

Horsham Branch Newsletter

<https://horsham.parkinsonsuk.group>



February 2025

Chairmans Report

Mike Onley

My flying career came to a grinding halt when



I was diagnosed with PD in June 2019 at the age of 60. Like many people who are diagnosed with PD, I went through a phase of shock and disappointment before coming to terms with the diagnosis.

Eventually, I decided to get involved with the PDUK charity and joined the Horsham Branch in 2021.

Following a period as the research member on the committee, I took over as chair at the beginning of 2024, following Tom Dellman, and before him, Paul Dodd; two big pairs of shoes to fill! Thanks to them, the rest of the committee, and you, the

membership, we have a solid base to work from. Treasurer Dennis is keeping our finances on an even keel, and we are generating funds that allow us to support various research projects and subsidise activities for our members.

Three of Tom's visions have borne fruit this year.

The Working Age Group (WAG), which is expertly administered by our very own Wagamama, Emma Brinton.

The PD Warrior program, which starts a second cohort in April,

and the website, which is now very much live thanks to the hours of graft put in by Jeremy and James.

Our branch meetings have covered subjects as diverse as Birds of the Amazon, guide dogs, research updates, and estate planning! We've enjoyed a quiz night, a brilliant Elvis night (thanks Trish), a summer day out, and a couple of January Christmas dinners! We've also run a few chess and games sessions, and we'll hopefully have time for more of that after the AGM.

There's plenty of things we can do better! Specifically with follow up support for members who become ill or go into care homes.

We would appreciate your suggestions, and if anyone would like to join the committee let us know.



However, if there's one sentiment that sums up my vision for the branch, it is a point made by one of our members at the WAG pub gathering the other night. They said that the branch had helped them find new genuine friendships with local people

I know we would all hand back our PD in a flash. But there's a silver lining to every cloud, we've just got to help each other find it.

Treasurers Report Dennis Saunders



I have been treasurer of the local branch of Parkinsons since January 2010 and this is my 15th presentation to the branch AGM.

The detailed submission has been sent to head office, and provisionally approved, and a summary of these was presented to the AGM on the 7th February.

1. Legacy money from Ron and Jean Kent of £4250 although this is the last year of this legacy amounting to £17,000 over the 3 years of the legacy.
2. Mannings Heath Hall activities which, due to the fact that most instructors give their time to our group, make a profit.
3. Collections from street, supermarket and garden centre collections raised about £3000 making a total of £33,600 since I started organising these collections in 2010.
4. General fundraising including 2 major events in 2024; The "Almost Elvis night" and the "Up country garden centre

Santa event "

5. Donations, Miscellaneous receipts and membership fees

We spent about £25,000 in 2024 made up of

1. £12,000 were sent to HQ to support research projects making £131, 000 sent to HQ since I started as Treasurer
2. Physios at Horsham hospital over and above members payments
3. PD warrior program with a second tranche planned for 2025
4. Art Classes
5. Monthly socials, lunches and outings

We have a healthy balance in the bank and the outlook for 2025 remains good however, the legacy money has ended and, in addition to the established fundraising such as collections, we will have to organize a major fundraising event to replace the money raised for the major events in 2024.

Media/Research Report

Jeremy Collyer



Website

Our website is constantly evolving. We are already on our 2nd major revision. We can provide much more information on the web than in a printed document. Current website content include:

- A news section, updated on a weekly basis
- An archive of most of the previous newsletters
- A list of previous branch meetings,

with links to videos of interesting presentations

- Access to an online calendar, so you can see what is on at a glance
- Useful Internet links to reliable sources of information about research in Parkinson's
- A comprehensive list of all of our activities, graded into high medium and low intensity

We value your feedback and encourage you to reach out if you feel there's something missing or something should be removed.

I'm also aware that some of our members may not have limited or no internet access, making it challenging for them to access the information they need. In light of this, we're planning to continue with the newsletter for the time being. We'll strive to keep it as concise as possible.

Research Update

As far as research is concerned, 2025 promises to be an exciting year. After the disappointing outcome of the Exenatide trial in Oxford, there are several other phase 3 trials involving similar drugs (GLP1 Agonists) which should be published this year. Many of these drugs are primarily used in diabetes and weight loss. They have also been found to slow progression of Parkinsons in phase 2 trials.

The possibility of a drug that can potentially slow the progression of Parkinson's has never been closer.

2 other exciting areas of research that are closer to real-world application include adaptive DBS (Deep Brain Stimulation) and stem cell transplantation. These are both at the phase 3 trial stage.

DBS has been refined to allow for a degree of auto-tuning, ensuring that the DBS is always at an optimal level. This auto-tuning happens continuously without the need for adjustment in the clinic

After numerous disappointments, it appears that many of the challenges associated with stem cell transplantation have been resolved. This is primarily due to the shift in usage from fetal material to IPS (induced pluripotent stem) cells. IPS cells are laboratory-processed stem cells derived from ordinary skin cells that are re-programmed to produce dopamine-producing cells.

These cells are then implanted into the brain. The progress made so far suggests that this approach is significantly safer than previous methods. Fetal tissue is not used, avoiding ethical issues. A very large number of cells can be produced in a very short space of time making the technique cost-effective..

The major downside is that it takes 2 years for the implanted cells to integrate with the rest of the brain. It also important to note that that these implanted cells may be subject to the same factors that produced the individuals Parkinsons in the first place, long term followup is needed to assess if stem cell recipients develop further Parkinsons in their repaired brain tissue. If you want to know more check out the link on our website.

Membership renewal

Carol Matthews

Please can you make sure that you have renewed your membership using the form either provided with the printed version of this newsletter or on the website.



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Website/research/news-letter

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Co-ordinator: Boxing/PD Warrior/Yoga/Working Age Group

Emma Brinton

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Co-ordinator: physio gym exercises/ Qi Jong

Cath Stead

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Co-ordinator Pilates/Table Tennis/Chair Dancing/Speech Therapy/Dance to live well

Sue West

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Co-ordinator: Boxing/PD Warrior/Yoga

Maija Bruce

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Co-ordinator: Argentine Tango

Paul Dodd

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Co-ordinator: Art Workshop

Aimee Bleach

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Dates at a Glance

February

27/2/2025 19:00

Black Jug social - Horsham
Contact Emma

March

5/3/2025 13:30

speech Therapy - new class - MHVH
Contact Sue

7/3/2025 11:30

Branch Meeting - MHVH
Test Pilot, Simon Wood

13/3/2025 19:00

Southwater social
Contact Emma

14/3/2025 09:00 - 16:00

Waitrose Collections
Contact Maija

27/3/2025 19:00

Black Jug social - Horsham
Contact Emma

29/3/2025 time & venue tbc

PD Warrior assessments
Contact Emma/
Jeremy

April

2/4/2025 16:00

MHVH
PD Warrior 10 week challenge

4/4/2025 time tbc

Branch Meeting - MHVH
speaker tbc

10/4/2025 19:00

Southwater social
Contact Emma

12/4/2025 09:00 - 16:00

Town Centre Collections
Contact Maija

21/4/2025 bank holiday

Pilates and social cancelled

24/4/2025 19:00

Black Jug social - Horsham
Contact Emma

May

5/5/2025 barbara away

Pilates and social cancelled

6/5/2025 barbara away

chair dancing cancelled

10/5/2025 barbara away

chair dancing cancelled

8/5/2025 19:00

Southwater social
Contact Emma

22/5/2025 19:00

Black Jug social - Horsham
Contact Emma

25/5/2025 19:30

Southwater Sports Club
Quiz Night - tbc

26/5/2025 bank holiday

Pilates and social cancelled

June

6/4/2025 time tbc

Branch Meeting - MHVH
Parkinsons Care Speaker tbc

12/4/2025 time tbc

Hilliers Garden Centre
Contact Sue

28/6/2025 19:00

MHVH
Summer Ball

For update see online calendar

