

Newsletter November 2024

Horsham and District branch

DATES AT A GLANCE

- 6th December 11.30 Guide Dog visit and maybe some Christmas Music.
- 3rd January 11.30 Birds of the Amazon Basin. Alan Wilkinson
- 18th January 12:00 Christmas Lunch Roffey Institute
- 7th February 17:30 AGM followed by games

ACTIVITY OVER CHRISTMAS PERIOD

- There will be no Pilates on Monday 23 December or Monday 30 December
- There will be no chair dancing on Tuesday 24 December or Tuesday 31 December
- There will be no table tennis on Wednesday 25 December or Wednesday 1 January

- There will be no dance to live well (aka ballet) from Wednesday 7 December to Wednesday 1 January
- There will be no physio led gym exercises on the 25,26 December and the 1,2 January

BRANCH NEWS AND UPDATES

BRANCH CHAIR

MIKE ONLEY

As the year swiftly comes to a close, December has arrived once again. The winter months can be particularly challenging for individuals with Parkinson's (PWP) and their carers or partners. The cold weather can exacerbate joint stiffness, while the dark mornings and evenings may sap our motivation and enthusiasm for participating in activities and social events, even though we recognize their benefits. Additionally, the medications we take can complicate engagement in festive celebrations, as



combining Parkinson's medication with alcohol can have adverse effects.

This underscores the significance of our group. We strive to offer valuable information, social interaction, friendship, various activities, and fundraising opportunities to support progress in combating this disease. Within our membership, we have witnessed successful outcomes from operations involving deep brain implants and medication pumps. Furthermore, several members are effectively utilizing devices such as the CUE 1, and many benefit from high-intensity exercise programs, which are now deemed crucial in mitigating symptom severity for PWP.

Reflecting on the past year, we have experienced numerous highlights. I must first acknowledge that none of these achievements would have been possible without the dedication and contributions of our committee, volunteers, and all our members, including both PWP and carers/partners.

2024 has been an exceptionally active year for our group. Thanks to the efforts of Paul, Dennis, and others involved, we raised substantial funds through collections, raffles, and Santa's grottos. Cher and her team organized an outstanding quiz night in the summer at the Southwater Sports Centre. The club generously allowed us to utilize their facilities for their monthly quiz, and we hope to host another event in 2025.

The highlight of September was the Elvis night, which was not only a fantastic party but also raised over £3,000 for our group. A special thank you to Trish for organizing this event. Diddy David Hamilton, who looked remarkably youthful, introduced the evening, and Elvis delivered an impressive performance. Although Trish has now retired, we aspire to host a similar event next summer.

Our branch meetings have generally seen good attendance, featuring diverse content ranging from

research presentations to game sessions. This approach will continue in January with a captivating presentation on South American birds, followed by a games session at the AGM in February. The Working Age Group (WAG), initiated by my predecessor Tom Dellmann and effectively coordinated by Emma Brinton, continues to thrive with new members joining. Meeting on the second and fourth Thursdays each month at the Lintot in Southwater for chat and chess, these gatherings have fostered strong friendships and given newly diagnosed PWP a chance to meet others with similar stories to tell.

Another significant development this year has been the launch of our branch website in October, intended to become the primary information source for our membership. My gratitude extends to Jeremy and James for their hard work in this launch. While we will continue to print hardcopy newsletters for some time, I encourage everyone to explore the website. I also want to acknowledge Sue's diligent work on the newsletter over the years, with assistance from Jenny. The newsletter was well-received within the Parkinson's community, and I hope the website will achieve similar popularity.

In conclusion, I extend my best wishes for a happy Christmas and a peaceful New Year. Let us remember absent friends in our thoughts and prayers. Sara and I look forward to seeing you at the next branch meeting in January or at the Christmas lunch.

PD NURSE UPDATE

STEVIE LEWIS, NIKKI EVANS



With the incidence and prevalence of Parkinson's disease rising, the workload of the local Parkinson's nurse team has increased. We are now fortunate to have two Parkinson's nurses: Stevie Lewis who has run the service for 4 years, and Nikki Evans, who covered Stevie's maternity leave, and is now working with Stevie 3 days a week.

Stevie works Monday- Thursday, and Nikki works Monday's, Thursday's and Friday's.

Nikki runs a clinic every Friday at Horsham hospital and Stevie will be setting up a clinic one afternoon on a Monday or Tuesday. They both also see patients in their own homes throughout the week.

Our service includes:

- Reviewing medication
- Providing lifestyle advice
- Emotional support
- Problem solving
- Helping patients access additional support and advice regarding symptom management
- Providing advice, information and support through telephone reviews and referrals

to multidisciplinary teams / agencies where needed

- Liaising with various healthcare professionals, including your consultants

How can I access this service?

- To access our service, patients must have a diagnosis of Parkinsonism; Idiopathic Parkinson's, Multi System Atrophy (MSA), Progressive Supranuclear Palsy (PSP), Corticobasal Degeneration (CBD), Vascular Parkinsonism, or Lewy Body Dementia
- You must have a consultant Neurologist.

Telephone: 01403 620 437

Email: sc-tr.parkinsonsdiseasenurse@nhs.net

Opening hours: Monday to Friday, from 8:00am to 5:30pm.

Referral information

- Patients must be over 18 and registered with a Horsham, Cowfold or Rudgwick GP.
- You are unable to self-refer to our service. All referrals must come from a GP or consultant

CHRISTMAS EVENTS

PAUL DODD

CHRISTMAS LUNCH

The Christmas lunch is scheduled for Saturday, January 18th at the Roffey Park Institute, Forest Road RH12 4TB. Arrivals are at 12:00 PM, with lunch served at



12:30 PM. Please note that there is a short walk to the restaurant and drinks area.

If you plan to attend, please inform Paul Dodd soon via text at 07818 709 359 or email at doddcp@yahoo.co.uk. Confirmation is required by January 1st along with your menu choices from the provided menu below.

STARTER

- Prawn and Crayfish Cocktail, Avocado and Sweet Paprika
- Smooth Chicken Liver and Cognac Parfait, Toasted Brioche and Fig Chutney
- Roast Mushroom Soup, Toasted Hazelnuts and truffle Oil (GF) CVG)

MAIN COURSE

- Roast Norfolk Turkey - All the Trimmings (GF)
- Fillet of Salmon - Crushed New Potatoes. Tender stem Broccoli, Caper and Parsley Butter (GF)
- Roast Cauliflower Steak - Spiced Lentils. Pomegranate and Coriander with Tahini Sauce (GF) (VG)
- Slow Cooked Feather blade of Beef -All the Trimmings (GF)

DESSERT

- Christmas Pudding
- Brandy Sauce (GF) M
- Chocolate Torte - Fresh Raspberries and Clotted Cream Ice Cream (V)
- Sussex Cheese - Brighton Blue, Sussex Charmer and Golden Cross (V)

HORSHAM BRANCH WEBSITE

JEREMY COLLYER

Website address:

<https://horsham.parkinsonsuk.group>

Scan this code with your Mobile device to access website



We are pleased to announce that we have launched a new website. When searching Google for "Horsham Parkinson's," our site currently appears around fourth on the list. We aim to improve this ranking over time with diligent efforts, eventually securing the top position. The primary objective of our website is to provide comprehensive information for individuals with Parkinson's and their caregivers in the Horsham area.

Websites are dynamic and continuously evolving. It is crucial to keep updating the content to ensure the website remains current and meets the needs of our community. Many people have contributed to the development of this website. Special thanks go to James, who's consistent and sound opinions, coupled with his technical expertise, have been invaluable in getting this website off the ground.

The website includes a list of all the events organized by our branch, along with an online calendar that you can subscribe to, allowing you to

receive event details directly on your mobile device. We recognize that not everyone is tech-savvy, and we plan to offer training sessions to help you make the most of our website. These sessions will be held in conjunction with other meetings in the New Year.

Your opinion about the website is very important to us, and we greatly appreciate your feedback regarding its content. If there is any additional information you would like to see, please let us know. Lastly, but importantly, we fully respect your privacy online. If anyone has any reservations or concerns about the content published on the site, please use the contact page to send us a message, and we will promptly address any issues.

GOING ON HOLIDAY AND HOW TO SURVIVE THE AIRPORT

EMMA BRINTON

You can read Emma's full report on our new website here:



Navigating an airport with Parkinson's Disease (PD) and focal foot dystonia can be challenging. Here's my experience using special assistance services with Easyjet at Gatwick. You can register online for special assistance. On arrival, you can use help points or speak with staff at the drop-off area. Before security, I proceeded to the assistance reception on the second floor of the North Terminal. The staff offered

me a wheelchair, but I declined as walking was fine. I went through a separate, quiet security area with minimal walking.

After security, I reached the dedicated departure lounge for special assistance. You can either wait here or take a buzzer to explore the main lounge. An agent will meet you when it's time to return and transport you and your luggage to the gate in an airport buggy. At the gate, an agent handles your passport and boarding pass and escorts you to the plane, ensuring you board first. A wheelchair is available if needed.

Would I use special assistance again? Absolutely. The process was easy, and the staff were exceptionally helpful and supportive. The minimal walking route through security was a major advantage, making the experience much calmer and quieter. Overall, this service significantly reduced travel stress and made the experience manageable.



RESEARCH UPDATE NOVEMBER 2024

JEREMY COLLYER

PROJECTS WE HAVE CONTRIBUTED TO THIS QUARTER

Slow-SPEED: Slowing Parkinson's early through exercise

Prof Bastiaan Bloom, Radboud Medical Centre

By the time you notice the typical signs of Parkinson's, a lot of damage has already been done. That's why stepping in early, before those symptoms show up, might be the best way to slow down or even stop Parkinson's.

The Slow-SPEED project is looking for people who might be at risk of getting Parkinson's or who are starting to show some early signs. They'll be asked to join an exercise program. The goal is to see if regular physical activity can help slow down the progress of Parkinson's in people who are more likely to develop it.

Predicting Parkinson's (PREDICT-PD)

Professor Alastair Noyce, Queen Mary, University of London

It's not exactly clear why some people get Parkinson's, but it's thought to be a mix of genes and things in the environment. The PREDICT-PD study wants to figure out these risk factors to help spot people who might be more likely to get the condition.

The project has already signed up 10,000 participants to help find some of the first signs of Parkinson's. The team will now collect more results from smell tests, DNA samples, and finger-prick blood tests.

The more we learn about the early stages of Parkinson's, the closer we'll get to finding better treatments and hopefully a cure.

HOW YOU CAN LEARN MORE AND GET INVOLVED IN PD RESEARCH

If you want to know more about PD research, there are many sources of information that you can trust, like the NHS website, Parkinson's UK, and the Michael J Fox Foundation. You can also talk to your doctor or nurse for updates and advice. Another way to stay informed and involved is to join clinical trials, which are studies that test new treatments and ideas for PD. Clinical trials are very important for PD research, because they help us find out what works and what doesn't. You can find out about trials that are happening near you by visiting <https://www.parkinsons.org.uk/research/take-part-research>. The barcode above takes you to this site. By joining a trial, you can help make a difference for yourself and others with PD, and maybe even find a cure.

EVENT REPORTS

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ART CLASS

AIMEE BLEACH



For October's art session we focused on Gel printing nature, inspired by local artist Thomas Honeywood. Honeywood was born in 1819 and became famous for his photography botanical prints. His collection of work can be seen upstairs in Horsham Museum.

We had an array of flowers and fauna and whilst listening to classical music I carried out a demonstration on how the gel plates work. Rolling acrylic paint on top, then placing the flowers and then pressing down a sheet of paper. We had lots of fun, and the results were incredible. We made a Gel print washing line in the hall with a rainbow of beautiful prints hanging off it.

Denise bought along home-grown Cosmos from her garden which she printed in a deep blue. The print came out stunning. After posting a photo of the Cosmo print on social media someone got in touch asking to purchase the print. It sold for £25 with all funds going to Horsham Branch Parkinson's UK. Big well done to Denise! Denise has now ordered some acrylics for home and is planning to do more printing. We're all very proud of you Denise.

The art sessions happen once a month on every 2nd Friday, focusing on different themes. We've had all types of musicians play for the class and learnt about lots of wonderful artists. All welcome to join! Please contact Aimee Bleach 07815969267 if you wish to come along.

BRANCH MEETING REPORT

JEREMY COLLYER

The most recent branch meeting took place on the 1st of November it was well attended, and we were lucky enough to have two excellent speakers. Follow the links for a synopsis of the presentation and a link to the video of the presentation:

- Chloe Lombard/Vicky Knight from LV Rehabilitation Physiotherapy

This presentation reviews the PD Warrior Challenge conducted by Vicky Knight and Chloe Lombard. It provides an overview of the PD Warrior program, which is designed to help individuals with Parkinson's disease through neuro-active exercise, long-term behaviour change, education, and community support. The presentation highlights the 10-Week Challenge, an intensive exercise program aimed at slowing Parkinson's progression. It includes details on the principles of neuroplasticity, the structure of the challenge, and the positive outcomes observed in participants, such as improved movement, body awareness, and reduced anxiety

- Eva Bunting, Senior Clinical Fellow in Neurology at BSUH, Hurstwood Park

This presentation explores the synergy between exercise and pharmacological therapy in managing Parkinson's disease (PD).

It highlights the benefits of intense exercise, such as improved cardiovascular health, balance, posture, mood, and cognition. The presentation also discusses the role of irisin, a myokine that rises with exercise, in mitigating PD symptoms by restoring mitochondrial function and reducing oxidative stress. Additionally, it emphasizes the importance of choosing enjoyable exercises. using medications to enhance motor ability and maintaining a positive attitude towards advanced therapies. Practical tips for integrating exercise into daily routines are provided

If you missed the meeting, you can watch the recording of the lectures on our new website by scanning this code:



ESTABLISHED PROGRAM MEETINGS

BRANCH MEETINGS

6th December 11.30 Guide Dog visit and maybe some Christmas Music.

3rd January 11.30 Birds of the Amazon Basin Alan Wilkinson

WORKING AGE GROUP - INFORMAL GATHERING OF PEOPLE WITH PARKINSON'S AND THEIR PARTNERS

The working age group continues to grow stronger, and it's amazing to see the positive impact it has on everyone involved. It's a joy to watch people with Parkinson's benefit from the exercises and the camaraderie that comes with our sessions.



We're also very excited about our Thursday night meetups. These gatherings are perfect for sharing experiences, discussing problems, and finding solutions together. Starting in the New Year, there will be a change to our meetup schedule. The second Thursday of each month will still be at the Lintott in Southwater, but the fourth Thursday will now be at the Black Jug in the centre of Horsham.

Please make sure to let Emma Brinton know if you plan to attend, as we need to manage numbers for the nibbles and to ensure the pub can set aside a suitable space for us.

Finally, we're delighted to announce a Working Age Group dinner on the 5th of December at Pizza Monteforte. This event is open to all people with Parkinson's and their families. If you would like to join us, please inform Emma of your attendance.

Looking forward to seeing you at these events!

For further details please contact Emma Brinton emma.brinton@sky.com or Tel 07970 898 740.

ACTIVITES MONTHLY ACTIVITIES

ARGENTINE TANGO

First Wednesday of the month, 7pm to 9pm, Mannings Heath Village Hall. All levels of dancers welcome, from complete beginners to experienced exponents. No booking required. No charge.

Refreshments served midway through session.

The session will start with tips on how to cope with poor balance and freezing in everyday life.

You'd be very welcome for these tips and refreshments only if you're not too keen on dancing!!

For further details please contact Paul Dodd 01403 266 173, e-mail: doddcp@yahoo.co.uk

Please note there will be no tango on Wednesday 3rd January.

ART WORKSHOP

Second Friday of every month, 11:30am to 12:45pm, Mannings Heath Village Hall. All welcome, no booking or artistic talent required. All materials provided. No charge. For further information contact Aimee Bleach Tel 0781 5969267 e-mail aimeebleach@outlook.com

WEEKLY ACTIVITIES

CHAIR DANCING

Tuesday, Mannings Heath Village Hall, 11:30am, Chair Dancing followed by tea, coffee and a chat

- Cost £4 per session.



No prior experience or booking necessary, just turn up! Chair dancing is open to all. It is excellent for people with Parkinson's (PWP) and anyone vertically challenged!

There will be no chair dancing on Tuesday 24 December or Tuesday 31 December

PILATES

Monday, Mannings Heath Village Hall, 2pm, Pilates followed by tea, coffee and a chat

Please note this class has very limited capacity to accept anyone new. If you would like to attend, and have prior experience of Pilates, please contact Sue West (Tel 01403 273 064) or Barbara Scarborough (Tel 01403 891 218) and they will advise you if a place becomes available. Cost £4 per session.

Pilates is essentially a floor-based exercise class. Participants must be able to get to the floor and back up unaided. There will be no Pilates on Monday 23 December or Monday 30 December

BOXING

Tuesday, Horsham Boxing Club, Horsham Park, 5:15pm
Boxercise



Release some of that pent up frustration Parkinson's leaves you with!

Numbers at boxercise are strictly limited. To check on availability or express interest in attending please contact Emma Brinton emma.brinton@sky.com or Tel 07970 898 740. There is no charge for boxercise.

YOGA

Thursday, Laurie
Apted Building,
Church Lane,
Southwater,
5:30pm, Yoga

Everyone welcome.
Cost: £4 per session
to be paid in
advance in blocks of
6 weeks, by bank
transfer.



The number of participants is restricted by the size of the venue. To check on availability or express interest in attending please contact Emma Brinton emma.brinton@sky.com. or Tel 07970 898 740.

QI-GONG

Friday, Mannings Heath Village Hall, 10:30am, Qi Gong

Everyone welcome. Cost £3 per session. No prior experience or booking necessary, just turn up! May be enjoyed seated or standing.

TABLE TENNIS

Wednesday, Mannings Heath Village Hall, 10:30am – 12 midday,

All abilities welcome. Cost £5 per session. Please note this is open to all and is not exclusive to people with Parkinson's. There will be no table tennis on Wednesday 25 December or Wednesday 1 January

DANCE TO LIVE WELL

Wednesday, Mannings Heath Village Hall, 3:30pm followed by tea, coffee and a chat

45 minutes ballet-based exercise followed by refreshments. Suitable for all, people with Parkinson's and anyone with balance problems. Cost £5 per session, No prior booking or experience necessary. There will be no dance to live well (aka ballet) from Wednesday 7 December to Wednesday 1 January

PHYSIO LED GYM EXERCISE

Wednesday 5pm and Thursday 5:30pm at Horsham Hospital

Please note booking is essential. Both sessions are currently full with a waiting list. Please contact Cath Stead for details on 01403 731 072 or 07789 778 094. There will be no physio led gym exercises on the 25,26 December and the 1,2 January

PDWARRIOR CONTINUITY

Wednesdays weekly, Mannings Heath Village Hall (MHVH), Mannings Heath, Horsham class begins at 5.45pm for an hour.

This session is primarily aimed at those who have completed the PD Warrior 10 week challenge. There are three zoom PD warrior sessions per month and one face-to-face with an instructor from LV rehabilitation.



However, there is an opportunity for people with Parkinson's to try a PD Warrior session and meet the instructors. This should give you a good idea as to whether this is for you or not,

PD Warrior requires a high level of financial and physical commitment.

Numbers on the initial programme are limited. For further details or to register an interest in this or subsequent programmes, please contact Emma Brinton on emma.brinton@sky.com. or Tel 07970 898 740.

OTHER ACTIVITIES

NEURO HEROES

Keen to exercise but can't
commit to PDWarrior?

Try the Neuro Heroes
programme

Neuro hero's is working
in partnership with
Parkinson's UK to help
remove the barrier to physical activity by subsidising
six classes for people with Parkinson's who would
otherwise be unable to join them.



search: Exercise Fund — Neuro physio led exercise |
Neuro Heroes