



Newsletter: December 2023

Message from Branch Chair Stephen Brannan

2023 a year of change/consolidation

What a year we have had in 2023. At the start of the year, I had no idea what to expect! However, as I look back, I can see it's been quite a year of change and consolidation both for me and also for the Edinburgh Branch of Parkinson's UK.

The activities of the branch had continued throughout the tough times of COVID, even although many activities had to be conducted remotely. 2023 saw the return of more face-to-face activities, coffee mornings, singing groups and exercise classes. There was more of a community spirit being developed and we decided to run a programme of branch wide 'Get-Togethers', where guest speakers would be invited to address the broader membership rather than just focusing on individual groups.

New Chair

March saw the branch's AGM take place, with the previous chairman David Adams standing down. I was then voted in as the new chair of the Edinburgh Branch, together with a new committee. A huge vote of thanks goes to David who served the Branch with an energy that belied his age. On reaching a significant age milestone, he felt he needed to focus his energy into fewer projects. Our loss is a gain for H3Uni, of which David is a founder and also Chair. The charity focuses on transformative learning.

New Venue

There had previously been a discussion within committee about the venues being used for committee meetings and more general branch meetings, for example the AGM. It was felt that although St Serf's was a handy location for people in the North of Edinburgh and Liberton Kirk was a handy location for people in the South of Edinburgh, we should try to find a more central location in town where both North and South members could congregate for Get-Togethers.

After an initial search we identified St Andrew's & St George's West on George Street. After some negotiation we came to an agreement with them where we could use the downstairs crypt area with its kitchen and small stage to deliver our Get-Together meetings. This location was then published in the programme of events which we distributed to all our members. It was disappointing therefore when the venue came to us telling us that they could no longer offer us the crypt and instead said we could use the upstairs church hall. For those of you who've been there you know this is a very large area which can easily handle several hundred people in both the ground floor and balcony areas.

Having run a couple of meetings there we've had difficulty first of all with the audiovisual equipment and secondly with the heating and the last meeting in November was particularly chilly. We had decided as a committee to try this venue for a year, however after a number of complaints from attending members, I think we need to try and find another place to have our Get-Togethers in central Edinburgh.

Volunteers

We owe a huge debt of thanks to all the volunteers who support the activities of the branch. 2023 has been a year of change (as outlined further in the Newsletter), but we remain committed to work on community and to reach a wider and more diverse population of PwPs in Edinburgh and the Lothians.

World Parkinson's Congress (WPC)

In July my wife and I were lucky enough to have the opportunity to visit the World Parkinson Congress in Barcelona. This event brought together 2500 people from across the globe including 700+ people with Parkinson's with the remaining number being made-up of clinicians, researchers, students, vendors of equipment and other interested parties. I learned so much about Parkinson's and the varying symptoms that people can experience. The three days of the conference provided stimulating presentations on items with deep scientific content, workshops for carers, and stimulating discussions about real life experiences of people with Parkinson's. I was delighted to have the opportunity to present some of my thoughts and reflections from Barcelona at the Get-Together we had in October.

Edinburgh Parkinson's Lecture

September saw another successful Edinburgh Parkinson's Lecture with a couple of hundred people attending in-person (back to numbers we had pre-COVID) and over 600 people viewing the lecture via live streaming. Many thanks to David Melton and his team for organising another interesting and engaging lecture on behalf of Edinburgh Branch. We are also indebted to staff from Parkinson's UK who assist. I encourage members to join the Research Interest Group to find out about exciting developments in Parkinson's research.

The Future

I am glad I can report that the Edinburgh Branch is in rude health as we close out 2023. I hope we maintain our level of activity over the next year and continue to support people with Parkinson's, their care-partners and families. I look forward to seeing you all next year and some of you at the Christmas lunch in early December. 2023 has been a year of many changes for the Branch. As we approach four years since Covid-19 turned our lives upside down, we feel as a Branch that we have survived, remained a constant for our members, and showed a resilience and strength.

Wishing you all a Happy Christmas and Best Wishes for 2024



Stephen Brannan

YP's January Meeting Date

The Edinburgh Young Parkinson's Support Group (EYPSG) meeting will be on the 11th January. (Unusually this is the second, rather than the usual first Thursday of the month – and is for January only).

Drew Wilson will be the speaker discussing the possible development of Walk Football. Amanda McKay, PUK Activity Co-ordinator tells us:

"We are quite keen to scope out if there is any interest from members of the YP group who may be interested in this activity. It is early days and we are in discussions with local clubs and groups to look at how they might support people with Parkinson's in current sessions or possibly develop a specific session if there is interest and we could demonstrate the need.

Drew Wilson is a walking football coach, currently volunteering with us at Parkinson's UK and is planning to provide information to participants on what has been delivered in Glasgow, gathering interest, and linking potential walking football clubs.

We do hope to offer some coach education to raise awareness of Parkinson's once we get some feedback from Walking Football clubs."



Scott Wilson, the Chair of the YP Group, and Gina Allen who helps coordinate activities and events have extended an invitation to any non YP members who may be interested. All are welcome to attend the meeting, which takes place at The Steading, Biggar Road, from 6.30pm for a 7pm start.

Appreciation and Thanks

Maggy Douglas

Maggy has been a volunteer for a few years and was instrumental in re-establishing the café and starting the Parkinsons' Walks. She is off to pastures new 'down South' to be closer to her sister.

Huge thanks Maggy, and we all wish you health and happiness in your new life. (Maggy is front and centre of the photo, taken at the end of the October walk, which ended at the Botanic Café).



Weir Brown

Weir has been our Branch Treasurer for the last 6.5 years and has been instrumental in streamlining our process and procedures and making sure the Branch reserves are getting the most return. He set us up with the Shop function recently which has made it much easier to set up events such as our Christmas Lunch, and many of our regular activities.

Weir very kindly helped us to source his replacement and in the New Year, we will appoint Niall Stirling as our new Treasurer. Hopefully you will meet him soon.

Louise Ogilvy

Despite standing down as Fundraiser, Lou has continued to help out by trying to drum up volunteers for the Can Collection (also see next page).

After many months, we are thrilled that Diane Drummond has offered to help with fundraising, which we greatly appreciate. Diane regularly attends the Get-Togethers, so you may see her there.

Lis Kirkness

Lis kindly stepped in to take over our Wednesday evening Singing 4 Fun. Unfortunately, we were not able to get numbers to sustain the session, and so we sadly have had to stop them. We appreciate that Lis volunteered to coordinate the session and remains active within the Branch.

Sally Jaquet

Sally was the Wednesday Singing 4 Fun Song Leader and very sadly when the sessions stopped, we had to say farewell to Sally. However, some of her videos are still available on the Singing 4 Fun website page.

News in Brief

January Branch Get-Together

Our first monthly Get-Together of 2024 takes place on Wednesday 10th January, from 2-4pm.

There is a change to the advertised speaker that we have in the tri-fold Branch Calendar.

We now have Tanith Muller from Parkinson's UK, who was originally scheduled for the May 2024 Get-Together.

Tanith (*also see next item*) will talk to us on the subject of: "People with Parkinson's can't wait - how can we change things?".

Blue Badge Issues

Branch Volunteer Stuart Smith, Tanith Muller (*Parliamentary and Campaigns Officer, P-UK Scotland*), Shona Lawson (*Parkinson's Advisor*) and Lesley Grieve (*her husband has Parkinson's*), met with representatives of Transport Scotland and the Scottish Government to discuss the various Blue Badge issues that are affecting PwPs.

They spoke about differences in the acceptance criteria between local councils, especially Edinburgh Council. The need for better training for non-medical assessors was raised and the delays in processing initial applications and reapplication. PwPs who have Blue Badges should not need to reapply. Renewal should be automatic.

There is a pilot scheme starting in Glasgow to see if people with MS can be fast tracked through the system. Our group above asked if a Parkinson's trial could be run in parallel but a lack of resources currently prevents this.

Paper applications are still acceptable for those who have difficulty with online applications.



Craigleith Can Collection Update

We had our final can collection at Craigleith Retail Park on 24th and 25th November. Martin Maxwell who is our liaison with the Retail Park, always helps out with the collection, and recently has been coordinating the volunteers on the days of the collection. Martin developed Covid and for the first time was not able to help out. Martin, we wish you well and hope you have made a speedy recovery. Thank you so much for all your support and hard work over the years.

We managed to raise £1069 over the two days. Special thanks to JP Morgan Edinburgh Offices for providing an army of volunteers on the Friday. And on Saturday a small but incredibly stoic group of Branch volunteers really did us proud.



London Marathon 2024: Fundraiser

Lisa England has asked for our help to promote her run in the London Marathon next year. She is hoping to raise over £2,000 for Parkinson's UK. Lisa tells us:

"My darling dad has been living with Parkinson's for the past 5 years. He now has no mobility, lewy body dementia and requires round the clock care. I have dusted down my running shoes and I'm running the 2024 London marathon to raise awareness and funds for Parkinson's as well as for him. Please help me to make a difference, every little bit helps. Thank you ""

There is much more information on <u>Lisa's Just</u> <u>Giving Page</u>



Christmas Quiz

1) Which one of Santa's reindeers has the same name as another holiday mascot?

2) Which country started the tradition of putting up a Christmas tree?

3) In the song "Winter Wonderland," what do we call the snowman?

4) Visions of which food danced in children's heads as they slept in the poem "'Twas The Night Before Christmas?"

5) Who wrote, "Christmas doesn't come from a store, maybe Christmas perhaps means a little bit more?"

6) What was Frosty the Snowman's nose made out of?

7) What is the name of George Bailey's guardian angel in It's A Wonderful Life?

8) What popular Christmas song was actually written for Thanksgiving?



Christmas Anagrams

- 1) mans own
- 2) garlic nol
- 3) my niche
- 4) dug piggy find
- 5) lent rear downwind
- 6) tiny vita
- 7) he bills legs
- 8) see bee zone grocer

Christmas Food & Drink Quiz

- 1) Julmust is a traditional, very sweet, stoutlike, Christmas soft drink from which country?
- Which country would you be in, if you were served Christmas damper, in a wreath or star shape, served with butter, jam, honey or golden syrup.
- Which northern European country serves Æbleskiver, a traditional spherical pancake sprinkled with powdered sugar and served with raspberry or strawberry jam
- 4) Christstollen is a traditional bread with bits of candied fruits, raisins, walnuts and almonds and spices from which country?
- 5) Allahabadi cake, a traditional rum fruit cake, is popular with Christians from which country?
- 6) Popular in the UK this Christmas drink made from apple cider, oranges, lemons, cinnamon, cloves, allspice and nutmeg is known as what?
- 7) Which country likes to start the festive season with a warming glass of Bombardino, a mixture of brandy and advocaat?
- 8) The popular Christmas starter gravlax is what type of fish?



Activities Review/Overview

Art Group

We are continually grateful to Lindsay McDermid who leads the art group. They meet on Thursdays at the Botanic Cottage. To sign up or get more information, coordinator Katrina is happy to help.

Bowling

Many thanks to Kenny Williamson for running the bowls. The session is on Mondays at Meadowmill Indoor Bowls, Tranent. Kenny tells us that new people ('fresh blood') are always welcome.

Neurodynamic Exercise

We appreciate the hard work put into the various sessions run by Sasha Baggaley & David Muir, and David Waughman who coordinates. To participate requires a pre-assessment. New programme starts Feb 2024. For details, contact Sasha.

Nordic Walking

Thank you to Trevor Jones who takes our Nordic Walking on Thursdays, at the Meadows. And appreciation for Dot Weir, who organises and takes care of the administration for the group.

Parkinson's Café

We are in safe hands with Sheila Edward who has been involved from the start and will supervise the monthly café, with Mike Coates helping.

Parkinson's Walks

Sheila Edward has done a great job helping organise some lovely routes for the walks. Sheila will be joined by Lynn Stewart and Nina Diviza in 2024. The walks are typically on the last Monday of the month. All are welcome.

Pilates

Many thanks again to Sasha Baggaley and David Muir, who take the Pilates classes. There are a couple of classes in-person and a couple via Zoom, which is ideal for those who don't like to venture out in the adverse winter weather.

Singing for Fun

We are grateful to Olivia Bell who coordinates our Tuesday afternoon S4F group. And special thanks to Penny Stone, our song leader for her hard work.

Table Tennis

Our YPs introduced this in Autumn 2022, though extending to welcome all PwPs, irrespective of age. It is the first weekend activity for the Branch and has proven very successful. In less than a year, the group became affiliated with Table Tennis Scotland. Some of the group won medals at the Scottish International Parkinson's Open tournament in August 2023. Huge thanks to Scott Wilson and Gina Allen for pioneering this activity.

Tai Chi

Tai Chi sessions are taken by Kevin Brown, a longstanding supporter of the Branch, often fundraising for Parkinson's in the Edinburgh Half Marathon. We appreciate his support and if Kevin is undertaking a run in 2024, we'll let you know.

There are also several activities Edinburgh Branch support and advocate:

Dance for Parkinson's: These weekly classes (Wednesdays) are delivered by Dance Base and have been very popular over the years. Dance Base recently faced issues with funding, but we were thrilled to learn that DfP is secure for the time being.

Punching with Parkinson's: These weekly sessions (Mondays) take place at Port O' Leith Boxing Club, which is situated in Craighall Road, at Trinity. You don't need any experience, and the class is for both men and women of all ages.

Yoga: we appreciate the support of Karen Watts at Theiya Arts, who takes weekly (Tuesdays) chairbased online classes for our members.

Support Groups

Carers Support Group: We are privileged to still have Cathie Quinn as our group leader. These monthly meetings take place the last Wednesday of each month (Jan – Nov). Cathie also runs the Side by Side Course, which runs a couple of times a year, and is for carers, family or friends of PwPs.

Edinburgh Young Parkinson's Support Group:

As mentioned on page 2, the YP's meet on the first Thursday of the month.

(Details of all these are on our **Branch Website**)

Festive Recipes

Diane from Fife Branch has a recipe you may like to try in the festive period.

Tasty Tray Bake

Ingredients for Biscuit Base

- o 225 g / 8oz broken biscuits
- o 50g / 2oz raisins
- 50g / 2oz glace cherries chopped
- o 2 tbsp syrup
- o 110 / 4oz butter
- 110g / 4oz milk chocolate melted
- (Optional: Nuts can be used in the base)

Method

Break up biscuits in a bowl. Add raisins and cherries. Melt syrup and butter together in a pan.

Add to the dry ingredients with the melted chocolate. Press into a greased tin 10 inch by 7 inch.

Chill in fridge for at least an hour.

Ingredients for Topping

110g / 4oz milk chocolate 50g / 2oz butter 175g / 6oz icing sugar

Method

Melt the butter and chocolate together. Add the icing sugar until blended. Spread evenly over the biscuit base and leave to set, then cut into fingers.



Individual Pineapple Treat

This can be made with any crunchy biscuit and the fruit / zest of your choice



Ingredients

- o 3 ginger biscuits
- o 1 tbsp butter
- 5 tbsp full-fat cream cheese (also known as soft cheese)
- 2 tbsp double cream or coconut cream
- 2 tbsp icing sugar
- o 1/2 lime, zest and juice
- 1/2 230g tin pineapple chunks or 1-2 pineapple rings in juice, cut into 8 small wedges

Method

1. Put the biscuits in a small, freezer bag and bash gently with the bottom of a pan or rolling pin, to make fine crumbs.

2. Melt the butter in a small saucepan or microwave and stir in the biscuit crumbs.

3. Spoon the buttered crumbs into the base of a glass tumbler. Use the back of a spoon to press down lightly.

4. Put the cream cheese, double cream, sugar, lime zest and juice in a bowl. Add 2 teaspoons of the pineapple juice from the can and whisk until thickened.

5. Spoon the creamy filling onto the biscuit base. Top with the pineapple chunks then place in the fridge for 30 minutes. Decorate with extra lime zest if you like

(Many thanks to Fife Branch for sharing this recipe)

Support Over The Festive Season

This time of year can be challenging for many, for a variety of reasons. There are some sources of support that we want to remind you of:

Parkinson's UK Helpline

P-UK Helpline is a free confidential service providing support to anyone affected by Parkinson's.

Monday to Friday: 9am to 6pm Saturday: 10am to 2pm (Helpline is closed on Sundays and bank holidays).

2 0808 800 0303 (freephone)

Samaritans

Samaritans are open 24/7 for anyone who needs to talk.

🖀 116 123 (freephone) 🖂 jo@samaritans.org

The Silver Line Helpline

Provides support, information, friendship, and advice for people (over 55) who may feel lonely or isolated.

Available 24 hours a day, 7 days a week 2000 4 70 80 90

And Finally...

It has been good to reflect on what the Branch has to offer, and to celebrate some of the successes. As Stephen Brannan acknowledged on page 1, we don't always get it right, and as with the new venue for Get-Togethers perhaps it hasn't worked as well as we had hoped. Which is why we hope that involvement by Branch members can help us to secure a new venue. If you have any suggestions, please to let us know.

We are also keen to introduce any new activities, or support any interests that members think others would enjoy. The Walking Football is an initiative we had hoped to introduce before, but perhaps with the YPs on board, as with Table Tennis we might now be successful.

We want 2024 to be a year where the Branch continues to grow and achieve more 'reach'. We want to stay relevant and responsive to the needs of our members. So please feel free to voice your opinion, your needs or wants, and we promise to give them meaningful consideration.



🛕 Wishing you all a Very Merry Christmas and a Happy New Year 🗱

Remember to visit our website regularly: https://www.edinburghparkinsons.org/ Please submit any contributions for future Newsletters to: communications@edinburghparkinsons.org

