

### DATES AT A GLANCE

- **6th September 5.15pm Branch Meeting at Manning Heath Village Hall - Social evening/games. Drinks provided, attendees asked to bring their own food**
- **14th September Elvis night fundraiser at Hurst Cafe, Hurst Road, Horsham**
- **4th October 11.30 Talk by speaker from Silvertime on various topics such as wills trusts, Lasting powers of Attorney and managing care fees etc**
- **1st November 5.30 Horsham PD Warrior outcomes presentation and update on research. Jeremy Collyer**
- **6th December 11.30 Guide Dog visit and maybe some Christmas Music.**
- **3rd January 11.30 Birds of the Amazon Basin. Alan Wilkinson**

### 7TH FEBRUARY 11.30 A TALK ON HEDGEHOGS TBC

#### BRANCH NEWS AND UPDATES

#### BRANCH CHAIR

#### MIKE ONLEY

Welcome to another edition of our newsletter, and thank you to Sue, Jenny and Jeremy for putting it together. The newsletter requires a great deal of work to produce, so we're always looking for assistance from any budding publishers out there!



I took on the Chair role at the beginning of the year, and it's gone incredibly quickly. I'd like to thank the committee for all your work and support. In particular, my thanks to my predecessors, Paul Dodd and Tom Dellman, for all the work they put into the role.

It was Tom who had the vision to set up what has become a really successful working age group. Emma Brinton has now taken on the organisation of that group; under her guidance it goes from strength to strength. While we are on appreciations, I am sure you will join me in thanking Dennis for keeping the sums straight as treasurer, probably the hardest and most time consuming job in the Branch!

I have met most of you at various branch meetings this year, but for those I haven't met yet, let me introduce myself. I spent most of my career as a pilot, first in the RAF flying Nimrod Maritime Patrol aircraft, then for British Airways flying various types. I finished my career as a Captain on the B787 Dreamliner; retiring in 2019 when I was diagnosed with Parkinsons. As is the case with most PWP, the diagnosis was a complete shock. It took a good few months for the implications to sink in. Once I had got past the denial and anger phases, I contacted Parkinson's UK in an effort to get involved with the charity. They put me in contact with Paul and I joined the Horsham Branch.

I was very interested in where we were going on the research side, so, following some really helpful guidance from Dorothy Hatfield, I got involved with publicising and selecting research projects for us to help fund as a Branch. Jeremy Collyer has now taken on this role, and of course, his huge medical experience will be a great benefit to us.

It goes without saying that I would much rather not have ever heard of Parkinson's, however, involvement with the Horsham branch has been really positive for me. I really enjoy working with all of you, and consider myself to be amongst friends. I think that is what the *raison d'être* of the branch should aim to be: an organisation which provides mutual support and friendship for PWP and their partners/carers/ significant others. I think we do quite a lot already, however, there are always new ideas and improvements to be made. With that in mind, I would love your suggestions and comments on the activities and services we provide. Any volunteers to join the committee or to fill the role of deputy chairman would also be very welcome.

One of the things we have brought in this year has been the games sessions. The idea started as an attempt to introduce a Chess session on a monthly basis. However, if you don't fancy Chess, bring along a game that you do fancy such as rummy, dominoes or cards and we can have a go at them. Presently, we are running a game session on the 4th Friday morning of the month at 11:30 at MHVH. We

also run it on the 4th Thursday evening, at the Lintot Arms in Southwater from 7 o'clock. Come along and give it a try, or just turn up for a chat. It would be good to see you there. If anyone fancies taking over the organisation of the Friday games sessions, let me know. As we go to press, the dedicated games sessions at MHVH have been suspended. However, you will have a chance to try them at the Sept branch meeting.

That's it from me for this issue, I hope you enjoy the newsletter. Sara and I look forward to seeing you all soon. Best wishes and Take Care.

## RESEARCH UPDATE AUGUST 2024

### JEREMY COLLYER

Do you or someone you know have Parkinson's disease (PD)? If so, you're not alone. PD is a common condition that affects the nervous system, making it hard to move, balance, and coordinate your body.



About 10 million people around the world have PD, and more people are getting diagnosed as they get older. PD has no cure yet, and the treatments we have now are not perfect. They can help with some of the symptoms, but they don't stop the disease from getting worse or affect other problems like memory loss, depression, or sleep issues. That's why researchers are working hard to find better ways to treat and prevent PD. In this article, we'll give you a quick overview of some of the most important and exciting topics in PD research, from how it all started to what's happening now and what's next.

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#### HOW PD WAS DISCOVERED AND WHAT CAUSES IT

The first person to write about PD was James Parkinson, a British doctor, in 1817. He called it a "shaking palsy", because it made people shake, lose muscle strength, and bend over and walk faster. He

didn't know what caused it or how to treat it. It took more than 100 years for scientists to figure out that PD was linked to a chemical in the brain called dopamine. Dopamine is like a messenger that tells your brain how to control your movements. It is made by a group of cells in the brain called the substantia nigra, which die off in PD. When you have less dopamine, you have more trouble moving and coordinating your body. That's why you get symptoms like tremor, stiffness, slowness, and balance problems.

### HOW PD IS TREATED NOW AND WHAT ARE THE DRAWBACKS

The main treatment for PD is a drug called levodopa, which turns into dopamine in the brain. Levodopa was first used in the 1960s and it's still the best drug we have for PD. It can make a big difference in how you feel and function. But levodopa has some problems too. It doesn't last very long, so you have to take it several times a day, and it can wear off suddenly, leaving you feeling stuck or frozen. It can also make you move too much or too fast, which is called dyskinesia. Other treatments include drugs that act like dopamine, called dopamine agonists, and a surgery that puts wires in your brain, called deep brain stimulation (DBS). These treatments can help with some of the symptoms, but they don't work for everyone and they can have side effects like nausea, drowsiness, confusion, or infection.

### HOW PD MIGHT BE CURED OR SLOWED DOWN IN THE FUTURE

The ultimate goal of PD research is to find a cure, or at least a way to stop or slow down the disease. To do that, we need to know more about what causes PD and how it affects the brain and the body. We don't have all the answers yet, but we have some clues. Some of the things that might play a role in PD are genes, toxins, inflammation, stress, and protein clumps. Researchers are also looking at how the gut, the part of your body that digests food, might be involved in PD. Some of the ways that researchers are trying to protect or fix the dopamine cells are gene therapy, stem cell therapy, immunotherapy, and

drugs that block or remove the bad stuff. But these methods are not easy or safe, and they need more testing before they can be used in people.

### 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



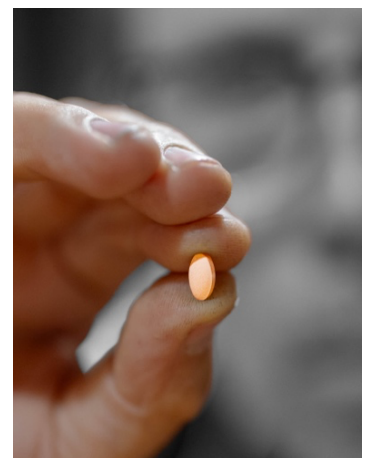
the Michael J Fox Foundation. You can also talk to your doctor or nurse for updates and advice. Another way to stay informed and involved is to join clinical trials, which are studies that test new treatments and ideas for PD. Clinical trials are very important for PD research, because they help us find 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.

### MEDICATION SUPPLY

#### SUE WEST

Here are the latest medication supply issues we are aware of.

Getting your prescription  
Pharmaceutical companies have shared they are facing supply problems with some medicines.



Please check with your local pharmacy, as they may have your usual medicine in stock.

However, if your area does have supply shortages you may not be able to get your usual prescription.

Alternatives may be suitable. Your doctor or pharmacist will discuss this with you.

Parkinson's drugs: current shortages

Updated 7 August 2024

Teva Pharmaceuticals

- Amantadine 50mg/5ml syrup 150ml will experience supply problems until the end of August 2024.
- Amantadine hydrochloride 100mg capsules x 14 and x 56 will no longer be supplied by Teva Pharmaceuticals, but will still be available. The manufacturer, Lucis, will continue to make the product but will no longer be distributing it through Teva Pharmaceuticals

#### .WHY THE UK HAS MEDICINE SUPPLY ISSUES

The UK has some specific challenges, but the NHS is not alone in experiencing drug shortages. A recent European Association of Hospital Pharmacists survey reported that 95% of hospital pharmacists across Europe were experiencing shortages.

The British Medical Journal (BMJ) points to a combination of factors including:

- Post pandemic factors
- Global supply chain issues
- UK-specific challenges are reported to include:
- Post-Brexit costs and paperwork
- A voluntary NHS annual spending cap on branded medicines

#### **PARKINSON'S DISEASE UK LOCAL ADVISOR**

#### **LYNNE BROPHY.**

Parkinson's have increased the number of Advisers who now cover smaller areas. Our adviser is now

Lynne Brophy, who some of you met at our branch meeting a few weeks ago.

Although new to Parkinson's Lynne's background and experience will enable her to help from the start.

If you have any problems with paperwork, grants, blue badges or anything else you need help with, Lynne is the person to contact, if she can't help she will know who can.

Contact details :- <lbrophy@parkinsons.org.uk>. Phone. 0344 225 3785

#### **ELVIS NIGHT**

#### **PATRICIA DAVIES**

Elvis evening fundraiser!

We are once again holding a fundraiser for the branch on 14th September at Hurst Cafe, Hurst Road, Horsham.

The Almost Elvis band will be entertaining us - some of you may already be familiar with this band

as we hired them some 7 years ago when we raised an enormous amount of money for the branch.

Tickets are £20, bring your own drinks and a light finger buffet is available. Doors open 7.00 pm and finish at 11.00 pm. There's free parking but you must enter your car registration into the ipad in reception. Please be aware there are limited spaces but you can park in the Pavillions car park which is close by.

DJ Diddy Hamilton (health permitting) will be joining us to open the evening and call out the raffle as well as our ex Conservative MP Sir Jeremy Quinn.

Many local businesses and members have donated a wonderful selection of raffle prizes. We would love to see you there!

Please contact Patricia Davies on 07720 448699.



## EVENT REPORTS

### HORSHAM WORKING AGE GROUP JULY 2024

JEREMY COLLYER & EMMA BRINTON

This group based in Horsham caters to people living with Parkinson's and is particularly targeted towards the younger demographic and those who are still employed. Despite its focus, the group is inclusive, welcoming retired individuals and those who may not be young by the number of years but possess a youthful spirit. Established in early 2023, this group has enjoyed considerable success with a schedule of regular activities.



Meetings include:

- Tuesday evening boxing classes at Horsham Boxing Club,
- Wednesday evening PD Warrior exercises (refer to the separate article on PD Warrior),
- Thursday evening yoga sessions at Laurie Apted Building in Southwater,
- Social gatherings post-yoga on the second Thursday of each month at The Lintot pub, in Southwater,
- Games/social gatherings post-yoga on the fourth Thursday of each month at The Lintot pub in Southwater.

The promotion of exercise within the group is seen as pivotal in improving health outcomes. A varied range of exercises that support one another appears key to these improvements.

One significant, yet often overlooked advantage of the group, is its positive impact on mental health. Many members have experienced feelings of isolation and found it difficult to find others who can

truly empathize with their struggles. The informal meetups at the pub in Southwater afford an excellent opportunity for members to casually discuss problems and share potential solutions.

If you want to get involved please contact Emma Brinton.

## SUMMER OUTING – PRAIRE GARDENS

JUDITH GORTON

This year our Summer Outing was at beginning of August to the Sussex Prairie Gardens, Morlands Farm, Warrants Road, just north of Henfield on the B2116. An exciting garden of approximately 8 acres using over 50,000 plants and over 15,00 different varieties, packed with colour from early summer to late autumn .



The gardens were opened early for us to be able to walk ( orin Alex's case on his mobility scooter! ) around while it was quiet and before open to the public. After making your way through the banana leaves you came to the pigs, yes that's right pigs! Rare breeds. Although Alex and I had been to the gardens before, it didn't disappoint , whatever time of year you visit, there is lots of colour from Rudbeckias, Lillies, Sedums and much more . There is a wide expanse of lawn down the middle with small wood chip paths off so you can get right inside the plants and explore. Swathes of different ornamental grasses billow and sway in between the flower heads . Did you find a peaceful seat amongst the plants?

We were introduced to Pauline McBride , the owner who lives on site.

Pauline was born and brought up on the farm but wanting to travel after she left University. We learnt a lot more from Pauline as she gave a short history of the gardens. With Paul, her husband, they designed and planned out the garden while working in Luxembourg. In 2008 all the plants were planted into spiral borders by family and friends and a year later it was opened to the public.

We were then treated to a cream tea and drink. Some sat outside in the shade on the terrace but unfortunately were bothered



by the dreadful wasps! We on the other hand had gone into the café where there was a small seating area away from the pesky wasps! The plain scones were large with strawberry jam and Rodda's Cornish cream, delish! There is also a doggy ice cream for our four legged friends!

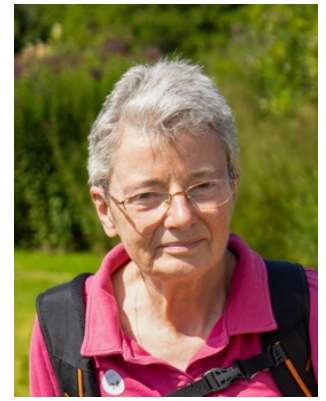
An added bonus was an Indian Bazaar summer market which had been set up for the month of August. Gorgeous cotton clothes, jewellery, vintage saris, accessories and much more. Something for everyone and all ethical from India.

It was a very pleasant Saturday in the sun and well worth a visit. Thank you.

## TENNIS – BUT NOT AS YOU KNOW IT

SUE WEST

Last week a friend and I decided to try out walking tennis. Weekly sessions (term time only) are run at The Holbrook Club by coach Mike on the initiative of the Sports Development Team at Horsham District Council.



We first warmed up by hitting the ball against the wall, then jogged, or in my case, walked, round the hall a couple of times before playing a game. The game involved hitting the ball over the net with a racket and hoping your opponent would be unable to return it thus scoring a point. Apart from this, any resemblance of the game played at Wimbledon was tenuous:

- It was played indoors on a badminton court
- The net was about 4 breeze blocks high (ie about 900mm)
- The racquet was short and stubby
- The ball was soft and squidgy
- The ball was allowed to bounce twice before going out of play
- The winners were the first to reach 10 points
- It may not have been lawn tennis but was most enjoyable and had the advantage that (sometimes) I could actually return the ball. I think I might go again!

Walking Tennis, Holbrook Club, Thursdays, term times only, 12 midday to 1o'clock, cost £10 a session.

## ESTABLISHED PROGRAM

### MEETINGS

#### BRANCH MEETINGS

6th September 5.15pm Social evening/games.  
Drinks provided, attendees asked to bring their own food

4th October 11.30 Talk by speaker from Silvertime on various topics such as wills trusts, Lasting powers of Attorney and managing care fees etc

1st November 5.30 Horsham PD Warrior outcomes presentation and update on research. Jeremy Collyer

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

3rd January 11.30 Birds of the Amazon Basin Alan Wilkinson

7th February 11.30 A talk on Hedgehogs. TBC

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

second Thursday of the month, from 7pm, at the Lintot pub in Southwater. This gathering is open to people of all ages.



For further details please contact Emma Brinton [emma.brinton@sky.com](mailto:emma.brinton@sky.com) or tel 07970 898 740.

## ACTIVITIES

### 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](mailto: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](mailto: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!



## 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.

## 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](mailto: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](mailto: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.

## 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.

## 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.

## 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 Briton on [emma.brinton@sky.com](mailto: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 Heros programme

Neuro Heros is working in partnership with

Parkinson's UK to help remove the barrier to physical activity by subsidising six classes for people with Parkinsons who would otherwise be unable to join them.



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

## OBITUARY

### DOROTHY HATFIELD

It is with huge sadness I announce the death of Dorothy Hatfield. Dorothy was quite simply unique, in more ways than one.

In 1956, having left school at the age of 16, Dorothy broke new ground and the culture of the day by becoming the first, and at the time only, female engineering apprentice with Vickers -Armstrong (Aircraft) Brooklands. Six years later she graduated with a first class honours degree in aeronautical engineering.

After taking time out to bring up her children, Dorothy returned to work and held a senior position with a flight simulation company before her retirement. She joined the Women's Engineering Society in 1962 and was elected President in 1990. She was instrumental in setting up the Daphne Jackson Trust and the Lady Finniston Award for first year female engineering students. She was made a Fellow of the Royal Aeronautical Society in 1996. For her work with the Women's Engineering Society, Dorothy was awarded the Isabel Hardwich Medal in 2007 and Order of the British Empire in 2014.

Diagnosed with Parkinson's, Dorothy worked hard for Parkinson's UK both locally and nationally only standing down as a committee member and research project lay reviewer when forced to by her failing eyesight. Dorothy was a joy to know, very enthusiastic and a pleasure to be with. If she let her Parkinson's, cancer and failing eyes get to her in the quiet of her own home, she certainly never let it show.

You will be much missed Dorothy.



### VALERIE BOWLES

It is with sadness I announce the death of Valerie Bowles.

Valerie was a great supporter of our branch, well after the death of her husband Ken, who had Parkinson's, She would be

the first to volunteer to sell Christmas cards at the museum shop and played a mean game of table tennis. Unfortunately in recent years her eye sight failed her and she was able to do less

