



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

Newsletter: Autumn 2022

Welcome to our Autumn Newsletter - we have given it a fresh look and hope you like it. Please also check our [website](#) where we add news items on the front page. If you have any news you would like to share, please email details to: communications@edinburghparkinsons.org

Edinburgh Parkinson's Lecture

This year's Edinburgh Parkinson's Lecture will take place at the Royal College of Physicians of Edinburgh (RCPE), 11 Queen Street, EH2 1JQ. It is on Wednesday 28th September with a 6pm doors open for the lecture at 7.15pm. The lecture will also be streamed live. This allows us to reach a global audience, as well as making the event accessible to those with mobility issues.



The Lecture will be delivered by Julie Jones from the School of Health Sciences, Robert Gordon University, Aberdeen. Julie is holder of the first Clinical Academic Fellowship jointly funded by the Scottish Chief Scientist Office and Parkinson's UK.

The Lecture is free, with booking done through Eventbrite:

- To attend the lecture at RCPE: [In-Person Booking Link](#)
- To attend the lecture online: [Virtual Booking Link](#)

We will also update the dedicated page for the [Lecture](#) on our website with more details, which currently shows the Eventbrite Information.

Tilo Kunath Promotion



Branch Chair David Adams offered congratulations from the Edinburgh Branch on Tilo's recent promotion to Chair of Regenerative Neurobiology at the University of Edinburgh.

Tilo has consistently provided significant support for the Edinburgh Research Interest Group, for the annual Parkinson's Lecture, for our Branch volunteers, and through his work, for those with Parkinson's.

Tilo replied confirming he was very touched by David's kind and supportive words. He expressed how his relationship with the Edinburgh Branch is very special and how he looks forward to more in-person interactions with us.

Branch Meetings Return

We are returning to our monthly Branch meetings being held in-person. Our first meeting will take place on Wednesday 14th September at 2pm. Thereafter they will take place on the second Wednesday of each month (from September to April).



Our new venue is Inverleith St Serf's Hall, 1A Clark Road, Edinburgh, EH5 3BD. This is close to Goldenacre.

At our first meeting Monica Wilkinson will introduce a new Music and Movement Research Project for People with Parkinson's (PwPs), in association with Queen Margaret University: Dalcroze Eurhythmics.

Dalcroze UK confirm "In Dalcroze Eurhythmics, music is experienced through movement – the teaching and learning process engages body, mind and emotion". ([Source](#))

Meeting with the Scotland Director for Parkinson's UK



Many of the Committee had the pleasure of a meeting with James Jopling on Monday 8th August.

We had a most valuable discussion, learning from James about his experience and ideas, and sharing our activities and aspirations for the Branch.

One of the areas we want to focus on is reaching out to more locations within Edinburgh. We recognise that this will be a challenge – historically, reaching some demographics has proved tricky. James has great knowledge and understanding of the charity field, having worked for British Heart Foundation, Samaritans and Cancer Research UK.

We have set up a Community Development Group who are looking at ways in which we might get our presence into outlying areas of Edinburgh. To do this, we need volunteers. This might be as simple as offering to go along to one of the cafés we hope to organise, using existing community hubs, such as Lifecare in Stockbridge, or Faith Mission at Gilmerton. If this is something you think you could help with, please contact David Adams (chair@edinburghparkinsons.org)

All volunteers are offered training and support from Parkinson's UK: [Details](#)

Donations to the Branch

We have been extremely fortunate in the past to have received donations in the form of legacies which fund some of the regular activities we provide. Our Treasurer Weir Brown is also highly appreciative when we receive donations from Branch Members, their friends and families, and from individuals, companies and groups/clubs who have raised money on our behalf. If you or someone you know is thinking about fundraising, remember that we have an Edinburgh Branch [Just Giving](#) page, where potentially the donation can increase with Gift Aid added.

Table Tennis

Our Edinburgh Young Parkinson's Support Group (Working Age) started weekly table tennis sessions. We've now opened the sessions to anyone with Parkinson's, regardless of age, including their friends, family members, or care-partners. It really is for all abilities, and sessions are proving to be great fun. Even if you haven't played since you were a child, the know-how and skills will come back to you!



When: Saturdays, from 1-3pm.

Where: North Merchiston Club, Watson Crescent, Edinburgh, EH11 1EP.

There's a small café in the centre if you want to have a coffee and a blether between games.

Contacts: Gina Allen gina@edinburghparkinsons.org or Scott Wilson scottwils180@gmail.com, mobile 07835 820898.

For more details, see our [Table Tennis](#) website page.

Dance for Parkinson's

Dance for Parkinson's Edinburgh resumes for their autumn term on Wednesday 7th September. No prior dance experience is required.

Classes take place every Wednesday from 11.30am-1.30pm. The session lasts for 90 minutes, followed by an informal 'social café' with hot drinks and biscuits provided.

For more details, please check our [Dance for Parkinson's](#) website page.

Singing 4 Fun: Tuesdays

The Tuesday sessions will be re-starting on 6th September, from 2.00 - 4.00pm at Marchmont St Giles, 1A, Kilgraston Road, EH9, 2DW.

Our leader, Penny Stone, makes sure we have fun, but at the same time includes physical and vocal exercises which can help anyone with Parkinson's to speak and be heard. Care-partners also benefit from the sessions. We sing anything from the Hallelujah chorus to tongue-twisters and African lullabies, with Scottish folk songs thrown in. There are no auditions; even if you think "I can't sing" you might surprise yourself.

The sessions are also open to people who do not have Parkinson's (not just care-partners). Cost is £3 per session (care-partners free), and a voluntary donation for tea or coffee. The Butterflies Café at Marchmont St Giles is welcoming, and it is possible to have a light lunch there before the singing.

Contact Olivia Bell, 07531 150097 or email: secretary@edinburghparkinsons.org

Singing 4 Fun: Wednesdays

The Wednesday evening Singing4Fun group at the BB Pollock Pavilion, 227 Ferry Road, Edinburgh, EH6 4SP runs from 7pm – 8.30pm (with a short break for tea). The sessions also take place during school term-time and will start on 7th September. Cost is £3 plus donation for refreshments.

These sessions typically run as a hybrid which means people can join by Zoom if they can't or don't want to attend in person. The format has been improved, as we use more technology to help people at home feel more integrated.

We hope to also include People with Parkinson's from around the country, who perhaps don't have singing groups in their area. Spread the word!

If you would like to join by Zoom, contact Cathie by email: cathie@edinburghparkinsons.org.

This group also welcomes people who don't have Parkinson's, so bring friends and family too!



Walking Group

Our walking group activity on the last Monday of the month is proving popular. Special thanks to Maggy, Olivia and Sheila who are the lead volunteers and have chosen some terrific walks.

The next walk takes place on Monday, 26 September 10.30am (our usual meeting time).

This is a circular walk from the entrance to Tesco Superstore, 7 Broughton Rd, EH7 4EW. (near Canonmills). Lothian Buses 8, 23, 27 and 36 pass nearby and there is 3 hours free parking at Tesco.

The October and November walk routes will be announced in due course.

Social Café

The Social Café is popular and is a place to socialise, with no real agenda. It is a wonderful way to relax and meet people. That said, there are people there who can help you to find information or point you towards sources of help you might need. From time to time, we will have a Parkinson's Adviser present to help with information in relation to benefits, how to apply for Blue Badge, etc.

The sessions are at Butterflies Café, Marchmont St Giles, 3 Kilgraston Road, EH9 3DW on Mondays, from 10.30am to 12 Noon. The dates for the remainder of the year are:

- 12 September; 10 October; 14 November; 12 December

Other Regular Activities

We have many other activities and opportunities to socialise, keep healthy and have fun. Please check out our [Branch website](#), and the link at the top of its front page as shown below.

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SCOTLAND

Edinburgh Branch

[Home](#) [About Us](#) [Activities and Events](#) [News](#) [Local support](#) [Research Interest](#)

Take Part in Clinical Trials

We have received a communication from Parkinson's UK outlining concerns that some research projects may have to be suspended if they cannot get enough recruits. This can sadly mean important new treatments could be delayed by years, or risk never being made available at all. So please, if you have Parkinson's, consider either of the two trials below:

- Exploring a new drug to slow progression in newly diagnosed people with Parkinson's
The pharmaceutical company UCB is investigating how effective and safe a new oral drug is for PwPs diagnosed within the last 2 years. The aim is to understand the effect of the treatment on the progression of Parkinson's. Researchers need 450 people between 40-75 years of age, diagnosed with Parkinson's in the past 2 years, and who have not taken drug treatments for their Parkinson's. You must be able to travel to a study site in Glasgow.
- Can a wrist-worn device help improve some symptoms of Parkinson's?
This trial is looking for PwPs across the UK, to help shape the design of a wrist-worn device to assist with day-to-day life, including prompting swallowing and reduction of drooling. Participants will be given the wrist-worn device to use at home and asked to give feedback to the research team about any problems as well as suggestions for improvement. You will be allowed to keep the device.

More details including information and links to apply for either trials are on our Branch website: [Link](#).

Share Your Views on Clinical Trials

Parkinson's UK are providing opportunities for people with Parkinson's to help shape clinical trials by sharing views on what encourages or prevents us from taking part in research.

The researchers need PwPs, even those who have never taken part in research.

You will be asked to complete an anonymous survey about key barriers, motivators and facilitators which might support or discourage participation in Parkinson's clinical trials. This online survey is anonymous, optional and should take no more than 40 minutes to complete.

The deadline is 31st October, so if you are interested in taking part (and we do encourage Branch Members to have their say), please use this [link to the survey](#) and scroll down the page until you see "Interested in Taking Part?"

Care-Partner Support

We have a monthly [Carer Support Group](#) and we run [Side-by-Side Courses](#) twice a year. But we want to make sure that care-partners have a wider support network.

Many of you know about [Vocal](#), but less about [Care for Carers](#). They are a voluntary organisation and differ in that they provide a range of support for care-partners, including local events and short breaks. They are for all care-partners regardless of age/disability of the person they care for.



First Steps



The Branch successfully completed the First Steps programme earlier in summer. The programme is delivered over 3 sessions in a 4-week period and is aimed at those with a recent diagnosis of Parkinson's who feel ready to meet other people recently diagnosed, their family, friends and care-partners.

Participants were from all over Scotland, and for some of them it was their first chance to talk to another PwP. It has made us even more determined to run further sessions. Ultimately, we hope it will be feasible to have the course as a hybrid, with in-person as well as Zoom meetings.

Special thanks to Nick, Iain and Kirsty who facilitated and hosted the inaugural First Steps. And of course, to the Parkinson's UK staff who supported and directed us to master the programme.

Parkinson's Nurse Specialists

We have recently updated information on our website regarding the Parkinson's Nurse Specialist Service.

Were you aware that there are Nurse-led clinics currently held at the Royal Infirmary Edinburgh, the Western General Hospital, St John's Hospital, East Lothian Community Hospital, Midlothian Community Hospital and Sighthill Medical Practice?

Please check the updated and additional information on [Parkinson's Nurse](#) page on our website.

Volunteering Matters

We do need more volunteers. We would like to reach more people with Parkinson's and their family, friends and carers.

We want to spread the word further about how we can offer support and ways in which everyone can try to 'live well' with Parkinson's.



Current Volunteer Opportunities

- Branch Vice Chair
- Quiz Master (online quiz evening – we will provide Zoom hosting)
- Walking Football Coordinator (we will help organise the initial set up and publicity)
- Online Meeting Assistant for First Steps ([Role Descriptor](#))

As mentioned in an earlier topic, we hope to find ways to reach more outlying areas of Edinburgh. Do you have knowledge or experience we can tap into? Venues, places to put posters etc? Or do you know anyone in your circle who might allow us to pick their brain?

Please see our website page for how to get in contact and more information about volunteering with us: [Volunteering Matters](#)