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

News and Information Letter for Cornwall and the Isles of Scilly

April/May 2024

Editorial Thoughts

The Branches' year closes with the AGMs in March and opens again with new committees. This year also brings a change in Newsletter Editor. I am Kay Maycock, for any newer readers I was Editor from 2018-2022. The new format of the Newsletter is an interesting challenge! The back page will again have the details of our countywide meetings, and will also contain the contact details and sources of information that used to be elsewhere in the edition. The front page will have my pick from the submitted articles each issue to be the "Feature Article". It was an easy choice for me this time as we have reports from the Branch AGMs.

I hope you will find something of interest between the front and back pages!

Feature Article

West Cornwall and Isles of Scilly Branch AGM Fri 15th March '24 - St Piran's Hall, Goldsithney



Front: John Hurr, President; Sheila Gannaway. Back: Emily Harris, Secretary; Helen Hichens, Vice Chair; James Belmour; Brian Gannaway, Treasurer

It was a Friday, though not the 13th, yet it seemed the fates were out to scupper our planned AGM this year. Even men digging up the access road tried to thwart us with Road Closed signs and their vehicles blocking the way!

Eventually, thanks to our committee member James, difficulties were overcome and in a first for the West Cornwall branch, the meeting was presided over by a Parkinson's UK representative in Oxford via a video link.

All existing committee members were willing to remain in position and were voted back unanimously. (Edward Bolitho, Chair, was unable to attend).

Mid Cornwall Branch AGM Wed 20th March '24 – East Taphouse

Jan Wilder was sadly unable to chair the meeting as she was in hospital. Her report was read by Acting Chairman Neil Stewart. After a presentation to Sue Whipps thanking her for her many years of service on the committee, the Parkinson's UK rep Karen Safe stood down the old committee and supervised the election. The meeting closed with a talk from Kay Maycock on the role of the Newsletter.

The new committee is
Neil Stewart, Chairman
Chris Maycock, Vice Chairman
Jane Selby, Minutes Secretary
Tom Bevan
Morag Coley
Steve Serevena
Nick Wilder

Bear Millard, Secretary
Pepe Millard, Treasurer
(Both pictured right)



West Cornwall Branch

Why not try a new activity in 2024? Here's what's on offer in the west of the County

- Monday Get moving with Caroline Schanche's Exercise to music, at St Piran's Hall,
 Goldsithney from 11.15 to 12.15, followed by refreshments. Caroline 07773 669667
- <u>Tuesday</u> There's short mat bowling also at St Piran's Hall, Goldsithney from 2 to 4pm. Table tennis also available. To check session dates, contact Arthur or Glynis on 01326 753098 or 07808 315700

Or NEW! Parkinson's specific exercise at Camborne Community Centre, 1.30 – 3.00, including refreshments, with Martha Huntley 07719 700993 martha.huntley@moveitorloseit.co.uk

 Wednesday Splash your way to fitness in the 34 degrees salt water hydrotherapy pool at Harbourside Physiotherapy in Newlyn 11.30 – 12.30. 01736 366224 or email main@harboursidephysiotherapy.co.uk

<u>Or</u> Exercise your voice with <u>Sing for Fun</u> led by Gail Hampshire. Whether a show tune or a shanty, there's bound to be something to take your fancy. At Townshend Village Hall on 1st and 3rd Wednesdays of the month, and on Zoom wherever you live on 2nd and 4th Wednesdays.

Gail 01209 698631 / 07421 765812 gailhampshire@outlook.com

• <u>Thursday</u> PD Active - exercise sessions led by physiotherapist Becky Duncan, in person at Helston and also on Zoom.

Contact Becky on 01326 561012

Also NEW! Dance for people living with Parkinson's at the Hall for Cornwall, Truro, monthly. For details contact Caroline 0773 669667 or Jayne 07840 109505 Email hello@innergrounddancecompany.com

• <u>Friday Parkinson's specific fitness session including boxing moves</u> organised by and held at Penzance Leisure Centre 2.15 – 3.10.

Penzance Leisure Centre 01736 874744

Join West Cornwall & Isles of Scilly Branch for a FISH & CHIP LUNCH

At Becks Fish & Chip Restaurant, Longstone Hill, Carbis Bay TR26 2LJ on Friday 12th April 2024 From 12.00 noon for 12.30 dining

Choose from menu and pay on the day

Small portions available. Fish in batter, grilled or steamed.

Gluten free option.

Please contact the restaurant for further information on options for special diets 01736 796241



All welcome, including family and friends

Please contact Emily Harris by 8th April to make a reservation

Email: empem108@gmail.com Tel: 01736 365267

Mid Cornwall Branch

A Message from the Chairman



Firstly may I say how pleased I am at being able to be there for you all as Chair of the Mid Cornwall Branch of Parkinson's UK. Like all of the committee I am a volunteer and, like many of you that read this, I have Parkinson's. At our recent AGM it was really good to meet everyone and I was heartened to see how many were keen to participate in the discussion. Thank you for the enthusiasm and encouragement. As new Chair with a new Secretary and Treasurer, we hope to bring some freshness to the group whilst valuing and working with the experience and wisdom of the more established people around us.

I feel strongly that it is important to raise awareness of Parkinson's, how it affects people and how others including healthcare professionals and the wider public can help, either locally or through Parkinson's UK.

As Chair I would like to take the opportunity to bring together the committee and volunteer teams of the Mid Cornwall Branch, working with them and helping us all develop so as to give the best possible support that we can to people who have Parkinson's.

As a volunteer, I have experience of being Chair of local charity branches including a counselling service, help for the unemployed and chair of a Scout group amongst other things. I was also on the training team of the local branch of Samaritans in Reading. Most of my professional life has been spent in people development, specialising in strategic marketing, and was for some time a member of faculty at the Chartered Institute of Marketing. I also worked as Marketing Consultant on their behalf. After retirement, as a mature, if that's the right word, student I finally, successfully completed and received my Master's degree.

I am married with three grown up children and four grandchildren. I enjoy being with the family, photography, history, digging in to the family tree and singing.

Neil Stewart

So what does go on at East Taphouse Drop-in?

Hello. I run the East Taphouse Drop-in which meets on the third Wednesday of every month (except August). But the name does not fully describe what actually goes on there. Every month people newly diagnosed or who have been too nervous to come along before now come and join in.

At East Taphouse we make the meetings light hearted, informal and welcoming. We try, as often as we can, to vary the day. We might have a quest speaker talking about their interest, somehods with a Parkinson



a guest speaker talking about their interest, somebody with a Parkinson's specialism who can share information, or a more practical programme of exercise or craft.

BUT, it's not all business, there's always plenty of time to chat and drink tea and coffee with others in the group and even join in with a quiz or two. At 12:15 ish, we break for lunch. You can pre-book a two course hot meal or bring your own packed lunch. (Partners are welcome and it saves cooking that day.) There is a smaller second room in which people can have more confidential chats if they wish. Groups of Care partners frequently meet in there while their partners with Parkinson's are taking part in the activity in the main hall.

So why is it called a Drop-in? Well nervous newcomers and people with appointments may not want to stay all morning. You can come and go as you wish: drop in and out as you want.

Come and try us out.

Sue Whipps

Looking Ahead

April and May Courses



Caring for Carers

• Caring for Someone with Mental Illness

 Dementia Carers and their Cared For: Caring for Dementia Carers

Managing Grief for Carers

Carers Coastal Walking Group

St. Michael's Mount

Minack Theatre

Saltash 8th May 10:00am-4:00pm Truro 11th April 10:00am-4:00pm

Lanivet 23rd and 30th April 10:00am-3:30pm

Truro: 22nd May, 5th & 19th June 10:00am-2:00pm Penzance: 3rd Wednesday of every month starting

April 17th meeting at 11:00am 22nd April 10:30am - 12:30pm

9th May 11:00am-1:00pm

Email – <u>info@promas.co.uk</u>

Website - www.promas.co.uk

Tel - 01736 339226 / 07775 756454

Expert patient programme

Online

Wednesdays, 24 April to 29 May 2024, 11am to 1.30pm



- Give you additional skills to self manage your long term health condition
- improve your quality of life
- · meet others and share experiences
- communicate better with family, friends and professionals
- make you feel confident and more in control of your condition

This course is for anyone with a long-term health condition and is delivered over 6 weekly sessions for 2.5 hours. The sessions are led by volunteer trainers with lived experience.

Course sessions will cover

- relaxation techniques
- dealing with difficult emotions
- exercise and how to eat healthily
- coping with depression
- pain and fatigue management
- planning for the future

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email cpn-tr.epp@nhs.net Call 078424 598626 or leave a message at 01579 373500 for details



FREE

COURSE

Medicine Chest

New infusion treatment for Parkinson's Disease



Some of you will have noticed the article in Parkinson's UK on Oct 26th '23 about Produodopa (Foslevodopa/Foscarbidopa). This is a subcutaneous infusion of medication delivered through a fine needle under the skin by a small pump worn 24 hours per day. The National Institute for Clinical Excellence has approved the treatment for use in England and Wales for people with Parkinson's who have inadequate control of motor symptoms on best oral therapy, but who are not suitable for Neurosurgical treatment' or Apomorphine infusion, or these

treatments no longer control their symptoms. This is likely to be relevant to a number of patients in Cornwall.

Your Community and Hospital Parkinson's team in Cornwall are in discussion with other Centres in the Southwest Peninsula to ensure we have a robust, equitable system for assessment for patients who may be suitable. We are applying to have the new treatment approved for our drug formulary so that it will be available for prescription. There is also work going on to ensure we have the staff (particularly nursing) the training, equipment and capacity to deliver the treatment which we will be discussing with our commissioners.

We were very pleased to hear the positive experience of 5 patients from Plymouth who took part in the clinical trial of Produodopa who are now established on treatment and we will be keeping you informed of our progress.

Lynne Osborne (Nurse Consultant) Jade Thomas (Specialist Registrar) Rod Bland (Consultant)

Research

Do you have 30mins to spare to talk about mental imagery (in person or on Zoom)?

We are planning to conduct some work on a new psychological intervention to help with motivation for people with Parkinson's. The psychological intervention involves teaching people to use mental imagery to achieve their goals. The approach has been used successfully in professional athletes, soldiers and a variety of medical conditions. But we don't know about the appropriateness of this technique in people with Parkinson's. That's why we would really like your help – to let us know how to adapt this technique for people with Parkinson's.

We are looking for 3-4 people with Parkinson's who would be willing to discuss (30 mins, online or on Zoom) this work.

If interested, please contact sean.fallon@plymouth.ac.uk

Peninsula Parkinson's Research Interest Group

If you've watched our "Sugar and Spice" video with Dr Laurie Mischely about Diet and supplements, and even if you haven't, this is an excellent companion. Her talk "What do successful people do to slow down PD progression" is a mine of useful information.

You can find her talk on the nosilverbullet4pd YouTube channel. Take some time out to watch this and maybe enjoy the dogs towards the end.



COUNTY WIDE MEETINGS

SOCIAL MEETINGS

Monthly meetings run by Parkinson's branches

BUDE group on 2nd Sat 01237 441913 TORPOINT Shuffle Club 1st Thu 01752 822870 GOLDSITHNEY Meeting 3rd Fri 01736 365267 LAUNCESTON Cafe 1st Tue 07502 246311

(Drop-Ins generously supported by Rotary Club members)

EAST TAPHOUSE 3rd Wed 07958 716882 ST AUSTELL 2nd Wed 01726 61502

THERAPY MEETINGS
Activities funded by Parkinson's branches

PD Active (Zoom) Thurs (term-time)

12.30-13.15 01326 561012

SINGING (Zoom) 2nd, 4th & alt 5th Wed

11-12.30 01209 698631

TOWNSHEND Singing 1st, 3rd & alt 5th Wed

11-12.30 01209 698631

SUMMERCOURT Trembellows every Mon

01726 61502

GOLDSITHNEY Exercise to Music every Mon 07773 669667

Parkinson's UK helpline 0808 800 0303

hello@parkinsons.org.uk

PARKINSON'S UK REPRESENTATIVES Local Parkinson's Adviser Kirsty Maidment

hello@parkinsons.org.uk 0808 800 0303

Network Support Officer Mary Jane Hunter mjhunter@parkinsons.org.uk 0344 225 3695

SOURCES OF INFORMATION

Neurological Advice Service Mary Eason and Bernadette Murray cpn-tr.NeuroRehab@nhs.net 1209 318106 (Answerphone)

Parkinson's Together – online support group Jane Rideout

parkinsonstogether@gmail.com
https://www.parkinsonstogether.uk

Parkinson's Specialist Nurse Practitioners
Mon – Fri 9.00 to 17.00 01209 318048
pdnurses.cornwall@nhs.net

https://cornwallft.nhs.uk

Appt. changes (NOT nurses) 01209 318050

BRANCH CONTACT DETAILS

Mid Cornwall

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vice-chair@parkinsonscornwall.com

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<u>Treasurer</u> Pepe Millard 07877 277642 treasurer@parkinsonscornwall.com

Membership Terry Littlechild 07508 093893

membership@parkinsonscornwall.com

YOPs: see Facebook group:

People with Parkinson's in Cornwall

West Cornwall and the Isles of Scilly

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DISCLAIMER. Whilst every effort is made to ensure all details in the News and Information Letter are accurate at the time of publication, the Editor, the Mid Cornwall Branch and the West Cornwall & Isles of Scilly Branch of Parkinson's UK do not accept any responsibility for the accuracy of the information. The views of the editor are not necessarily those of Parkinson's UK.

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DEADLINE FOR NEXT ISSUE 15th May 2024

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