Lastly, we are always looking for more Volunteers, if you know someone who could help, please let us know.

Kevin Young, Branch Chair

Fundraising / Donations

There's no update from last month on this topic until after the PPU5 event on 24th Sept, so, apart from a few ins and outs the account balance sheet remains similar to reported last month.


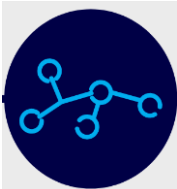

The branch aims to increase and also to consolidate all charitable fundraising efforts so that a consistent level of support and communication is available and for the total raised in the year to be distributed to chosen research and also to cover branch support costs effectively for 2023 activities as agreed by your committee.

Where do our fundraising donations go?

Our Branch is a self-funding organisation from donations, In Memoria's, collections, fundraising events and so on, so some of the funds raised go towards paying for or subsidising our speakers and activities (as decided upon by your committee).

At the end of the year, we make donations to PUK for research. Parkinson's UK is the largest European charitable funder of Parkinson's research, currently there are 37 research projects in various stages of the research pipeline, and we, as a branch can select which of these research projects, we want any donations raised by our fundraising activities to be allocated to.

Research Pipeline Explained:

Scientific Discoveries 	Researchers attempt to find out what goes wrong in Parkinson's and come up with ideas for how to fix it.
Developing Treatments 	Dedicated teams turn the most promising scientific discoveries into potential new treatments.
Clinical Trials 	New treatments that have been proven safe and effective by all other methods are carefully tested in volunteers.

Below is a link to the current 2022 Research Projects:

https://www.parkinsons.org.uk/sites/default/files/2022-06/CS3789%20Active%20research%20projects%20May%202022_Final%20%281%29.pdf

There are **two types** of Research project:



Cure Projects: - working towards treatments & strategies to slow, stop, reverse, or prevent Parkinson's, and includes developing new treatments, improving diagnosis and monitoring of the condition



Life Projects: working towards treatments and strategies to improve the symptoms and quality of life of people with Parkinson's. This includes better therapies and management for issues such as falls, anxiety, and thinking and memory problems

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.

Steam Train trip 6th September - Cheltenham to Broadway via Toddington for lunch



A very good event, more members should book for this event next time it's planned. Those who attended (and their care support) had a lovely day out with lunch and good catch up.

Up-coming activities booked by the Branch for Members and care supporters:

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

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- Re-scheduled AGM and Cobalt Health 17th October St. Lawrences Hall, Cirencester – *a talk from Jenny and Irene on the latest diagnostic technology to enable earlier and more accurate diagnosis*
- Phil Collins Ukulele Workshop – 21st November St. Lawrences Hall – *called “Fun with a G string”*
- Xmas Lunch at Minchinhampton Golf Club, 12th December

Other events in our area to be aware of:

- **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>

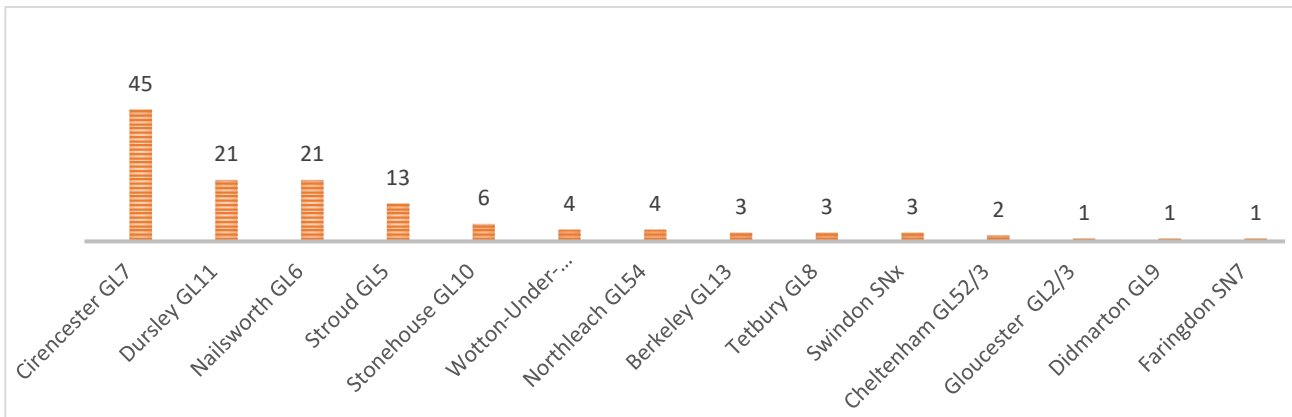
- **Walking Group** – the first walk has been confirmed as 1st October around Minchinhampton Common with lunch at The Lodge afterwards, thanks go to Richard and Lyn Alcock for kindly organising, if you wish to join future walks please contact richard.alcock@randl.clara.co.uk
- **Parkinson’s Living Aids** - Sue Mills, Parkinson’s UK Trading Manager in May 2023 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 to book a slot (awaiting confirmation of restart dates).

Remaining Program for 2022			
	October	November	December
WK1	1st Walking Group The Lodge, Minchinhampton Common 10:15	1st Committee Mtg Frampton Village Hall (2:30-4:30pm)	
	3rd Committee Mtg Frampton Village Hall (2:30-4:30pm)		
WK2			5th Committee Mtg Frampton Village Hall (2:30-4:30pm)
WK3	17th Branch Mtg St. Lawrences Church Hall, Cirencester (14:00 - 16:00) AGM (re-scheduled) and a talk from Cobalt Health	21st Branch Mtg St. Lawrences Church Hall, Cirencester (14:00 - 16:00) Phil Collins Ukuele Workshop	12th Xmas Lunch Minchinhampton Golf Club 1-3pm
	20th Cam & Dursely Local Group Mtg Cam Parish Council Rooms (10:00 - 13:00) Claire Greenwood (comedian)	17th Cam & Dursely Local Group Mtg Cam Parish Council Rooms (10:00 - 13:00) Cotswold Dogs & Cats Charity	
WK4	25th Members' Pub Lunch The Ram, Bussage (12-2pm)	22nd Members' Pub Lunch The Ram, Bussage (12-2pm)	

The details for the 2023 program will be here very soon, keep watching this space!

Membership

This section provides an update on our membership. There are no new or changed details to report from September edition, but the following chart showing our membership demographic further demonstrates the rurality of this Branch for information. The other diagram is taken from the 2021 census and shows that we have a very small number of members in our Branch from the county population of 1,600 diagnosed (less than 10%). Your committee will be working on trying to support as many people living with Parkinson's in our area as possible.



Parkinson's in Gloucestershire

Ethnicity	Percentage
Asian	<1%
Black	<1%
Mixed	<1%
Other	<1%
White	98%

20 People living with Parkinson's in Gloucestershire are from Black, Asian, Mixed Race or other minority ethnic groups

500.8
Thousand
Population over 20

1,600
People living with Parkinson's

200
People aged over 45 diagnosed with Parkinson's each year

This is likely to increase:



PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

14%
of people with Parkinson's are under 65

42%
of people with Parkinson's are 70 to 79

17%
of people with Parkinson's are over 85

5%
of people living with Parkinson's are living in the **most deprived areas**

Gloucester has the **115th** highest number of people with Parkinson's living in deprivation in the country

560
people living with Parkinson's are living in **rural areas**

1,040
people living with Parkinson's are living in **urban areas**

Source: 2021 Census

P-UK UPDATE (from Jane Henderson):

Replacement for Sarah Wakeman (Fundraising) - new starter joining the team at the beginning of September to replace Sarah: Aaron Coleman who has approx. 15 years of community fundraising experience from Marie Curie and a local hospice.

Living Well



New Section

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

Alison's Story (written by Alison Anderson)

"Hello, I'm Alison, I was diagnosed with Parkinson's in 2015 at the age of 46, I'm married to John, and we have three grown up sons. My diagnosis came as a complete shock to me, but I was determined to live as well as I possibly could with the condition. When I read that exercise has been shown to delay disease progression, I got out an old bike and started cycling. I have since cycled thousands of miles and had some wonderful adventures while raising funds for research into Parkinson's. Tennis, boxing, dog walking, the gym and yoga have added variety to my exercise regime over the years and I find meeting friends to exercise with or joining a group can help to make it more fun. I'm an ambassador for the World Parkinson Congress which is being held in Barcelona 4-7th July 2023 and of course, I plan to cycle the 1,600kms from home to Barcelona! As well as a number of friends, cycling alongside me will be another eight others living with Parkinson's. I write a blog about living with Parkinson's to help raise awareness and will chronicle our training and travels throughout this next adventure."

Have a read of Alison's Blogs at this link www.theramblingsofacyclopeth.com

The **Young Ones** is an informal network of people of working age, from around Gloucestershire and the surrounding areas, living with Young Onset Parkinson's. Established in 2019, the aim is to share information and to support and encouraged help each other to live well with Parkinson's. We meet approximately monthly for a short walk followed by coffee. Smaller groups might meet independently to play sport / exercise together / go for lunch / have an evening in the pub and a range of other activities. We share relevant information and can offer 1:1 support for anyone newly diagnosed. A warm welcome is offered to anyone of working age living with Young Onset Parkinson's. Partners are very welcome too. Please call or message Alison on **07775 525 053** if you are interested in finding out more.

An Update of Chief-PD Trial (from Richard Alcock)

You may have heard of a Parkinson's research trial called Chief-PD which is all about trying to prevent falls. This repurposes an existing drug so, if successful, it could be available quickly. I have been taking part in this trial since the start of August and so far, it has been completely trouble-free.

It began with a questionnaire and an assessment visit to Gloucester hospital. A pack containing the medication, or a placebo arrives by post. A fresh patch is applied to the arms or torso once a day and any falls are recorded on a daily tick box sheet. The trials team phone regularly to check that all is OK. The hardest part is remembering to change the patch as I completely forget that I am wearing it!

This drug could bring huge benefits to Parkinson's sufferers who are susceptible to falling, not least a reduction in pain and bruises! So, if you have had a fall in the last 12 months, please think about taking part. A further 200 participants are urgently required to make sure the project goes ahead.

More information is available on the Parkinson UK website, or the trials team can be contacted on: chief-pd@bristol.ac.uk, telephone: **0117 42 83113**

Breath-taking!!

There was a story in the Daily Mail recently about a lady who can smell Parkinson's and how there may be a simple swab test coming soon.

Joy Milne from Perth in Scotland sniffed Parkinson's in her husband 12 years before he was diagnosed. Her incredible nose has been a major asset to scientists, as a 'super-smeller' she can diagnose strangers who have the disease simply by sniffing T-shirts. Now, experts have created the first ever test based on odour that alerted her. Read the article here: -

<https://www.dailymail.co.uk/sciencetech/article-11187123/Thats-breathtaking-Meet-woman-sniffed-husbands-Parkinsons.html>

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 <https://parkinsonsnewstoday.com/news/probiotic-supplements-ease-parkinsons-constipation-small-trial/>

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

Chair – Kevin Young cirenstroudpuk@yahoo.com

Treasurer – Stuart Keay cirenstroudpuk@yahoo.com (**POSITION AVAILABLE** after AGM 17th Oct)

Secretary – Karen Young cirenstroudpuk@yahoo.com

Local Group Coordinator (Cam) – Diane Shelley 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 please feedback any comments to your committee.

Branch Meetings (at the moment)

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

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

Pub Lunch @ The Ram, Bussage – 4th 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)

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 (ghn-tr.parkinsonsteam@nhs.net)

Cheltenham Branch: 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 (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
- **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
- **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
- **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
- **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
- **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
- **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



- **National Trust** - Discounted and free entry
<https://www.nationaltrust.org.uk/features/access-for-everyone>

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.

- **The Young Ones** – 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 group