

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

News and Information Letter for Cornwall & the Isles of Scilly

Feb / Mar'23

Editorial Thoughts

A Happy New Year to everyone and we trust you all had a good Christmas with family and friends.

In our pages this month you will find notices for the AGMs of both West and Mid Cornwall branches, which are followed by a very serious plea for more help within Mid Cornwall branch. Please read this and see if you can come to our aid.

Nobody contacted us with the answers to our Christmas quiz, so we've decided to give you more time, the Dec N/L was very late, and we're intending to carry the quiz over to this coming Christmas. We will have to eat the prize and get another for next year!

In our last newsletter we mentioned our new committee members John and Steve and here is a little bit about John.

'Hello, readers. I feel I have fallen on my feet in meeting in person and by zoom, really nice people in the Parkinson's organisation. I feel it's a privilege to be part of the mid-Cornwall group and I am trying to patiently get to know people.

Sometimes I feel impatience and want things to happen quickly, but I now realise I need to be on the organising committee for a time before I can think about any sort of public role. However, I am happy to function in public making tea and coffee and can normally hold a

conversation with anyone I meet, as I do when I visit the Bethel Drop-In.

I live at Gorran with my wife Ruth. In theory we are both retired, but it never seems to be that simple. I have spent 40 years or so in education leading schools for pupils with complex physical and learning difficulties. Thank you for the welcome you have all extended to me. I hope to do and say positive things as time goes by.'

John Murfitt

We'll have a little bit about Steve next time, and now we look forward to the AGMs, World Parkinson Day April 11th and awareness week, and in May, the Coronation.

Jan & Nick

Points West

Notification of West Cornwall Branch AGM 2023

to be held at St Piran's Hall, South Road, Goldsithney,
TR20 9LF on Friday 17th February 2023 at 1.30 pm.

AGENDA

1. Chairman's Welcome and Notices
2. Apologies for absence
3. Approval of last Annual General Meeting Minutes held on 18.3.22
4. Consideration and adoption of Chair's Report for year ending 2022
5. Consideration and adoption of Treasurer's Report for year ending 2022
6. Any other reports
7. Nominations and election of Committee for 2023
8. AOB

Please note that copies of the aforementioned documents will be made available at the AGM.

We would welcome nominations onto the committee. Please let Emily Harris know of any nominations at least two weeks before the date of the AGM or as soon as possible by emailing

empem108@gmail.com

'Sing for Fun' Celebration!

Those attending 'Sing for Fun' were delighted to welcome their founder and former singing leader Kelsey Michael to the first meeting of 2023 at Townshend Village Hall.

There was of course singing, including the energy-sapping but great fun, "Can Dilly Song", (similar in some ways to the Twelve Days of Christmas). After catching our breath, Kelsey was presented with a farewell and thank-you gift of a Jubilee Pool Voucher. A keen sea



swimmer, Kelsey said she would look forward to swimming in the pool's geothermal section, which she hadn't yet experienced. She was also given a Dunoon mug for a warm-up cuppa after her swims. Kelsey left the group last year to concentrate on recording an album of her own songs and performing, with which we wish her much success.

Kelsey has passed the baton to Gail Hampshire, who now leads the 'Sing for Fun' sessions. Gail was also presented with a mug and thanked for continuing to make the well-established Wednesday singing sessions both therapeutic and fun.

The group, including partners, then enjoyed a 'bring and share' lunch. It was a lovely occasion, which we hope to repeat.

If you would like to join 'Sing for Fun' sessions there are two ways to do so:

Sessions are held each week on a Wednesday morning, alternating between in-person and Zoom sessions.

In-person sessions are held every fortnight at Townshend Village Hall in West Cornwall, from 11.00 – 13.00.

Zoom sessions are held every fortnight from 11.00 – 12.30.

Contact Gail Hampshire 01209 698631 or Emily Harris 01736 365267 for more details and a link to join Zoom sessions.

All welcome, including partners and carers.

Emily Harris

Back Chat

Notification of Mid Cornwall Branch AGM 2023

to be held at East Taphouse Community Hall
Salts Meadow, East Taphouse PL14 4TA,
on Wednesday 15th March 2023 at 11.00 pm.

AGENDA

1. Chairman's Welcome and Notices
2. Apologies for absence
3. Approval of last Annual General Meeting Minutes held on 28th March 22
4. Consideration and adoption of Chair's Report for year ending 2022
5. Consideration and adoption of Treasurer's Report for year ending 2022
6. Any other reports
7. Nominations and election of Committee for 2023
8. AOB

Please note that copies of the aforementioned documents will be made available at the AGM.

We would welcome nominations onto the committee.

Please let Sue Whipps know of any nominations at least two weeks before the date of the AGM by emailing secretary@parkinsonscornwall.com

Tamar Crossing Concessions

Remember what Emma Edwards mentioned about concessions crossing the Tamar in the last newsletter. There is a Mobility Scheme, which allows certain individuals to purchase a pass for £5, which gives them 100 'free' crossings.

If you follow this link, it'll take you to the webpage that has all the information, including the application form.

<https://www.tamarcrossings.org.uk/prices/mobility-scheme/>

Thank you Emma.

Mid Cornwall Branch

The Mid Cornwall Branch of Parkinson's UK covers the county from the border with Devon to Camborne. When I moved to Cornwall in 2009, there were three 'Hubs', run by Rotary, with an employee paid to oversee them. The volunteers of Mid Cornwall Parkinson's UK ran other meetings, moving around the county. Later the Mid Cornwall committee took over the task of running the then Hubs, now Drop-Ins, using volunteers. We relocated them and increased the number to seven.

Since Covid however, we have lost volunteers due to ill health, poorly partners or, let's face it, age. We have had to reduce the number of groups we can organise. The good news is that we have started singing groups and exercise groups on Zoom, still have four Drop-Ins, a face to face singing group and face to face exercise groups.

The 'not so good news' is that our pool of volunteers is diminishing further and those of us left need help, extra hands. I already run two Drop-In groups a month as well as organising two face to face exercise groups each month. This is alongside my committee work for the branch.

You don't have to have been affected by Parkinson's to help.

Are there any small jobs you could help with? YES.

- *You could take turns to open up a hall and arrange chairs for a meeting.*
- *You could help make the refreshments.*
- *You could chat to newcomers and make them feel welcome.*
- *You could work with committee members to start an informal coffee shop meeting.*

If your leaning is more toward 'backstage' help, could you

- *join the committee and help us with decision making?*
- *shadow another committee member ready to stand in if illness prevents them from temporarily carrying out their tasks?*
- *be a representative of working age people to help us design suitable support for younger people?*
- *become the Branch Secretary to receive and send a variety of letters?*

It's not all work though. Over the years, working with the branch has taught me a lot about living with Parkinson's. I have a greater knowledge of the condition and drugs, and it has enabled me to get involved with researchers and research projects. Who knew it would lead that way for me?

I have made many friends up and down the county, and the community of Parkinson's is one I feel privileged to belong to.

It's been fun.

For more information contact Sue on 01503 262166
Or Mary Jane Hunter on 0344 225 3695

Trembellows Christmas Party

The Trembellows singing group held their Christmas Party on the 12th December at their usual meeting place, Summercourt Village Hall. The last time we celebrated Christmas together was in 2019 when we went to a restaurant for Christmas lunch, but we decided that in the current circumstances we were better holding the celebration on our own, and this worked very well. Most of the group that were able to make it, are in the picture



We had an excellent turnout and a good time was had by all. For the first half of the meeting we sang carols and other Christmas songs. We then

moved on to afternoon tea. Everyone had brought some sort of Christmassy food with them, so we had a full table to choose from. This was followed by party games organized by Hilary Crewe, one of our

team of three singing leaders. The main game consisted of throwing dice and eating chocolate and was a great hit.

2022, having started with the shadow of Covid hanging over, finished in a very happy way.



However, 2023 began with some sad news. One of our longstanding members, Nigel Price, pictured here perfecting his chocolate eating technique at the party, died of pneumonia on January 2nd. A small consolation is that he appeared to really enjoy his final

occasion with the Trembellows, and we saw a little of the person he used to be, re-appear that afternoon.

Nigel's wife, Jacque asked myself, Nikki Wilhelmsen and Hilary, as the three leaders of Trembellows, to lead the singing of Nigel's favourite Trembellows song, "Sailor, leave your roaming" at his funeral service. We sang this with the congregation, which contained most of the other Trembellow's members.

The Trembellows meet from 2:30 pm to 4:30 pm every Monday afternoon (except for bank holidays and August) at the Village Hall in Summercourt and is open to anyone suffering from Parkinson's, their carers and/or partners. There is no audition and no requirement that you can sing at all. You are welcome to just come and listen and meet people. If you need any further information, my telephone number is below.

Pre covid, we occasionally visited Old Peoples homes and inflicted our singing on their helpless residents, who generally seemed to enjoy the experience. We have not yet restarted this, as I don't know if these homes are ready to receive us yet with the continuing levels of covid and flu. If anyone knows of a home that would like such a visit perhaps you could let me know.

Martin Roden

Phone: 01637 873656

LOCAL CONTACTS AND SOURCES OF INFORMATION

Parkinson's Nurse Service

Parkinson's Nurse Service

01209 318048

Pdnurses.cornwall@nhs.net

(Recorded message covering the whole county with advice, and explaining the current service)

Appointment changes only (NOT Nurses)

01209 318050

Neurological Advice Service

Mary Eason and Bernadette Murray

01209 318106

cpn-tr.NeuroRehab@nhs.net

(Answerphone service – please leave a message and one of the advisors will call you back)

Living Well with Parkinson's Programme

Jane Rideout

livewellwithparkinsons2021@gmail.com

Website

<https://www.livewellwithparkinsons.uk>

Parkinson's UK Representatives

Local Parkinson's Adviser

Kirsty Maidment 0808 800 0303

hello@parkinsons.org.uk

The whole of Cornwall and Isles of Scilly

Network Support Officer

Mary Jane Hunter 0344 225 3695

mjhunter@parkinsons.org.uk

LOCAL CONTACTS AND SOURCES OF INFORMATION

Contacts for Mid Cornwall, West Cornwall & IoS Branches

Mid Cornwall

<u>Chairman</u>	Jan Wilder 01726 61502 chairman@parkinsonscornwall.com
<u>Vice Chairman</u>	Position vacant
<u>Secretary</u>	Sue Whipps 01503 262166 secretary@parkinsonscornwall.com
<u>SE Cornwall Rep</u>	Tom Bevan 01579 321132
<u>Newsletter</u>	Nick & Jan Wilder 01726 61502 newsletter@parkinsonscornwall.com
<u>Membership Sec</u>	Terry Littlechild 01726 813704 membership@parkinsonscornwall.com
<u>Treasurer</u>	Nick Wilder 01726 61502 treasurer@parkinsonscornwall.com
<u>YOPs</u>	see Facebook group People with Parkinson's in Cornwall

West Cornwall and Isles of Scilly

<u>Chairman</u>	Edward Bolitho 07980 826613
<u>Vice Chairman</u>	Helen Hichens 01736 788309
<u>Acting Secretary</u>	Emily Harris 01736 365267
<u>Treasurer</u>	Rob Burt 01326 221330
<u>Membership Sec</u>	Terry Littlechild 01726 813704 membership@parkinsonscornwall.com

Parkinson's UK Helpline 0808 800 0303

hello@parkinsons.org.uk

Bethel Drop-In at Christmas

We are very fortunate having Wendy, a wonderful volunteer who happens to be the local florist, and subsequently each Christmas, members who drop in to our December meeting are treated to a table of Christmas herbs, coloured ribbons, oasis rings etc. kindly supplied by her, and loads of foliage Wendy had previously extracted from our garden.



So a good time is had by all making, with the odd instruction and helping hand, lovely decorative Christmas wreaths for their homes.

We are eternally grateful to Wendy and her husband for supplying the necessary pieces to make this all possible.

Ed.

Medicine Chest

An update from the Parkinson's Service : January 2023

Hello All,

I thought I would update you all about the new staff members within the team, as well as our ongoing project work.

The team has been joined by two new part time Parkinson's Practitioners. Nicky is a Physiotherapist working in North & East Cornwall and will be working in the same way as Loraine. Sarah is a nurse working with Karen in the west of the county and this brings our

clinical team numbers up to six. Dawn joined the team towards the end of the year and is working with Annie from an admin perspective.

We continue working with colleagues within the community Hospitals in Cornwall to ensure that medication is administered on time. All the community Hospital wards are now engaged with this project work, and it is very pleasing to see that this project is working.

The Physical Self Management Group continues to be delivered by the Parkinson's Neuro Physiotherapist Dr Sophia Hulbert for people who are newly diagnosed.

We are also one of eight Parkinson's UK accelerator sites nationally to enhance multidisciplinary links in Cornwall and this is going well.

The National Parkinson's UK audit has taken place and we await the results of this early this year.

A research study called "Live Well with Parkinson's" is still running at the current time. This study has a 50% chance of people receiving a facilitated toolkit to manage their Parkinson's symptoms. Usual care continues but would be enhanced, proving knowledge and support to recognise and self manage symptoms you may have. For further information please contact Charlotte Moorehouse, Research Nurse via email charlotte.moorehouse@nhs.net

Have you been diagnosed with Parkinson's for a number of years (known as the complex stage) and consider yourself to be in the difficult situation of speaking to a number of different healthcare professions about your symptoms?

As part of our Parkinson's UK work to develop multidisciplinary care in Cornwall, Sophia Hulbert and myself would like to ascertain your views, via an online meeting, or face to face at Camborne Redruth Community Hospital.

If you feel you could help us with this valuable piece of work by answering a few questions about your experiences, we would be very grateful. To register your interest please email Lynne Osborne, Consultant Nurse Parkinson's Service via pdnurses.cornwall@nhs.net

Lynne Osborne, Consultant Nurse Parkinson's Service



Pill Timers

Do you want help to get your medication on time? We have the Tabtime Super 8 pill box, on which you can set up to 8 daily alarms, available at £5 each (inc postage), subsidised by the Mid Cornwall Branch.

For more information on how to get one, phone Rowena on 07813 548767 and you will need to send a cheque, made out to Parkinson's UK, to the Treasurer Mid Cornwall Branch, The Elms, Trethowel, St. Austell. PL25 5RR. or arrange with him, see middle pages, to pay by bank transfer, treasurer@parkinsonscornwall.com

Please note that this is not a Parkinson's UK product and is not endorsed by Parkinson's UK, though they are sold in their shop @ £26. Parkinson's UK is not responsible for the quality, insurance or upkeep of this product, nor for any loss or damage incurred as a result of its use.

Research

ED: We unfortunately misfiled this next piece by Dr Christine and it should have been in the Dec n/l. Our apologies

Research News Update from Dr Christine Schofield

**and the Research Team at the Royal Cornwall Hospitals Trust
based at Treiske, Truro but covering all of Cornwall!**

The Research Team needs your help!

First of all **THANK YOU** to all the people who have contacted us to join the **new AND-PD study** . Its proving to be a popular study in Cornwall so we can make a real contribution nationally. We can now accept more people so if you would like to take the next step,

please get in touch *as soon as possible*. Details were in an earlier newsletter but as a reminder....



AND PD

- The pattern of anxiety and depression in PD differs from that in people without PD.
- The differences can sometimes be reflected in some PD people with differences in their patterns of tremor, sleep and other physical features.
- It can be linked to differences in emotion pathways in the brain

- The AND study is for people with **or** without anxiety or depression
- Partners or friends of a PD person can join the study as a 'control' if their partner also joins up
- Assessments include medical history, medical examination, questionnaires, optional blood and saliva tests
- The various tests can be done online including via the hospital video system 'Attend Anywhere'. We may be able to also offer in person visits at the research clinic at Treiske hospital, Truro
- There are 3 visits: baseline then 6 months and 12 months
- There is an entirely optional MRI scan but this is done in London if anyone wanted to combine it with a visit to the capital!

- It does not involve any medication
- The study is open to people between 18 and 89 years
- The study excludes people who have had a serious head injury or who have atypical PD

Although we can no longer accept people for the ADEPT-PD study , we are still open for OCEAN and PD Frontline



OCEAN: is a short 6 month study looking at the effect of opicapone (an existing PD medication) on pain of any type in Parkinsons. It involves several visits to the Knowledge Spa research unit at Treliske. You must not previously had opicapone which is taken as one tablet, once a day.



PD Frontline: is a study looking at common genes in Parkinsons done entirely at home online answering a short questionnaire. You also provide a saliva sample by post. For further information and to join if you wish to, contact

www.pdffrontline.com

Important: Please give RCHT Royal Cornwall Hospitals Trust as your 'home' area when asked.

Please get in touch! Christine.schofield1@nhs.net

I can then ring you for an informal chat so we can see if the research is right for you and you are right for what the study needs.

You can also ring Suzy Dean, the team's senior research nurse on 01872 255177

Wishing you a happy new year!



Looking Ahead

Promas CIC: Face-to-Face Courses Feb to May **Informative Courses**

Caring for Carers (10am-4pm)
1 day May 9 Truro Library

Caring for Dementia Carers (10am-3:30pm)
2 Days March 7 & 8 Penzance

Managing Stress for Carers (10am-4pm)
1 day March 1 Truro Library

Recreational Courses

Making Time for Art for Carers (10am-4pm)
5-week course: May 4, 11, 18, 24 & June 15 Truro Library

Nordic Walking (10am-12)
Every two weeks: starting March 3 Trelissick Gardens
Weekly sessions: Every Wednesday Wadebridge

Mindfulness Class (1.30pm-3.30pm)
every three-weeks starting March 16 Pool

Contingency Planning (10am-1pm)
1 day March 21 Liskeard

Managing Grief for Carers (10am-2pm)
Every 2 weeks starting Feb 9, 23 ending March 9 Penzance

Social Meet Events

Feb 21 Newquay Zoo 11am

March 14 Trelissick House & Gardens 11.30am

April 19 Seal Sanctuary 10am

May 16 Trerice House & Gardens 2pm

Email – info@promas.co.uk

Website – www.promas.co.uk

Tel – 01736 339226 / 07775756454

COUNTY WIDE MEETINGS

We have a number of monthly meetings run by our Parkinson's groups and branches, they are:

	Contact nos.
BUDE group on 2 nd Sat	01237 441913
TORPOINT Shuffle Club on 1 st Thu	01752 822870
WADEBRIDGE Drop-In on 4 th Mon	01503 262166
GOLDSITHNEY Meeting on 3 rd Fri	01736 365267

These are generously supported by local Rotary Club members

EAST TAPHOUSE Drop-In 3 rd Wed	01503 262166
ST AUSTELL Drop-In 2 nd Wed	01726 61502

ACTIVITY MEETINGS run by the branches

PD Active on Zoom Thurs (term-time) 12.30-13.15	01326 561012
SINGING on Zoom every Other Wed 11-12.30	01209 698631
TOWNSHEND Singing every Other Wed (Alt. with zoom)	01209 698631
SUMMERCOURT Trembellows every Monday	01726 61502
GOLDSITHNEY Exercise to Music every Monday	07773 669667

MOST DO NOT MEET IN AUGUST, CHECK WITH THE CONTACT

Wherever you live in Cornwall and the Isles of Scilly, you are all welcome at any of the meetings and events mentioned in this newsletter.

Just follow the instructions to make a booking.

DISCLAIMER. Whilst every effort is made to ensure all details in this News and Information letter are accurate at the time of publication, The Editors, The Mid-Cornwall Branch and the West Cornwall and Isles of Scilly Branch of Parkinson's UK or any Committee Member do not accept any responsibility for the accuracy of information or of any technique, medication or treatment.

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THE DEADLINE FOR NEXT EDITION IS 15th March