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

Slough, Windsor and Maidenhead Branch

The aim of the Branch is to support anyone in this area whose life is affected by Parkinson's.

If you would like advice or information about anything to do with Parkinson's please phone: Parkinson's UK Helpline: 0808 800 0303 (see P.11)

Welcome to our new members, their families and supporters.

Christmas/New Year

This newsletter takes us from Christmas through to the New Year.

If we take time to reflect on the past 12 months we can appreciate how much has happened in the Branch. We have welcomed many new members and their supporters, met up with old friends and made new ones at the meetings and activity sessions, shared our various experiences, started new activities and listened to interesting and varied speakers at our monthly meetings.

We have had two very enjoyable Branch events - the summer Afternoon Tea and the Christmas Lunch (photos on pages 4 and 5) when we welcomed guests to join us.

During the year we have received some generous donations as the result of fund raising and a legacy fund. We were able to secure a date in November for a bucket collection at Tesco in Slough (photos on page 3).

We will be holding our Annual General meeting on Wednesday March 12th, followed by a talk from Katy Slade, Area Development Manager - Southeast, Parkinson's UK. All papers related to the AGM will be sent with the February/March newsletter If you have any spare time and would consider joining the committee, please contact Bernard (chairman@parkinsonsswm.org.uk) to discuss what this would involve. Our website needs updating and reviewing so anyone with IT/web design skills would be very welcome!

Katy Slade has been facilitating support for young, working aged people with Parkinson's in Berks and the first meeting was on 5th December. There are plans to meet in the future and possibly set up their own informal group. If you would like to have more information, please contact Katy (kslade@parkinsons.org.uk).

Friday April 11th is World Parkinson's Day and the beginning of Parkinson's Awareness week. The Branch is hoping to mark this day by having a stall at Wexham Park Hospital. Please let Neru know if you would like to be involved:

(secretary@parkinsonsswm.org,uk)

Branch Information

Newsletter

The newsletter is produced every two months. A large amount of information is repeated as a reference. For more information about anything in the newsletter please contact Paulann:

info@parkinsonsswm.org.uk

Branch bank account

If you would like to pay money into our Barclays account by bank transfer, our bank details are: Sort code: 20-00-00 Account no: 23631753.

The name of the account is the trading name of Parkinson's UK:

The Parkinsons Disease Society of the United Kingdom.

If you are typing this on your internet banking form, you will run out of space but write what you can.

If you prefer to write a cheque, please make it payable to: **Parkinson's UK SWM branch.**

Branch membership

We encourage everyone in our Parkinson's community to join Parkinson's UK and our Branch. Membership of Parkinson's UK is free but donations are welcome.

You can join by 'phoning the Parkinson's UK Helpline (0808 800 0303) and speaking to the membership dept.

<u>Please tell them you would like to join Parkinson's UK and the Slough, Windsor and Maidenhead Branch – this won't happen automatically</u>

We ask you to contribute £10 annually to the Branch. The Branch does not receive any funds from Parkinson's UK and relies on your membership fees, donations, and fundraising events.

You can set up a standing order with Parkinson's UK to pay your Branch annual fee and add Gift Aid if you choose. The Branch cannot collect Gift Aid.

If you are already a member of Parkinson's UK, you can join the Branch directly. Make your payment of £10 using either method described in the Branch bank account section below. For more details about becoming a member, please contact:

treasurer@parkinsonsswm.org.uk

Fund Raising

If you would like to give a donation to the Branch or are considering a fund-raising event or activity, please use our JustGiving page which is easy to use. It also allows you to give Gift Aid. We can help you set up your own page which will give funds directly to the Branch. Please pass this information to your family and friends if they would like to donate to Branch funds:

https://www.justgiving.com/fundraising/swmbranch

Parkinson's UK will help you organise a fund-raising event or you can take part in one that is already planned:

https://www.parkinsons.org.uk/events#?cludoquery=*&cludosort=iso date%3Dasc&cludopage=3&cludoinputtype=standard

If you have an idea for some local fund raising, we can organise support. Please contact Neru:

secretary@parkinsonsswm.org.uk

Tesco Collection

Many thanks to those who helped raise not only over £300 at the recent bucket collection at Tesco, Slough but also awareness of Parkinson's UK and our Branch







Branch Christmas Lunch December 4th at the Grovefield House Hotel, Burnham

A selection of photographs of a busy and happy occasion attended by 79 of our members and their guests. With thanks to the Grovefield House Hotel for their hospitality and for looking after us so well.





































Two of our activity organisers – Susan (Boxercise) and Tara, (yoga) who joined us for lunch

News

Medication supply issues

There continue to be problems obtaining some Parkinson's medication. If you are unable to obtain your usual medication, please speak with your pharmacist or

contact the Parkinson's UK helpline: 0808 800 0303

Contacting your consultant or Parkinson's specialist nurse

- If you need to see your consultant or nurse specialist urgently, please contact the Neuro Hub: 0300 614 7227
- If you have a general query, please contact the Parkinson's UK Helpline:
 0808 800 0303 and ask to speak to a nurse practitioner.

Exercises

Being Active with Parkinson's

We all know that people with Parkinson's should keep active and this recently produced guide from Parkinson's UK explains more about why and how we should do this: https://www.parkinsons.org.uk/sites/default/files/2023-

03/CS3869%20Being%20active%20with%20Parkinson s Web%20version.pdf

There are plenty of opportunities to attend exercises in local venues or online if you are unable to attend those organised by the Branch. Details below:

PureGym

If you listen to the Movers and Shakers podcasts you may have heard that they have partnered with PureGym to give individuals with Parkinson's free PureGym memberships.

Members who are interested in signing up to a free membership must email PureGym with the following details:

- Full name, date of birth, email address, mobile number, home address and which PureGym location you would like to use.
- Also, do you require access to their DDA, easy access door (otherwise entry will be via their POD system): Yes/No

There are two PureGyms locally: Maidenhead- Unit 2, Stafferton Way, Maidenhead SL6 1AY Burnham - 821 A Yeovil Road, SL1 4JB

For membership enquiries and further information please contact: purehelp@puregym.com.

Online exercise classes

If, for any reason, you are unable to go to your normal activity session there are a large number of Parkinson's UK YouTube classes available online. Many of these were used during periods of lockdown. Open this link:

https://www.youtube.com/playlist?list=PL1ixQpbHed3asr5w0ge6ufxNTt1a4KpP

Braywick Leisure Centre, Braywick Rd, Maidenhead SL6 1BN

If you live in the Borough of Windsor and Maidenhead and have an Advantage Card, you may have a membership discount. If you have proof of a disability, such as a benefits letter, you may be entitled to a further discount.

If you are a registered carer (ask your GP for a registration form) you may be entitled to a Time Out membership – which is free.

Contact the Membership Team for more information: <u>01628 685333</u> <u>https://www.leisurefocus.org.uk/our-centres/braywick-leisure-centre/.</u>

Parkinson's UK collaboration with Everyone Active

This gives free membership to everyone with Parkinson's and their carers. Membership includes:

- use of gym equipment, swimming facilities (where applicable), group exercise classes
- EXi digital, a prescribed physical activity programme and Synergy Dance online

Our local centres are:

The Centre (Slough)

Slough Ice Arena

Salt Hill Activity Centre

Langley Leisure Centre

Bracknell Leisure Centre

For more details and how to apply for membership:

https://www.parkinsons.org.uk/news/everyone-active-offers-free-membership-people-parkinsons-and-their-carers

Neuro Heroes Community Exercise Fund

Parkinson's UK have awarded a new physical activity grant to **Neuro Heroes**, an online physical activity provider which supports people with neurological conditions.

Neuro Heroes offer physiotherapist-led classes to help people living with Parkinson's and will use the funding to subsidise the first six activity classes for people with Parkinson's who would otherwise be unable to attend. The classes will present more opportunities for people with Parkinson's to participate in physical activity.

Anyone with Parkinson's who claims Universal Credit or Pension Credit can sign up for six subsidised classes by completing a Neuro Heroes application form here.

Contact helloneuroheroes@gmail.com for more information or visit their website: https://www.neuroheroes.co.uk/community-exercise-fund

Branch Meetings

The Huntercombe Hall, Burnham Park Hall, Windsor Lane, Burnham, SL1 7HR

https://www.burnhampark.co.uk

We usually meet on the second Wednesday of each month.

<u>The room is booked from 1pm</u> and the meeting starts at 1.30pm. The speakers begin their presentation at 2pm.

On arrival, please register your car on the touch pad by the reception desk otherwise you may incur a fine.

You are invited to contribute to the fund-raising raffle and we welcome plants, bottles, small boxes of biscuits or sweets. Thank you.

Dates of meetings

There is NO MEETING in January.

Wednesday, February 12th at Burnham Park Hall

Speaker: Dr Helen Read, Conservation Officer at Burnham Beeches

2pm Talk: Ancient Trees

Wednesday, March 12th at Burnham Park Hall (Please note change of time) The Branch Annual General Meeting at 1.15pm- 1.45pm

There will be a short break after the AGM

Speaker: Katy Slade

2pm Talk: Current news from Parkinson's UK

Wednesday, April 9th at Burnham Park Hall

Speaker: Ruth Marriott, Hospital Team Leader, Carers Bucks

Talk: The Carers Bucks' Hospital Support service

Carers

Please join us for our **Carers' Coffee Meetings** on the third Wednesday of each month. We meet at the **Café at Dorney Court, Court Lane, Dorney SL4 6QP any time between 10.30am and 12pm.**

The next meetings will be on **Wednesday 15th January and Wednesday 19th February** Please contact Paulann for details:

info@parkinsonsswm.org.uk

Carers UK

If you are a carer, have you registered with your GP?

Ask your GP practice for an application form or contact **Carers UK** who have an excellent website that includes information about what help and support is available:

https://www.carersuk.org/

They also have many useful leaflets on various topics. Their contact details are:

e-mail: mailto:advice@carersuk.org telephone: 0808 808 7777

Carer's Emergency Plan

Have you completed a Carer's Emergency Plan and is it up to date?

If you are a carer and are unexpectedly unable to provide care what will happen to the person you care for?

Carers UK have a useful online interactive tool called MyBackUp:

https://carersdigital.org/mybackup/

It takes the form of a questionnaire which when completed gives you suggestions and useful information.

Bucks Carers have a form to download and complete. If you do not live in Bucks you will need to change some of the information

https://carersbucks.org/information-for-carers/adult-carers/guide-to-caring/what-to-do-in-an-emergency/

Local links for Carers:

Slough Carers' Support: sloughcarers@slough.gov.uk 01753 303428

Signal 4 WAM Carers: https://www.signal4carers.org.uk 01628 94797

Bucks Carers https://carersbucks.org 0300 777 2722

Branch Activities

If you would like to know more about an activity, please contact Neru who can inform the activity leaders and/or add you to any waiting list: activities@parkinsonsswm.org.uk,

Please do not go to the activity without prior arrangement as the organisers need to plan and organise numbers to accommodate all attendees. In some cases, assessments are required before being accepted on a course. Please contact Neru first (as above).

Please remember when you pay for your activity sessions by bank transfer to put your name and the activity as your reference (e.g. walkeryoga)

Sort code: 20-00-00 Account no: 23631753

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treasurer@parkinsonsswm.org.uk

Boxercise with Susan Garner

Fifield

Thursdays 12- 1pm

The course of four sessions will cost £16. Please pay at the beginning of the course.

For more details and to join the waiting list contact: activities@parkinsonsswm.org.uk

Indoor Bowls

Desborough Bowling Club, 10 Green Lane, Maidenhead, SL6 1XZ Fridays from 12.30pm to 2pm

Cost is £4, payable on the day.

If you are interested in attending, please contact: activities@parkinsonsswm.org.uk

Hydrotherapy

Hydrotherapy Pool, Rehab Department, Wexham Park Hospital, SL2 4HL

The course consists of four classes on Tuesdays from 5-6pm and currently have four participants with one physiotherapist in the pool and an assistant outside. We are asking all participants to wear nonslip waterproof shoes which can be obtained by arrangement with the physiotherapist.

It will cost £24 for the course, and you can pay at the beginning of the course. You will receive more information when you are accepted for a class.

For more details or to join the waiting list contact: activities@parkinsonsswm.org.uk

<u>Yoga</u>

Holyport War Memorial Hall, Moneyrow Green, Holyport, Maidenhead SL6 2NA The classes, led by Tara Sutthoff Crist, are on Tuesday mornings from 10.45 to 11.45am and cost £6.50.

For more details, please contact: activities@parkinsonsswm.org.uk

Nordic walking with Derek Holloway

Mondays 3-4pm

Derek Holloway is an experienced Nordic walking leader and works with two other Parkinson's UK branches. Please look at his website: https://derek.webador.co.uk/ His sessions will usually start in the car park at the **Braywick Leisure Centre**, **Maidenhead SL6 1BN**.

Each course of four sessions will cost £20. Please pay at the beginning of the course. For more details, please contact Derek Tel: 07843 584900

Physiotherapy with Horizon Rehabilitation

Wednesdays at Burnham Park Hall, Windsor Lane, Burnham, SL1 7HR

1.30-2.30pm

Seated Exercise

This group is suitable for those who have not been assessed, assessed as level 3 or who prefer to exercise whilst sitting.

Seated exercise is a moderate intensity activity so you get a bit out of puff. It also includes co-ordination and brain training activities to stimulate the neural circuits affected by Parkinson's.

These sessions are fun and engaging, mixing up the music and activities so there is something for everyone.

Everyone can benefit from these exercises, no matter what your ability level.

If you're not sure if this is for you, we highly recommend that you give it a go. It takes a bit of practice and repetition to give those brain circuits a shakeup, but you'll soon be able to join in and do the movements.

2.30-3.30pm

High level standing class

This group will be run by a qualified physiotherapist and supported by a second member of the Horizon Rehabilitation Team. The exercises will be adapted to be suitable for all those attending, and participants will need to be assessed before they can join in this class.

Carers, friends, partners are asked to remain on site for the participants who need support with mobility or personal needs. Where there is space, you are welcome to join in the class.

If you are interested and have not been assessed, we recommend that you come along to the seated class first (space permitting) and our physiotherapist will be able to complete the screening tasks with you.

<u>Please do not attend without first registering your interest</u> as we may have to turn you away if no spaces are available.

For details, please contact Neru: secretary@parkinsonsswm.org.uk

Useful Links

CEA Card

The CEA Card is a national card scheme developed for UK cinemas by the UK Cinema Association (UKCA) which enables a disabled cinema guest to receive a complimentary ticket for someone to go with them when they visit a participating cinema.

To apply you will need:

- proof of eligibility (the awarding letter from DWP or a statement confirming receipt of the allowance for the applicant dated within the last 12 months).
- a photo
- payment of £6.00 (annual membership)

You can pay for your card online or by post.

Contact:

Telephone: 01244 526 016 https://www.ceacard.co.uk/

Maidenhead and Windsor Shopmobility

If you would like to hire a mobility scooter or borrow a manual wheelchair or powered chair look at the Shopmobility website for more information:

https://www.people2places.org.uk/

AbilityNet

AbilityNet is a charity that provides expert advice on using computer technology for people with Parkinson's and other disabilities.

They have a fact sheet specifically for people with Parkinson's:

https://abilitynet.org.uk/factsheets/parkinsons-and-technology

Parkinson's UK

Helpline

0808 800 0303, or email hello@parkinsons.org.uk

The helpline is a free confidential service providing support to anyone affected by Parkinson's.

The trained advisers, including specialist Parkinson's nurses, can provide information and advice about all aspects of living with Parkinson's, such as medical issues, including: symptoms and treatments, employment and benefits, health and social care, emotional support, local activities, signposting to other sources of information. They can also put you in touch with a Parkinson's adviser if you need more local or in-depth support. Opening times:

Monday to Friday: 9am to 6pm

Saturday: 10am to 2pm

closed on Sundays and bank holidays.

Parkinson's UK Shop

If you are looking for certain aids to daily living, adjustable beds or stair lifts the Parkinson's UK shop has a good selection available. There is also stationery, gifts and Parkinson's merchandise.

https://shop.parkinsons.org.uk/? ga=2.138595194.818334147.1716725973-1864905410.1690799857

First Steps Programme

https://www.parkinsons.org.uk/information-and-support/first-steps-programme

If you have been recently diagnosed, you might like to consider attending a First Steps programme- currently being run online. You will receive lots of information including what support is available.

For more information, please contact the First Steps team:

020 7963 9381 or email firststeps@parkinsons.org.uk

Fighting Fit

The organisation was established at the start of 2018 specifically to support active people with Parkinson's by providing a weekend residential programme of exercise, information, and friendship.

If you are interested, please complete the 'contact us' page of the website: https://fighting-fit.org.uk/contact-us/.

The Yellow Card scheme

Parkinson's UK are promoting the Yellow Card scheme to the Parkinson's community, to make sure everyone knows where to report any medication side effects they may experience.

They've picked up reports on social media that some people with Parkinson's have experienced side effects from their Parkinson's medications after being switched from a branded product, like Sinemet, to a generic product. For more information:

https://www.parkinsons.org.uk/news/report-your-medication-side-effects-through-yellow-card-scheme

Campaigning

Are you aware of the work done by the Campaigns Team at Parkinson's UK? You might like to get involved by sharing your story, volunteering or joining the Campaigns Network to keep up to date with current campaigns. Information is available on the Parkinson's UK website.

https://www.parkinsons.org.uk/get-involved/campaigning-change

Benefits

If you would more details about your eligibility to claim benefits and for **free** help with completing any forms you may find the following websites helpful:

- Citizen's Advice <u>www.citizensadvice.org.uk</u>
- Department of Work and Pensions (DWP)
 www.gov.uk/government/organisations/department-for-work-pensions
- and you can contact the Parkinson's Local Advisors:

hello@parkinsons.org.uk 0808 800 03303

Research

Would you like to be involved with research – whether you have Parkinson's or not? If you would like to take part in a research study this may mean completing a questionnaire or trialling a new drug, some done at home or visiting a hospital or research centre. To take part in research or find out more follow this link: https://www.parkinsons.org.uk/research/take-part-research

You can join one of the Local Research Interest groups who meet regularly, to keep in touch with the latest news. The South East of England Group, linked to the University of Kent, is probably our most local group.

https://www.parkinsons.org.uk/research/local-parkinsons-research-interest-groups

Legacy Grants for Transport to the Branch social meetings and activities.

If you have difficulty accessing transport to any of our meetings or activities, please apply for a Legacy Transport grant to pay for your taxi. Each grant is up to £200 per year, per member and is not means tested so all members are eligible. You arrange and pay for your own taxi, then claim this back from the treasurer.

For more information, please contact Bernard:

chairman@parkinsonsswm.org.uk

FOR SALE

<u>Quingo Ultra scooter</u> - very good condition as it was hardly used. Kept in garage and batteries regularly charged. Cost nearly £3,000. Will accept £1,000. Very stable for someone with Parkinson's due to a third front wheel. Richard loved it, but unfortunately was only able to use it a few times.

<u>Black leather rise/recliner chair</u> - good working order and very comfortable. FREE to anyone who can collect it.

<u>Powered wheelchair</u> - also FREE as it will need a new battery and possibly charger. It has a joystick so a bit fiddly to control but comfortable and worked well until the battery or charger fell on the floor. Bought from CareCo in Hayes.

If interested please contact Mary Tuck on 07721 089080.

General Information and Contact Details

Branch Chairman: Bernard Delahaye <u>chairman@parkinsonsswm.org.uk</u>

Secretary: Neru Obhrai <u>secretary@parkinsonsswm.org.uk</u>

Treasurer: Harj Mahil <u>treasurer@parkinsonsswm.org.uk</u>

Activities <u>activities@parkinsonsswm.org.uk</u>

Coordinator:

Research Robert Behrman info@parkinsonsswm.org.uk

Champion:

Committee Mary Tuck info@parkinsonsswm.org.uk

member:

Newsletter: Paulann Walker info@parkinsonsswm.org.uk

Janice Gibbs (copy

editor)

Neurology HUB helpline 0300 614 7227

To make appointments with your Neurologist and/or Parkinson's Specialist Nurse.

Parkinson's Specialist Nurse Evphi Kalkantera
Parkinson's Specialist Nurse Andrew Houghton
Parkinson's Specialist Nurse Karen Williams

Parkinson's UK Local Advisors 0808 800 0303

Kay Andrews <u>hello@parkinsons.org.uk</u>

Anita Browne

Parkinson's UK Helpline 0808 800 0303

PALS

Patient advice and liaison service Frimley Health Foundation trust https://www.fhft.nhs.uk/services/pals-patient-advice-and-liaison-service