

The Swindon Parkin Lot Newsletter May / June 2023

Editor: Ruth Panting. **Email:** ruthpanting@yahoo.co.uk

Thank you to.....

.....WASP (Wiltshire and Swindon Sport)

which has donated a grant to help fund the walking football activity over the next 6 months and to help to restart Tai Chi and Boxing.

We are very grateful for the continued support this organisation provides for our activity group.



.....David Roblin

for his continued fundraising for the Swindon Activity Group.



David Roblin presenting a cheque for £1535 to Neil Fallon for the Walking Football on 24th April.

Events in March and April

Lunch at New College, North Star Campus 16th March



On 16th March, 40 of us arrived for lunch at North Star College where an area of the car park was cordoned off for us. We were met by a member of the College staff who welcomed us and directed us to the lift. Having previously chosen our choices of menu, once we were all seated, it was not long before service began. Our meals were cooked and served by young people who are training at the College to be chefs, waiters etc. overseen by Faith - one of the staff. It was nice to see many people chatting to the students and thanking them.



The food was excellent, everybody enjoyed themselves, and I hope that we will be going there again before long.

Anna Newman Secretary

Concert at Bath Road Methodist Church 25th March

Choral Treasures Evening

On Saturday evening 25th March those who attended the “*Choral Treasures Evening*” concert were treated to some of the finest singing Swindon can offer. The Concert was organised by Swindon Male Voice Choir, to include the Thamesdown Ladies Choir, and the understanding was that we, the Swindon Activity Group, would have any money left after outgoings. We benefited from over £500.

The evening started with Kirstie Smith directing The Male Voice Choir singing some of the beautiful harmonies that only a male choir can do justice to, this was followed by Shelly Morgan directing a section with Thamesdown Choir reminding us that a ladies choir can also make a sound that is unique to them.

They both had us experiencing a range of emotions from the melancholy through to the downright hilarious; we were even treated to pirates and sea shanties with folk songs thrown in just for fun. Dee and I are fans of show tunes (Dee converted me a few years ago!) so for me the highlight was a solo from a member of the Thamesdown Ladies singing “*On My Own*” from “*Les Miserables*”. When the Male Voices joined in with their backing harmonies it brought a lump to my throat!

*Thank
you*

At the end of the concert, Anna came on stage to thank the choirs for a wonderful evening.

We left the Bath Road Methodist Church with tunes ringing in our ears.

Graham Vaughan Group member



Buddy Holly Show 8th April

We arrived in Bath early and were dropped in Queens Square shortly before 11 o'clock, in good time for refreshments, shopping and sightseeing before the doors opened at the New Theatre Royal at 2 o'clock. The group was made up of 10 members from Swindon Parkinson's Group, 6 members from Malmesbury and 11 guests.

The reason for our visit was to see the matinee performance of the Rock 'n' Roll West End musical "The Buddy Holly Story". The show follows Buddy Holly and the Crickets through their early months as they struggled to get airtime on the local radio station in Texas, which only wanted them to play Country and Western.

It was Rock 'n' Roll all the way with lots of our favourite songs from that time; many of them have been covered by other bands/singers. These included.

<i>It doesn't matter anymore,</i>	<i>Heartbeat,</i>	<i>Rave on</i>
<i>Crying, waiting, hoping</i>	<i>Everyday</i>	<i>Peggy Sue got married</i>
<i>Maybe baby</i>	<i>Oh, Boy!</i>	<i>and many more.</i>

We saw the reproduction of Buddy's final concert with the Crickets where he was joined on stage by his friends, the Big Bopper and Ritchie Valens. The Big Bopper sang "Chantilly Lace" and Ritchie Valens "La Bamba".

In real life, the three friends were killed in a plane crash immediately after the concert, but of course they were all back for the finale of the show and the audience were on their feet clapping and joining in with the singing. And then, after encores, the show was over.

We all made our way back to Queens Square, where Mark, our driver from Ellisons was waiting to transport us home. We all had an excellent day out and our thanks are due to Sue Grice for arranging it. *Ian Davey Group Member*



Information Stall at Tesco

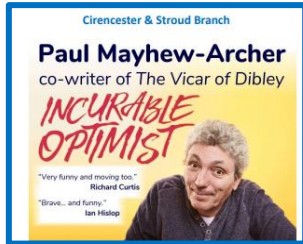


During Parkinson's Awareness Week, my daughter Katy and her colleague Jamie had an information stall about Parkinson's at Tesco's Express, Woodshaw, Royal Wootton Bassett, with pamphlets and information available to customers. Katy (bought the sweets and jars) also did a "guess how many sweets in the jar" competition involving 3 jars at £1 per guess. This raised a fantastic £136.59. Tesco's Woodshaw store also donated 2 jars of coffee and a large bag of teabags, in time for the Walking Football trophy match refreshments on April 17th and for future events.



Neil Fallon Volunteer for Walking Football.

Paul Mayhew Archer Concert 12th April



On 12th April some of the Swindon Parkinson's group went to Bingham Hall, Cirencester, for an evening of entertainment given by Paul Mayhew-Archer.

Some of you may know of Paul already but if not I'll introduced him. He spent the last 30 years as a comedy script writer. His main claims to fame are that that he wrote the "The Vicar of Dibley" with Richard Curtis and he produced and wrote "Mrs Brown's Boys". He has also worked on radio with the programs such as "I'm sorry I haven't clue".

Several years ago he was diagnosed with Parkinson's and decided to find the funny side of the condition. Having been writing comedy all his career he hadn't appeared on stage since his University days, so he wrote a stand-up routine and titled it "The Incurable Optimist". He says Parkinson's has given him a reason to perform and you can see he enjoys it. What resulted was an irreverent show where he talks about many aspects of Parkinson's and nothing is off-limits for him. So from tremors, dyskinesia through to constipation and sex he finds the laughs in everything.

The Cirencester Parkinson's Group hosted the evening with a raffle and donation buckets. The event was very well attended and as he related his experiences from being diagnosed through to his current symptoms, the hall was filled with the sound of laughter. His long-suffering wife was the butt of many anecdotes that had us laughing all evening.

He is also one of the contributors to the "Movers and Shakers" podcast that some of you may have heard. I find that trying to see the funny side of this horrible condition sometimes helps in dealing with it.

So a good evening all round..... *Graham Vaughan Group Member*

Putting Competition 14th April

Putting Power for Parkinson's Awareness

Despite weather conditions the **PUTTING COMPETITION** and **AFTERNOON TEA** went ahead on 14th April to help raise awareness in Parkinson's week. We had an excellent turnout and, thanks to Carole Lee's organisation, we were able to have the competition between showers and a lot of fun and laughter, as well as consuming some amazing cakes, bakes and scones. Not a soggy bottom in sight!!

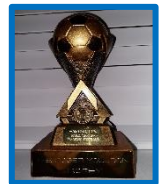
Thank you to everyone who donated the bakes and supported us with your attendance and donations. £280 was raised for the Swindon Parkinson's Activity Group and £85 for the Golf Club. Enormous thanks to Cat Attewell for creating 30 beautiful 'treasures' for the Treasure Trove raffle.

Thank
YOU

The winners of the putting competition were rewarded with cups and medals kindly donated by Carole and presented to Dave and Daphne Logan, Les Fuller and Margaret and John Hern. Congratulations! *Kerry Hartman Parkies Pals*



Walking Football Match April 17th



Parkinson's Patients Win Back The Trophy.

On 17 April after a two-year gap due to the Covid Pandemic, Great Western Hospital's Parkinson's patients walking football team (the Shakers) won back the Walking Football Trophy. They had lost to GWH's Parkinson's Services football team (SPARKS) the previous match, having won the first match of the annual series prior to that.

The Mayor of Swindon, Councillor Abdul Amin, graced us with his presence and support and thoroughly enjoyed the competitive match. One of the Mayor's first duties was to re-name the trophy "*The Roger Youldon Trophy*". This was in memory of Roger's commitment as our Committee Fund Raiser and organiser of the first two Walking Football matches against our medical team. Roger's wife Teresa attended accompanied by their daughter Tracy Hutching. They had sadly lost Roger during the pandemic. .



After the Mayor renamed the Trophy he presented it to Teresa and Tracy before the match started. They were both delighted with this gesture and Tracey spoke on behalf of the family. "*I just wanted to say thanks on behalf of Mum and the family for doing this in memory of my Dad. It was very thoughtful of you; we really do appreciate it. Thank you*". They then both stayed for Cup Match.

This was our third walking football match against our GWH Parkinson's medics. Their team for this match consisting of Parkinson's Nurses, Physiotherapists and Speech and Language Therapists. Although it was played sportingly, no quarter was given by either side who were determined to win. Their goal was scored by Julia Campbell. The remainder of their team were Emma Galos, Lucy Sweetman, Sue Thompson, Cheryl Davidse, Beth Robbins and Julie Charman.

The good-natured match finished with a 4 – 1 win by the Parkinson's Patients team, 'The Shakers', with goals from Mark Jee, Les Fulcher, Dave Logan and Mark Case. The other team members were Graham Vaughan, Shirley Tucker, David Beams, Fred Howe, Mick Hughes and Neal Scott Fallon in goal. The Mayor of Swindon, Councillor Abdul Amin presented the trophy to the Shakers.



The match was followed by tea, coffee and cakes in the upstairs spectator room. Gail Fallon sends her thanks to Dee Vaughan for helping serve the refreshments and also Daff Logan for the Millionaires shortbread, help and tip.

Thank
You



Thank you Julian Farmer our FA Coach, Sports England for their financial support and Supermarine Super Dome for their help and support. Thank you Councillor Abdul Amin, Mayor of Swindon for attending and your support.

Dave Logan Volunteer

Julian Farmer, Head Coach of Shakers FC, said:

“It was a pleasure to be a part of this fixture for the first time. Both teams played extremely well with the Shakers just about edging the win. We will need to be well prepared if we wish to retain the trophy next year. Well played SPARKS.

You were an absolute credit to Walking Football.”

Dave Logan, Parkinson's walking footballer with Shakers FC, said:

“It was great to be a part of the walking football tournament and to see so many people from the local community take part. It's a really enjoyable sport and I hope that more local people with Parkinson's want to give it a try.”

For more information about the new Swindon local walking football sessions, contact Julian Farmer, julianfarmer@btopenworld.com or call 07900 931 355



Fish and Chip Supper and Quiz 24th April



From the feedback I have received, what a good evening everyone seemed to have. There were 57 people at the quiz, so the competition was quite fierce. David Roblin, who set and presented the quiz, gave us a good variety of topics and questions which got our brains working overtime.



We started at 5pm and finished the first half at around 6pm, when we all had fish and chips. These were very tasty and were followed by tea and coffee. We then held the raffle before the second half of the quiz. The evening was wrapped up with a presentation of the quiz trophy for 2023 and some goodies.

The evening would also not have been a success without the invaluable help from all the volunteers who helped set up the room, sell raffle tickets, made the teas/coffees and donated Raffle prizes. A big thank you to all those people. Our raffle raised £106 for the group.

Thank You

Sue Grice Membership Secretary. Photos Graham Vaughan

Fundraising



300+ Club Monthly Draw



Winners for April

1 st G Vzor £91.70	2 nd R&A Morrison £39.30
Bonus: P Keating £10 Voucher	

Help our fundraising efforts by joining the £300+ club at a monthly cost of £1 Per number

If anybody would like to join to support the club and have a chance of winning a prize in the monthly draw please email or text.

Jackie Cowley.

Her contact details are j.cowley27@btinternet.com

and 07554006501

Jackie can then send you the documents that are required to set you up as a new member. All the funds raised by the club go towards supporting our activity classes and social events.

The club is currently below 260 members therefore there are 40+ vacant numbers which need new members.

Swindon Parkinsons Activity Group



Proudly supporting those affected by Parkinson's in the Swindon Area since 1978.

300 Plus Club Monthly Draw

Standing Order to join the 300 Plus Club

If you would like to join the 300 Plus Club monthly draw please complete, sign and return the form to the address below:

Jackie Cowley
3 The Willows
Swindon
SN5 5DG

I have read, understood and accept the rules of the 300 Plus Club monthly draw and would like to join and agree to pay £.....per month by Standing Order.

You will need to give a copy of the Standing Order to your Bank so payment can be made on a monthly basis.

Signed:..... Date:.....

Full Name:.....

Address:.....
.....

Please tear off the Standing Order below and give it to your bank.

Standing Order

Please deduct by Standing Order on the 9th day each month the amount of £.....from my account

Account No:

Sort Code:

and send it to the Swindon & District Branch of Parkinson's UK, charity number 258197 at The Royal Bank of Scotland:

Account No: 10025749

Sort Code: 16:33:11

Name:

Signed:Date:

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Parkinson's UK - Swindon & District Activity Group. Contact: E: anewman.parkinsons@outlook.com. It is a local Group of Parkinson's UK (PUK), and responsible for raising all funds to support those affected by Parkinson's in the Swindon and District area. The Group carries the same charity number as PUK which is the operating name of the Parkinson's Disease Society of the United Kingdom. A company limited by guarantee. Registered in England and Wales (258197) and in Scotland (SC037554)

Don't forget these future events:

Care and Share



Parkinsons.Me
Supporting you and your family



Parkies Pals



Home Instead.
To us, it's personal

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

Parkinson's Care and Share
Friday 26th May 2023
1.30pm–4.15pm
(Evening Drop-In 5–7pm)

You don't have to have Parkinson's to want to know more!

**At: LLOYD Lindsay Rooms, High St,
Ardington, Wantage OX12 8PS**

Parkinsons.me, Parkie Pals and Home Instead, are hosting this event for people both with and without Parkinson's, and for anyone interested to understand more about living with this condition.

A Parkinson's Nurse and a Physio will be speaking, there will be a "Move Me" exercise taster session and there will be representatives from other helpful organisations including Carers Oxfordshire and Dressability.

Reserve a place by emailing or calling either:

justine@parkinsons.me or call 07729801048

parkiespals@outlook.com or call 07875416236

cat.attewell@homeinsteadswindon.co.uk or call 01793 232585

New Parkinson's Cafes



NEW PARKINSON'S CAFES

Gerard Buxton Sports Ground
Brinkworth Road
Royal Wootton Bassett
SN4 8DS

Thursday 11 May
Thursday 3 August
Thursday 2 November
2:30-4:30pm

We'll host two cafes on the day - one for carers and partners and one for people living with Parkinson's.

Join us for conversation, laughter, friendship, and mutual support.

Everyone welcome, no booking required.

For more information contact Jane on 0344 225 3694
or jhenderson@parkinsons.org.uk

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

Research

Hope for those living with Parkinson's who suffer from Levodopa induced dyskinesia

It is thought that 40% - 50% of people living with Parkinson's suffer from dyskinesia – involuntary movements - a side effect of taking levodopa-based medication for several years.

Using Virtual Biotech Initiative strategies has allowed Parkinson's UK to work with other organisations to provide funding to speed up research development of new and better treatment of Parkinson's. PUK has teamed up with Neurolix, a biopharmaceutical company in the US (<https://www.neurolix.com/en/news.html>), and The Michael J. Fox Foundation (<https://www.michaeljfox.org>) to look at repurposing a drug NLX 112.

NLX-112, was found to reduce L-DOPA-induced abnormal movements in animal models of Parkinson's disease (PD). Neurolix then conducted a Phase 2 clinical study in Parkinson's disease patients with L-DOPA-induced dyskinesia. This study, completed in March 2023, was a success; NLX-112 was tolerated in patients, reduced their dyskinesia and found to be safe. Neurolix is now looking to advance the development of NLX-112 in larger clinical trials. It is hoped to have a new treatment in five years.

<https://www.parkinsons.org.uk/news/early-phase-clinical-trial-results-offer-new-hope-dyskinesia-treatment>
<https://www.neurolix.com/en/company/pipeline/nlx-112.html>

Blossoming Swindon



Information

Swindon Parkinson's Activity Group Facebook Page

We have grown to 52 members gradually since we started at the beginning of March. Included are lots of photos and fun plus reminders of forthcoming events.



It would be nice if people felt able to add their own contributions although I am happy to do so if they are not confident, just send me a message to:

dearymee66@gmail.com

Any suggestions to improve it are welcome.

Dee Vaughan Group Volunteer

Parkies Singers



On alternate Mondays at Des Moffatt Western Community Centre, Somerset Road, SN2 1NF, you will find a jolly band of folks singing their socks off. Kathy Hobson leads us, with her trusty accompanist Chris, with warmup breathing exercises and a couple of scales. Then we spend the next hour singing a variety of popular songs.

There's no judgment; we have a variety of abilities. It really doesn't matter if we hit the right notes. The point is, singing is proven to help people with Parkinson's.

“Singing, both individual singing as well as participation in choirs, has been studied for people with PD. Singing may be helpful in PD by: enhancing voice volume and quality; PD can cause hypophonia (low voice volume) and monotonous speech. Singing as therapy can improve these symptoms.”

Dee Vaughan Group Volunteer

Parkies Pals Progress

Dear Pals
Welcome to new members.



Remembering Flo Cole

Flo Cole was always a supporter of Parkies Pals and we were very sad to hear of her passing shortly after her 100th birthday. Her family presented us with a generous donation to be used towards local fitness and exercise resources as was her wishes.

Diary Notes:

- **Friday 26th May** Parkinson's Care & Share event is being arranged with the Wantage Parkinson.me group in Ardington. (See Page 9)
- **July 3rd** – Nan Pratt – slide show and update on the nature reserve project at Tuckmill Meadows
- **August** – we will have a stand at the village show ... any bottles of bubbles or bottle bags would be grateful for the 'Bubbles or bubbly' tombola.
- **TUESDAY 5th September** – Please note Parkies Pals will be meeting 1st Tuesday of the month from September
- **Sept table sale – Sept 30th** at the Golf course.. details to follow
- **Community café.** Don't forget Carole runs the fabulous friendly Community Café meets at the Shrivenham Park Golf Club on alternate Fridays, 2 – 4pm to include putting, chat and a cuppa for £2. May dates are 12th and 26th Everyone welcome. JUST COME ALONG AND JOIN THE FUN.
- **Cricklade Café** – every 3rd Wednesday of the month at Cricklade Café, 10.30 -12, Cricklade High Street SN6 6AY



Please remember you are NOT ALONE with Parkinson's. Sharing the load helps us all to cope. Thank you for all your support. Please contact me if you want any more info:

Kerry Hartman Text/Call 07875416236 Email: Parkiespals@outlook.com website: www.Parkiespals.co.uk

Next Parkies Pals Meeting will be June 5th, 10.00 - 12.00 am
at the Shrivenham Golf Club

Kerry Hartman, Parkies Pals



Group secretary needed



Sadly, our Group Secretary/Co-ordinator, Anna Newman, will be stepping down from her volunteer role this summer so:



"The group needs someone to join the team and have an overview of what is going on across the area. You will like admin, be organised and have a laptop. The role can be done from home and you'll use phone, email and occasionally Zoom to keep in touch with volunteers and take enquiries. Training is available for all aspects of the role as needed and best of all, it's a good sociable group to be a part of."



"We are therefore looking for a volunteer to shadow Anna for a couple of months and then take over from her. The role involves the following tasks:"

- Sending out the monthly Meeting Agenda.
- At the committee meeting, taking the minutes and sending them out to all committee members and Jane Henderson.
- Keeping copies of the minutes.
- Maintaining a list of committee members and contact details and sending to all committee after any changes.
- Sending thank you letters for all grants, donations etc.
- Sending out condolences when appropriate.
- Receipt of info from PUK and general enquiries which in most cases can be passed on to relevant people.

If you are interested please give Anna a call to chat about it on 07948 850234

From Jane Henderson at Parkinson's UK:
You can apply using this link:

<https://volunteer.parkinsons.org.uk/opportunities/44221-group-coordinator-home-based-2023-02-28>

Or contact Jane at Parkinson's UK for more details - 0344 225 3694
jhenderson@parkinsons.org.uk Network Support Officer for PUK.

Volunteers needed to organize social events

For several months now, both Sue Grice and Anna Newman have been organising events for people to get together, meet and have some fun. As many of you know, Anna will be stepping down from the Secretary role very soon, and, we are now looking for one or two members who would be prepared to take on a social event. It is not hard – just let us know what you are proposing so we can check that the date is not clashing with anything else, and let us know of any requirements – i.e. money to book a room, or boat trip etc. and then take charge of the numbers who wish to attend. If you have an idea (quiz nights, meals out, bingo afternoons or anything else that you can think of), please let us know and we will back you up.

Contact: Sue Grice on 07712 003271

We are an Activity Group, and this includes all members.

Bumblebee 'Bike' <https://www.thealinker.com/>



Maggie and her new bike. We wanted to share our experiences with you of “**Bumblebee the Alinker**”

In December, we saw a random photo on PINTEREST of a yellow “Walking Bicycle” A curious looking mobility aid which could be the lovechild of a balance bike and a penny farthing. We searched the web for more information and became fascinated by it and wondered where we might get one. Alinker UK are based in

Eastbourne and they have a Facebook page and can be contacted at: uk@thealinker.com and the importer is Karen Richards. By a stroke of good fortune, whilst searching for more information on the Alinker, we came across a used one for sale on GUMTREE in Wales and bought it on 30th December 2022.

Maggie was a bit nervous to start with and we set up a track indoors for the trial runs and adjustments. Since then, there has been no stopping her. So far, as well as trailing around Cricklade, Maggie has circumnavigated Peatmoor Lagoon and Westonbirt Arboretum on Bumblebee. The name was chosen due to the colour scheme and the extra bee graphics that we have added since.

The CEO of Friends of Westonbirt Arboretum came and spoke to Maggie and told her that they are the fundraisers who provide the mobility scooters to the arboretum and that they would consider purchasing some Alinker's for visitors to use there.

It's been great for me to see Maggie so happy. With a big grin she calls back to me “come on, keep up!” It puts a huge smile on my face too, seeing her striding along and upright. Maggie is planning on bringing Bumblebee to the June PUK Cricklade Café for all to see. The moral of the story is: there are many mobility aids out there that might make your life a little easier or indeed, more fun! *Vincent and Maggie Mobey*



Get it on Time



In the last newsletter we published an article concerning a research programme about Parkinson's medication management in hospital. Further to this Dave Logan has informed me of the following: he spent four years with the help of Sir Robert Buckland MP getting the Self Medication Procedure into the Great Western Hospital and now Self Medication can be employed by patients deemed capable of doing it.

*Thank you to all those who have contributed to this newsletter.
The deadline for articles for the next newsletter is July 3rd.*

**Swindon Parkinson's Activity Group
Proudly supporting those affected by Parkinson's in the Swindon Area since 1978**

Permission for Photography

I'm afraid we are going to have to change our practices going forward as far as taking any photographic shots for our newsletter/website/facebook. We must have your written consent to include yourself in any photo or video. Every member needs to complete one of these forms and either agree or refuse to be

included in any photo or video. If you have not done so, please fill in the form and return to Sue Grice

Photo/film consent form

Parkinson's UK produce a wide range of communication resources (from booklets and newsletters to short films and web pages) to tell people affected by Parkinson's about support and services available to them and to raise money for our work. By completing this form, you give us permission to use the photograph(s) we have of you in our communications. These may depict you as someone involved with Parkinson's UK, or as someone affected by Parkinson's. If you prefer NOT to be depicted as someone with Parkinson's please tick the 'opt out' clause below.

Thank you for your help. It is good to show real people involved in our work.

First name		Family name	
Address			
		Postcode	
Telephone			
Email			

We would like to be able to use your photo(s) in a range of communications. These may include printed publications (booklets and campaigning materials); adverts; electronic materials (e.g. DVDs, presentations and website); media work (press releases) and display materials (posters).

Please state here if there are any ways in which you do NOT want us to use photo(s) of you:

Please tick this box if you **do NOT want to be depicted as a person with Parkinson's.**

Occasionally we may share our images with associated organisations.

Please tick this box if you **do NOT want us to share pictures of you** with associated organisations.

I understand and accept the purposes for which Parkinson's UK use the photo(s) taken of me. If you are under 18 years, your parent or legal guardian must sign this form on your behalf.

Signed or type if emailed		Date	
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Data protection statement

The information that you give us here will only be used to contact you about these photo(s). Will not pass the details recorded on this form on to any other organisation without your permission.

For internal use only:			
Name of shoot / event			
Location of shoot / event		Date	