

Edinburgh Branch

March 2026 Newsletter



Contributions to the newsletter or the website are welcome. Please send anything to:

communications@edinburghparkinsons.org

News in Brief

Some snippets of news we feel important are outlined below:

Date Change: April Get-Together

Our guest speaker Professor Tilo Kunath is unable to come to the originally scheduled meeting in April. As Tilo is so knowledgeable, interesting, and always popular – we decided to change the date of the meeting, rather than forfeit a chance to hear latest news from Tilo.

For those newer members who may not have had the pleasure of hearing Tilo speak – here is his profile from the Cure Parkinson's Trust:

Professor Tilo Kunath is a Senior Research Fellow and Group Leader at MRC Centre for Regenerative Medicine, University of Edinburgh. His research group focuses on mechanisms of neurodegeneration with two main areas: to understand how the protein, alpha-synuclein, causes degeneration of neurons in Parkinson's, and to produce a cell-based therapy for Parkinson's from human pluripotent stem cells.



Art Group Resumption...

There is some progress, and we potentially do have someone who is willing to take over the art group. The previously identified group facilitator sadly for us, but wonderful for her, got a job offer that means she can't now help us.

The plan now is to run a taster session in the near future with the new person. The aim is to find out what people want the sessions to focus on, and to judge the likely numbers who are interested in the new art group.

This session will take place at the Botanic's cottage where the Art Group previously took place. We expect that the day the group meets will remain Thursday afternoons – and the session to be on that day of the week.

We will send out final details when they are confirmed.

Frame Running Research Opportunity

Ruyi Xu, a PhD student at the University of Edinburgh is leading research into the effects of frame running on psychosocial and physical health of people with Parkinson's. There is now a wonderful opportunity for additional participants.

Frame running is an activity for people who find it difficult to walk or who can walk but find it difficult to run. Frame running allows them to propel themselves using a large three-wheeled frame with a saddle but without pedals.



This study is following a similar study for adults with MS, which is reported here: [Taking it in your stride: how an adapted sport could help people with MS get active | MS Society](#)

As part of Ruyi's PhD study, she is conducting a 7-week frame running programme for people with Parkinson's. Participants go to the university for pre-testing before attending a weekly frame running session and then visit the university again for post-testing.

The sessions take place each Friday at Meadowmill Sports Centre, in Tranent. Sessions are free to attend for people taking part in the study.

There is a session between 1-2 pm and another between 2-3 pm.

There are currently some participants across both sessions, but Ruyi is keen to add more and has decided to extend the sessions until the start of May to allow additional participants to take part.

For more details please see the [Participant Information Sheet](#) (may download automatically).

If you do want to sign up, please complete this [online form](#). It includes a health screening questionnaire, as they will need to determine it is safe for you to participate (this is standard for all exercise studies). Naturally, all health information is treated confidentially.

AGM: Summary of Key Points

Our AGM was on Wednesday 11th March. Branch Chair Stephen Brannan gave a summary of how the Branch fared in 2025. The meeting was well attended, and we were pleased to be joined by some key staff from Parkinson's UK.

Stephen began by outlining the range of activities on offer. These range from exercise type activities, to support groups, and social cafés. Despite some challenges with Morningside Pilates, and hiccups with the art class resumption, overall, we feel we are meeting the needs of the majority of our members.

Outreach

We now have three social cafés. The original Butterflies Café at Marchmont St Giles (next one is on 13th April). The second Café is Niddrie Café at Hays Business Centre (next one is on 23rd March). And our most recent is Fairmilehead Café at Fairmilehead Church (next one is 18th March).

The plan now is to introduce a new café in the Northwest side of Edinburgh. If you know any potential venues, do let us know. If you would also be willing to attend on a monthly basis to facilitate, that would be incredible.

Finance

We sustained a loss of around £10,000 in the financial year 2025/26. The previous year we had received a large legacy (£27K) which allowed us to introduce and subsidise some of the activities on offer.

Stephen outlined that as we are a charity we of course are non-profit, but we do have to remain viable. We set a 50% recovery for the activities in which we use activity leaders. These are professionals, who of course charge for their time, and we have to pay for room hire. So, we do welcome contributions and have suggested prices, which can be paid for in the Shop on the website. However, nobody should feel they can't attend any classes or activities due to hardship – we absolutely want all people with Parkinson's to keep active, socialise and make use of range of activities and support groups.

Edinburgh Parkinson's Research Interest Group (ERIG)

Chair of ERIG David Melton gave overview of ERIG, and the success of the 2025 Lecture. The work of the guest lecturer Dr Agnete Kirkeby and her team on Stem cell therapies for PD is so successful that in the USA they have skipped a phase and are now in the last phase before being licenced for use in patients.

Committee Changes

There were two new members who joined the Committee in 2025/26:

Frank Ribbons: became Membership Secretary

Diane Drummond: joined the committee and added activity coordinator to her role as fundraiser.

Gina Allen: Gina has stepped down from the committee but will remain as the 'exercise' type activity coordinator.
Stephen thanked Gina for the huge amount of hard work she has undertaken in the last few years.

Parkinson's UK Scotland Director: James Jopling

James gave an insight into the data from recent research. The study looked at 18 million patient records alongside hospital admissions data across the UK.

Some of the key findings are:

- In 2025 around 28,000 people in the UK were diagnosed with Parkinson's. That's someone being diagnosed every 20 minutes.
- There are approximately 166,000 people living with Parkinson's in the UK, of which around 14,000 live in Scotland.

By 2030, the UK number is expected to reach 173,000, as the population grows and ages.

- On average, people living with Parkinson's were diagnosed at age 69.
- 59% of people living with Parkinson's in the UK today are men.

He outlined the resumption of the TOP HAT study, which is a Parkinson's UK funded clinical trial testing whether the medication ondansetron can safely reduce visual hallucinations and delusions in PwPs or Lewy Body Dementia.

James also spoke of the importance of the groups and branches around the country and reiterated the benefits of exercise, companionship, and community.

Activities: Monthly Spotlight

Each month we are going to spotlight one or two of the many activities the Branch offer, or external sources who focus on Parkinson's. It may be useful to have a bit more insight into what is entailed and who take the classes/sessions.

Parkinson's Walks

We confirmed the introduction of walks in September 2021. At that point in time, we were still extremely cautious and careful due to the Covid 19 restrictions but felt it was time to introduce a walking group. Initially it was billed as 'Walks in the Park,' and our first three walks were:

- Sep: Inverleith Park; Oct: The Meadows; Nov: Hermitage of Braid

We ensured that at least two committee members or volunteers would be at the meeting points, though emphasised that there was no formal registration – if people wanted to join, they just turn up on the day. We were fortunate to have Maggy Douglas take over the organisation of the walks for a long time, aided by Sheila Edward and Olivia Bell.

Maggy moved away, and we had a bit of a wait until Lynn Stewart came onto the team and she and Sheila have done a great job of coordinating and leading the walks.

As the walks get more popular, we are thrilled to have a new member of the team, Morven Stirling, who is going to begin as a volunteer for the walks.

The walks were and still remain free. As with all good walks they cumulate with option to go for coffee, and cake or lunch if you prefer.

The image is from the January walk at Leith Links, with some of the walkers and organisers Lynn and Sheila (to the right of the statue).

The March walk is on 23rd March, which will be at Saughton Rose Garden.



More details are on the [Parkinson's Walks](#) webpage.

Can Shoogling: Volunteers Please

We start our annual fundraising with the first of four dates where we are allowed to do a can collection at Craigleith Retail Park.

Diane our fundraiser would appreciate volunteers to hold (but not actually shoogle) cans, on the following dates/times:

- Friday 10th April: 10am–Noon; Noon–2pm; 2pm–4pm
- Saturday 11th April: 10am–Noon; Noon–2pm; 2pm–4pm

If you can't commit to the full 2 hours, we would welcome any time you can give us. If you are able to help, please email: diane@edinburghparkinsons.org



Singing 4 Fun: Summer Slots

Our Singing 4 Fun takes place during term time. During summer, there is potential for a long spell without any sessions. Olivia and Penny the Song Leader have once again introduced additional summer sessions.

- These are Tuesdays 2–4pm: 30th June; 7th July and 14th July
- The venue for these is: Inverleith St Serf's, 280 Ferry Road, EH5 3NP



Everyone is welcome – you don't have to attend the usual session to come along.

We do ask for a contribution of £4 per person, or £6 for a PwP and their carer.

The usual sessions back at Marchmont St Giles will resume on 8th September.

Please see the [Singing 4 Fun](#) webpage for more details.

Megan Boxall: Run Britain

Megan is the niece of the late Tom Issacs, and she is currently on a quest to run 200 marathons in 200 days, running the coastline of Britain, raising money for The Samaritans. The distance will be 5240 miles, starting on 21 October 2025 on Sizewell Beach, Suffolk and finishing on the same beach on 9 May.

Tom Issacs was diagnosed with Parkinson's at the age of 27. He was Co-Founder of the Cure Parkinson's Trust, and he did everything he could to raise awareness. By April 2003, Tom had walked 4,500 miles around the British coastline, climbed the highest mountains in England, Scotland, and Wales, and run the London Marathon, raising over £350K. Tom passed away in 2017.

Megan was inspired by her uncle (who wouldn't be!) and is currently around 144 days into her big adventure.

She should be in Edinburgh early April, so we will let you know, and hopefully we might be able to have some people cheer her on along her route.

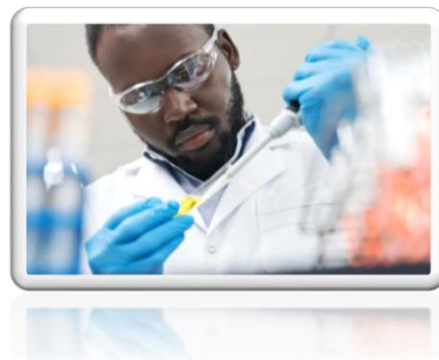
The photo below is taken on Day 144, where she is in John O'Groats. This image is taken from Megan's [Daily Diary](#).



Megan has a [Just Giving page](#) if you did want to donate. Samaritans is a very worthwhile cause, who “are available round the clock, every single day of the year providing a safe place for anyone struggling to cope, whoever they are, however they feel, whatever life has done to them” ([Samaritans](#)).

Research Opportunities

Parkinson's UK have some opportunities for people with Parkinson's and their supporters to take part in research in person and online. Please do consider taking part in studies, many can be done remotely. Some current opportunities are outlined below:



What Matters Most: Better Conversations In Parkinson's

Many people with Parkinson's experience problems with communication. A PhD student wants to support people with Parkinson's and their loved ones to have better conversations. They want to learn what changes to communication are most important. [Please click for further details](#) (there is tight deadline for this, 18th March for PwPs and 26th March for their supporters).

The NEULARK Study

The research aims to understand whether the effects of an investigational drug, called NEU-411, can slow down Parkinson's in people who have changes in their genes that mean that a protein linked to Parkinson's (called LRRK2) is working harder than it should. Please [click for further details](#)

Attitudes of PwPs to Tracking Devices

Parkinson's symptoms can be difficult to manage. Using devices like smart watches to monitor symptoms could help health professionals improve care. Researchers want to understand how people with Parkinson's feel about using these devices. [Please click for further details](#)

How Do People With Parkinson's Experience Head, Mouth And Face Pain

Researchers want to understand what pain people with Parkinson's experience in their head, mouth, and face. They want to find out if this pain changes at different stages of the condition. [Please click for further details](#)

Inactive Account Manager

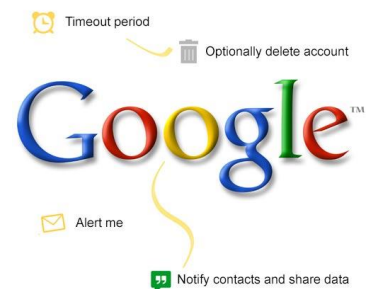
Were you aware that there are inactive account manager schemes you can set up with some digital service providers? These tools allow users to pre-determine what happens to their data if they stop using the service for a set period.

Recently we have sadly lost a number of members of the Branch. Our thoughts go out to the family, partners, and friends.

It was at one of the Carer Support meetings that it was brought to attention the difficulties there are in accessing information on the phone of someone who has passed away. Gone are the days when shops on the likes of Leith Walk would unlock any phone! So, it might be worthwhile considering being proactive in assigning access to your phone if anything happens to you.

From [Google](#), there are a couple of key things that might be worth considering:

- Active Management: you can define a "timeout period" (e.g., 3, 6, 12, or 18 months) after which the account is considered inactive.
- Trusted Contacts: you can designate up to 10 people to be notified or given access to specific data (like Photos or Drive) upon inactivity.
- Account Deletion: Users can choose to have their account automatically deleted after a specified period of inactivity.



Apple have a slightly different system, called [Apple Legacy Access](#).

Here, if you want your data to be accessible to designated beneficiaries after your death, you can set up Legacy Contacts on your account.

As so many of us now use our phone rather than address books, this could be well worth considering setting up.

Edinburgh Leisure: Parkinson's Friendly Classes

Edinburgh Leisure have various Parkinson's friendly classes available across 11 venues in the city.

Classes include Active Sit, Strength & Balance, Strength & Cardio, Seated Yoga, Active Dance and Active Aqua (none of these require a referral).

Some details are available within the [Low Intensity](#) section of the Edinburgh Leisure website.

For more information on the classes please contact the Active Communities Advisor Team on 0131 458 2260 or email active@edinburghleisure.co.uk

Venues where classes are held include:

Ainslie, Leisure Centre; Craiglockhart Leisure Centre; Drumbrae Leisure Centre; Glenogle Swim Centre; Gracemount Leisure Centre; Leith Victoria Swim Centre; Meadowbank Sports Centre; Portobello Swim Centre; Queensferry High School; Royal Commonwealth Pool, and Warrender Swim Centre.



*Photo Attribution: Chris Watt
Photography via Edinburgh Leisure*

Edinburgh Leisure also runs Healthy Active Minds

Healthy Active Minds is a 12-week programme designed to introduce you to and support you to take part in regular physical activity. For more details please see the [Healthy Active Minds](#) webpage.

The requires a referral. To make a referral please speak to your GP or nominated Mental Health Professional.

For more information about this programme or to discuss a referral, please contact their Active Communities team on 0131 458 2260 or email active@edinburghleisure.co.uk