

Edinburgh Branch

June 2025 Newsletter



This edition has quite an eclectic selection of entries! One of which is a reminder that after the Highland Show in June, the Edinburgh Fringe and Festivals are not far away!

(contact details for newsletter contributions (most welcome!) or for further information on any of the content please email: communications@edinburghparkinsons.org)

Neurodynamic Exercise

The latest 10-week programme has ended. A huge success, with many attendees planning to carry on with the weekly continuation classes.

Sasha is working on organising the autumn programme, potentially taking place around October. While she has some people on a wait list from the spring programme, she is open to taking names for the autumn one.

Please email: <u>sasha@edinburghparkinsons.org</u> and you can also view the **Neurodynamic Exercise** page on the website for more information.

Quality of Life Group

This is a group for People with Parkinson's. Importantly the group is not facilitated but rather is self-led, and a place to share, among kindred spirits.

The group meet on the first Thursday of the month from 2-3.15pm, at Roseburn Place. From the June meeting one of those who attended for the first time said: *"I wouldn't have expected to walk into a room full of strangers and feel at home."*

So please do consider this group which is strictly for PwPs only – and therefore a great forum to offload. See the **QoL** page on the website.

Carers Support Group

This monthly group provides an opportunity for partners, family or close friends of PwP's to meet, share, support, and learn from each other's experiences.

This long-established group takes place on the last Wednesday of the month, from 10.30am, at the BB Pollock Pavilion, Ferry Road, Edinburgh. As with the Quality of Life Group, this is a wonderful opportunity to share, vent, learn and in equal measures have fun, friendship - and in this group, Cathie's amazing scones \cong .



Singing for Fun: Extra Sessions

We are holding two extra sessions of our very popular Singing4Fun. If you haven't been before, and would like to give it a try, why not come along.

The dates are Tuesdays: July 22nd and 29th, from 2pm-4pm at St Serf's church in Clark Road, just off the Ferry Road near Goldenacre.

Tea or coffee and biscuits will be provided, and the cost will be $\pounds4.00$ for a single person, or $\pounds6.00$ for someone with Parkinson's and a companion.

We do some vocal exercises to loosen your muscles and sing a wide variety of songs something for everyone. You don't need to read music or play an instrument, and even if you haven't sung since you left school, you can still enjoy it! As Penny, our song leader says, "if you sing a different note, it's all harmony!"

For more information, contact Olivia: secretary@edinburghparkinsons.org

Walking Football: More Lionesses Needed!

Parkinson's Walking Football in Edinburgh is a partnership with Walking Football Scotland, Hibernian Community Foundation and Parkinson's UK.

This activity has really taken off, and we are so happy that it is well attended. However... there are not as many women players as we would like. While maybe not an activity you had thought about – we really do think it's great for women as well as men. And who knows, perhaps in time we might have an Edinburgh Ladies Walk Football Team as they have in Midlothian (pictured below). For more details see the **Parkinson's Walking Football**: Edinburgh Group page on our website.



Sporting Memories for Parkinson's

Parkinson's UK Scotland and Sporting Memories have a partnership with an aim to have some fun through the power of sporting reminiscence.

Sporting Memories is a charity and social enterprise that helps people to reminisce, replay and connect. These sessions are for anyone affected by Parkinson's who are looking to keep mentally active. You can look forward to reminiscing, camaraderie, team quizzes and some light movement, which can be done seated.

When: Thursdays from 10.30am to 12pm Where: Liberton Northfield Church, 280 Gilmerton Road, Edinburgh EH16 5TT

For more details please see the **<u>Sporting Memories</u>** page on the website.

Myrtle Throgmorton: Me and Parky

Jennie Chalmers, diagnosed by with Parkinson's in 2023, is returning to the Edinburgh Fringe this year to present a new one-woman comedy show.

Jennie is a former BBC radio comedy producer. She presented near sell-out shows in 2015 and 2017 to great acclaim. This show features Myrtle's musings on life and looks at the best of Parkinson's – focussing on it's positive and humorous side.

Details:

- o Dates: 11 16 August 2025
- o Time: 17:20 (45 mins)
- Venue: Venue 236, Greenside @ George St.
- Website: <u>www.myrtleproductions.com</u>
- Tickets: <u>www.edfringe.com/tickets</u>
- Facebook: <u>www.facebook.com/myrtlethrog</u>

The show isn't all about Parkinson's, but it hopes to find the best of it.

Myrtle Throgmorton: Me and Parky marks Jennie's 70th year and will raise funds for Parkinson's UK. We hope many of us support Jennie and attend the show.



'Poles and Parkinson's'

Kinga Kabala was diagnosed with Parkinson's four years ago, at age 45. She lives in Edinburgh and belongs to the Polish community.

Kinga is a very proactive volunteer for Parkinson's UK and Edinburgh Branch. She has been instrumental in pushing for the success of our Niddrie Café. The café is open to all with Parkinson's, and we would welcome more people from the Polish community. Please feel free to share details of the café to anyone you know who may be from Poland and has Parkinson's, or their friends and family.



Spotkania dla Polaków z chorobą Parkinsona oraz ich bliskich

Zapewniamy bezpłatne napoje i przekąski, fantastyczną ciepłą atmosferę, ciekawe tematy do rozmowy, porady i pomoc.

Nie zostaniesz sam z chorobą, masz nas !!! nikt Cię tak nie zrozumie jak my

Gdzie : The Hays Business Centre, 4 Hay Avenue, EH16 4RW Kiedy : w <u>każdy czwarty poniedziałek miesiąca</u> o godzinie 14:00

Bezpłatne miejsca parkingowe dostępne są na okolicznych ulicach. Autobusy linii Lothian nr 2, 14, 21 i 30 przejeżdżają w pobliżu Hays Community Hub, tuż przy Niddrie Mains Road.

Można po prostu przyjść w dniu wydarzenia lub, jeśli chcesz uzyskać więcej szczegółów, napisz do Kingi Kabała kabala.kinga@gmail.com

The next Niddrie café is Monday 23rd June. For details of this and the other two cafés (Marchmont and Fairmilehead) please see the <u>Café</u> page on the website.

Kinga's goal further extends to finding other Poles with PD living in the UK. She has created a support group on Facebook and again we would love to help her reach more people from Poland who are living with Parkinson's in the UK.

Scanning the QR code in the image below will take people to the Facebook page, to request to join. You are welcome to share either this whole newsletter or simply download and send the photo below to anyone you think would benefit – it's not just for Edinburgh based people, so feel free to share on a wider perspective.



Sadly, we were too late to print to advertise Kinga and her plan to undertake Walk for Parkinson's on 7th June, for which we are really very sorry.

Last year, at the walk at Lochore Meadows in Fife, 65 members of the Polish community took part in a show of support for Kinga. We are sure she would get a great turnout again.

To find out more about this amazing woman who has overcome so much and gives so much back, please do read a super bio done by Parkson's UK:



Community united to Walk for Parkinson's

https://www.facebook.com/share/p/1BQ8GkUryY/

Table Tennis: Continued Success!

Once again, the Saturday Table Tennis group have done brilliantly at the recent Scotland Tournament. Well done to all those who took part.

Scott Wilson who organises the Saturday Table Tennis (along with Gina), shared some fantastic news from a recent competition.

"Well, what a great days table tennis at Perth & Kinross competition today (Sunday 18th May). The Edinburgh YP Table Tennis Club had 8 players representing our club and everyone put great games in a round robin format.

We came home with a silver medal (Frank) and a bronze from (James) losing bronze finalist (Ian) other players Robert, Scott, Diane, Joan and Alison won some great matches. Everyone done the club proud! 👋 🔎 Well done all".

Picture collage below from the event, (reproduced with permission from Scott).



For more information, please see the **<u>Table Tennis</u>** page on the website.

Astley Ainslie: Potential Relocation

NHS Lothian have submitted a planning application to completely demolish the Millbank Pavilion on the Astley Ainslie Hospital site. We understand there is potential plans to relocate services to East Lothian Community Hospital.

Research uncovered a **Freedom of Information response** in which NHS Lothian confirms when asked when did discussions about relocating patients start?

"In April 2024, the management of Astley Ainslie Hospital was transferred to the East Lothian Health and Social Care Partnership. Since then, an assessment of inpatient and outpatient services, as well as the overall infrastructure, has been conducted and presented to the NHS Lothian Corporate Management Team. The findings highlight ongoing environmental and operational challenges at the AAH site, posing risks to both patient and staff safety. As a result, it has been recommended that, as a matter of business continuity, urgent consideration be given to exploring off-site service options for inpatient care".

Ian Murray (MP for Edinburgh South) on the I Love Morningside Facebook Page, is encouraging people to have their say and make a comment on the proposal for the **demolition of the building** (closing date 20th June).

But in terms of the impact on services for people with neurological issues, Parkinson's UK Scotland are working to collate views of the impact of relocation to Haddington. Tanith Muller (Policy and Campaigns Manager, Scotland) is doing a fantastic job of liaising with organisations (including Neuro Alliance of Scotland) and ensuring the concerns of People with Parkinson's is heard.

We will keep you posted when we have more information.

Side by Side Course: Autumn Delivery

We were saddened to have to cancel the spring course, for those who know, live or work with someone with Parkinson's, due to low number of enrolments.

However, we hope the course will run in the Autumn, if we can get enough people enrolled. Please register interest with the organiser, Cathie Quinn (cathie@edinburghparkinsons.org) and see the **Side by Side with Parkinson's** page on the website for more details of what the course entails.

Mindfulness

The 8-week online programme delivered by Cath Ashby ended on 10th June. We would like to express thanks for her offer to run these sessions.



There were a limited number of places, and so we know a few people were unable to attend, though Cath did her very best to accommodate as many as possible.

If we are lucky enough to be offered more sessions, we will let you know.

Date for Your Diary: Lecture 2025

The eagerly awaited annual Edinburgh Parkinson's Lecture 2025 is taking place on the evening of Thursday 2nd October 2025.

For the fourth year in a row, we have a female guest lecturer. We are thrilled to have Dr Agnete Kirkeby give her lecture: Stem cell therapies for Parkinson's Disease – where are we now?

Agnete is Associate Professor at University of Copenhagen and Lund University. She is group leader for Kirkeby Group. The aim of the Kirkeby Group is to develop novel stem cell transplantation therapies for neurodegenerative diseases as well as to use the stem cells as a tool to understand the pathogenesis of brain disorders.

We are in the process of finalising details and as soon as they are available, we will share booking details. Once again, the event will be live in person and simultaneously streamed online.

Please keep checking the **Edinburgh Parkinson's Lecture** page on our website.

BeechBands: Early Access Offer

BeechBands can have an incredible impact on symptoms for many PwPs. The wrist device, designed by Carl Beech is powered by Parkinson's UK

Before the bands go on sale, Parkinson's UK have secured 500 free BeechBands to give to our community and they are particularly looking to support those who may benefit from the band but are <u>digitally excluded</u>, or who wouldn't be able to afford to purchase a BeechBand.

Click on the image below (courtesy of BeechBand Facebook page) to see a video.



On Monday 16 June at 9am, Parkinson's UK will open a <u>Google Form</u> for members of the various Parkinson's UK branches/groups to register. Bands will be allocated on a first come, first served basis whilst stocks last and limited to one per person.

If you know of anyone who might benefit from a band, and are unable to complete the form themselves, could you potentially do so on their behalf? Anyone putting an order in for someone else will need to know the following:

First Name; Surname; Address; Town; Postcode; Email address (Parkinson's UK collect this information to be able to contact the individual if there is an issue with the information needed for delivery. If the individual doesn't have an email address, please provide the contact details of someone who can make contact with them if needed. Phone number - as above with email address.

In return for receiving a BeechBand, recipients will be asked to share feedback with the team at BeechBand so they can further develop the product. In the box with device, is information about how to share this feedback both on- and offline.