

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

Newsletter: April 2023

Please also check our <u>website</u> 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

Branch Get-Together

Our next monthly Branch Get-together is to be held at 2pm on Wednesday 12th April, at Inverleith St Serf's Church Hall, Clark Road, Trinity EH5 3BD.

Tea and coffee will be provided. Buses 14, 21, 23 stop close by.

Michael McLaughlin, a Postural Stability instructor from Edinburgh Leisure's Steady Steps programme will discuss how to improve balance, strength and confidence.

A short taster exercise session will also be available for those who would like to try Michael's gentle exercises.

The Steady Steps programme is ideal for anyone who is concerned they might fall. Instructors help you identify personal goals and ensure you exercise in a safe supported environment. Michael will also tell you how to access the <u>Steady Steps programme</u> which is available at Edinburgh Leisure venues all over the city throughout the year. (See page 5 for more details).

Contents

As we have a larger than usual Newsletter, here is a contents list:

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Recent AGM

Our AGM was held at St Serfs, Goldenacre on 15th March. We are pleased we had a good turnout.

We said goodbye to outgoing Chair, David Adams (pictured left), and formally welcomed new Chair, Stephen Brannan (pictured right).





During the AGM, David reflected on the year's achievements. Some highlights include:

- FIRST STEPS Programme which the Branch delivered in June 2022
- o Complementary Therapies programme launched
- Community Development Group expanded
- Activities & Events resumed in person and we introduced Table Tennis

David thanked all the volunteers, of which we have more than 30 regulars, with special mention made of Gina Allen who won a volunteer award from Parkinson's UK. He also reminded us how important our service providers are – all those who deliver the regular activities and support our Members.

We sadly lost a Member of the Committee earlier this year, Dave Wilson, who is greatly missed.

Finance Update

Our Branch Treasurer Weir Brown gave us an overview of the Branch Finances. While the Branch is doing quite well overall, our expenditure is exceeding our income. The regular activities account for quite a shortfall, which is something that is not sustainable. Hence, we plan to introduce a small increase in the cost per class. We hope that you understand the necessity for this, and continue to support and attend our wide range of activities and support groups.



Weir thanked those who gave donations, both from collections at fundraising in conjunction with other charities and events. And we were kindly left a couple of legacies from wills, which boosted Branch funds.

Louise Ogilvy our outgoing Fundraiser deserves special mention, with much appreciation for all her years of service. And huge thanks are due to Martin Maxwell, who is key to us getting the slots to collect at Craigleith Retail Park. Martin also collects *every* day we are there. That is 6 hours per day for 6 days each year – in all weathers. We are exceedingly grateful.

ERIG

Chair of the Edinburgh Research Interest Group, David Melton, gave an overview of the very busy year for ERIG.



The pinnacle of the year is the annual Edinburgh Parkinson's Lecture. Last year's was very well received and the legacy from the lecture continues to support and correlate the Branch commitment to encourage our Members to participate in exercise. (See page 7 for details of this year's Lecture).

ERIG have meetings several times a year, on a Saturday.

Scotland Director

James Jopling gave an overview of Parkinson's UK Scotland and his plans for 2023 and onwards:

These include:

- Better access to treatments for advanced Parkinson's
- People with dementia and Parkinson's, struggling with their mental health and Parkinson's
- Developing groups and better presence in deprived communities, YP, friends family and carers, newly diagnosed, remote and rural communities
- 10 new local authority support areas for Parkinson's Active
- Supporting grant applications for physical activity, Parkinson's nurses and clinicians – people and projects



New Chair Aspirations

Stephen Brannan highlighted some key areas he will focus on, including...

- First Steps Programme (improving support for people coming to terms with their Parkinson's)
- More Branch Get-Togethers
- Continuing In-person Activities
- Community Development Group
- Branch Social and Participative Events
- Continuing Patient and Public Involvement PPI



Fond Farewell to David

We are grateful to David Adams for his tireless work over 8 years. The Branch is fortunate to have had such strong leadership over many decades. We were pleased many came along to show their gratitude as well as to welcome our new Chair.

(Back row L-R: David Adams, David Melton, Stephen Brannan, James Jopling, Weir Brown. Front row: Olivia Bell, Alice Hall, Claire McNeill from Parkinson's UK)

Non-Branch Media

Movers and Shakers

Thanks to Maggy Douglas for sharing a link to the Movers & Shakers Podcast.

These are a group of six friends living with Parkinson's who aim to raise awareness of the condition. Among them is Cure Parkinson's Trust Patron and Vicar of Dibley co-writer, Paul Mayhew-Archer. We have been fortunate to count Paul as a friend of the Branch for a number of years. In the Podcast, Paul is joined by Jeremy Paxman and Rory Cellan-Jones, among others.



To listen to the Podcast use this Link

Evidently Cochrane

This is a blog for people living with Parkinson's, and those who support them. One of our volunteers, Lis Kirkness, who has Parkinson's, relates her experience of exercise, and the benefits she has felt, both in relation to her Parkinson's symptoms and to her overall well-being.



Out-Thinking Parkinson's



Parkinson's Disease

Dr Gary Sharpe, is a scientist and engineer by background, diagnosed with Early Onset Parkinson's Disease in 2009. He started "Out-Thinking Parkinson's" in order to pursue pragmatic and practical Progressive Symptom Reduction Strategies for solutions towards progressive symptom reduction for people with Parkinson's.

Gary and colleagues from around the world share their knowledge, philosophies and experience of living well with Parkinson's, and, also, record their stories of recovery. If you have Facebook, you might want to check this out: Link

Steady Steps: Improving Balance, Strength And Confidence

Steady Steps is a community-based physical activity referral programme delivered by Edinburgh Leisure within their venues, over 16 weeks. Participants attend weekly physical activity sessions and are encouraged to complete home exercises twice a week for the duration of the programme.

Who is it for? Anyone who has had or is at risk of having a fall.

How much does it cost? Each session lasts 1 hour and 30 minutes and costs £1 to attend (this includes complementary refreshments after the physical activity session).

Who delivers the sessions? All sessions are delivered by a Postural Stability Instructor who has completed specialist training. Volunteers also play a key role. They will help identify your goals and ensure you exercise in a safe, supported environment. This enables them to provide a personcentred experience for participants during the session and over a well-deserved tea or coffee afterwards.

How can I access it? Referrals can be made by a range of Health professionals including Parkinson's Nurse Specialists, Physiotherapists and Occupational Therapists. If you feel you would benefit from taking part in Steady Steps speak to your health professional who can make a referral on your behalf. Once Edinburgh Leisure receive your referral a member of the Active Communities team will contact you and invite you to your first session.

What happens at a session? The sessions include a warm-up followed by specific exercises designed to improve balance, endurance, strength and flexibility. Then a cool-down followed by a 30-minute refreshment and an opportunity to chat to other participants. All exercises will be adapted to individual ability so that no exercise is too easy or too difficult for you. There are also seated alternatives available for all exercises. In the first and last session there will be some quick and simple physical assessments and questionnaires to help measure your progress. Care-partners are welcome to attend and support where required. If this would help, please ask your health professional to note it on the referral form.

What happens after the programme? At the end of the 16-week programme, you should feel more confident taking part in physical activity. A member of the Active Communities team will discuss a range of options to meet your needs and allow you to continue to be physically active.



(photo attribution: Edinburgh Leisure)

Parkinson's UK Related Information

Parkinson's Information Packs

Parkinson's UK have developed information packs for those newly diagnosed with Parkinson's. It contains a range of information, including an updated 'Parkinson's and you' booklet, 'Physical Activity and exercise leaflet', 'Information and support leaflet', 'Get involved with research leaflet' and a 'Team Parkinson's form' to join Parkinson's UK. You can order the pack free at: Parkinson's UK shop.



Poems for Parkinson's

Scottish Poetry Library has teamed up with Parkinson's UK to help promote Poems for Parkinson's for World Parkinson's Day on 11th April.



They are asking for people to submit a short poem (5-10 lines for the Poetry Library), telling how Parkinson's has affected you or someone you care about.

They welcome entries from people of all abilities, so even if it's your first time writing a poem, why not submit it. They are happy to receive poems in English, Scots and Scottish Gaelic.

From the **Scottish Poetry Library** comes the following information:

"Share your poem on the social media of your choice – Twitter, Instagram or Facebook. You could record your poem on TikTok or YouTube too. Remember to use the hashtag #WorldParkinsonsDay and be sure to tag @ParkinsonsUK and @ByLeavesWeLive (on Twitter)".

From **Parkinson's UK** come some tips:

"Your poem can be about any aspect of living with Parkinson's. It could be funny, happy, cheeky, sad or thoughtful. You could write about:

- receiving a diagnosis
- everyday life, living with Parkinson's
- living or working with someone who has Parkinson's
- the stages of Parkinson's
- meeting others with Parkinson's
- a particular symptom or challenge caused by Parkinson's
- any opportunities you've had because of Parkinson's
- your hopes or fears for the future"

To submit a poem directly to Parkinson's UK use this Link (for P-UK, poems can only be up to 5 lines)

(also see page 11 for another way to support/celebrate World Parkinson's Day)

Focus on Parkinson's & Research

Edinburgh Parkinson's Lecture 2023

This year's <u>Edinburgh Parkinson's Lecture</u> will take place on the evening of Wednesday 20th September at the Royal College of Physicians of Edinburgh (and also be streamed live).

The 2023 Edinburgh Parkinson's Lecturer is Professor Camille Carroll (pictured). She is the new Professor of Clinical Neuroscience at Newcastle University and is also a Consultant Neurologist.

The title of Professor Carroll's Lecture is: Learning to Listen – a patient-centred approach to Parkinson's care and research.



Cure Parkinson's Trust have released a video of a talk by Professor Roger Barker: Dopamine cell replacement therapies for Parkinson's – where are we now?

Roger delivered the very first Edinburgh Parkinson's Lecture in 2012 and came back again for our tenth Lecture in 2021. Many of you will be familiar with Roger, and we are sure you will enjoy this video.

Many Thanks to Cure Parkinson's Trust for making the video available.

CURE PARKINSON'S

Research Update Meeting February 2023

Dopamine cell replacement therapies for Parkinson's – where are we now? Prof. Roger

Research focus: Cell replacement therapies for Parkinson's – where are we?

With Professor Roger Barker

Thank you for joining the Cure Parkinson's Research Update Meeting. The welcome and presentation is due to begin at 2:30pm.



View the talk at this Link

World Parkinson's Congress (WPC)



Edinburgh Branch is still keen to send delegates to Barcelona 2023. As we confirmed previously, we are offering bursaries towards the cost of attendance. (More details are on our <u>website</u>)

In return, supported delegates are asked to report on their findings and experiences at a subsequent Branch meeting, probably later in 2023.

The closing date for Bursary applications is 31st March. Applying for our Bursary is not an onerous process. Even if you simply intimate interest in the first instance, that would be much appreciated. To do this, please email Branch Treasurer Weir Brown: treasurer@edinburghparkinsons.org

Research Participants Needed

Parkinson's UK recently outlined three studies where participants are needed:

1. Public opinion on treatments that change brain functioning

Researchers at the University of Nottingham are exploring what the public believes is the most desirable treatment to stimulate changes in brain functioning, called neuromodulation. Neuromodulatory treatments can include medication, brain implants and electrical, magnetic and ultrasound stimulation. Deadline is 1st July 2023.

The researchers need 1,000 people with or without Parkinson's. The level of involvement is completing an online survey, which should take around 10 minutes.

For more information, please read the <u>participant information sheet</u>

2. Exploring difficulties recognising facial expressions

PhD researchers at the University of Birmingham are exploring why people with Parkinson's may have difficulty recognising facial expressions.

The researchers need 11 people with Parkinson's who have been diagnosed within the last 7 years, and are currently taking medication for it. Deadline is 1st October 2023.

The level of involvement is two 45-minute tasks in recognising facial expressions and which will be completed on two separate days. You will be asked to delay your Parkinson's medication for a few hours on one day of the study, undertake a problem solving task and complete surveys about yourself, which will take about an hour.

For more information, please read the <u>participant information sheet</u>

3. Understanding why some people with Parkinson's develop hallucinations and delusions Researchers at the University of Oxford are looking to understand what factors may increase the likelihood of people with Parkinson's developing psychosis. You can find out more about psychosis here.

The researchers need 200 people with Parkinson's, both those who experience hallucinations and/or delusions, and those who don't. Deadline is 1st January 2024.

The level of involvement is that you will be asked to complete a survey about yourself, your lifestyle and your health, which will take between 30 minutes and an hour to complete. The survey can be done online or by post. For more information, please read the participant information sheets for taking part by post or taking part online

For more information on participation in these, or other research, please see the <u>Take Part in Research Hub</u> on the Parkinson's UK website.



Branch Related News

WPC Video Competition

Branch volunteer Alison Williams and Will Adams (son of outgoing Chair, David) have produced a wonderful short video which they have entered in the video competition section for World Parkinson's Congress. We are so proud that they have made it to the last 12 out of 50 entrants!



There is a 'People's Choice Award', where we can vote among the Top 12 videos.

Voting is now open! You can view all videos from this Link

Place your vote (for Alison 2) at this Link (voting deadline is 24th April)

Best of Luck Alison and Will. An amazing video. We are so proud of you!

Edinburgh Young Parkinson's Support Group Meeting



The 'EYPSG' Group have a guest speaker for their next meeting on Thursday 6th April. Venue is The Steading, Biggar Road. Time: 6.30 for 7.00pm start.

The guest is David Melton, Chair of the Edinburgh Research Interest Group (ERIG).

David will be giving an informal talk in layman's language and will then take a Q&A session.

David will talk about Stem cell therapy for Parkinson's. He will reflect on what stem cells are. What can they do? How are they relevant to Parkinson's? What evidence is there that stem cells could be therapeutic for Parkinson's? What is the current situation with clinical trials using stem cells for Parkinson's? What's next?

This will be a popular talk so please let EYPSG Chair Scott Wilson know beforehand if you plan to go along, so that he can arrange seating. You can email Scott at scottwils180@gmail.com or phone 07835 820898.

For anyone newly diagnosed this would be a great first step towards getting support and asking any questions you and your partner or family may have about Parkinson's.

The 'YPs' are a pretty relaxed and informal group and welcome new faces. You are very welcome to bring along your partner or a friend if you like. Some of the group meet at the Steading around 6pm to have a bite to eat. Feel free to go early and get some dinner and meet some of the group.

Indoor Bowling



The Bowling group meet on Mondays at Noon, at Meadowmill Indoor Bowls, Tranent. They welcome new members. It's a terrific activity, suitable for all levels of ability and mobility. And even better, it's open to those with any conditions or disabilities, not just Parkinson's. Adapted wheelchairs are available.

More details are on the dedicated website page

As with some of the other activities and events, bowling is a very social activity, and this can be super important, both for people with Parkinson's and also their care-partner. They recently celebrated the birthday of one of the group (as per photo). So as well as staying fit and active, you can make friends. However, if you just want to play bowls, that is equally fine.



Nordic Walking

Our Nordic Walking group meet on Thursdays at Noon, at Jawbone Walk, the Meadows. They are always happy for people to come along, and poles can be provided if you don't have your own. As the weather improves, perhaps you will feel more movitated to get out and about. And as with many of our activities, aside from the physical benefits, the social aspect is really important.



Dance Base

You may have seen Dance Base in the news in February. Unfortunately, their funding has been cut and their running costs have increased. While we are very saddened they have been forced to reduce classes, lay off some of the dancers and cancel their Edinburgh Festival Fringe programme, there is a silver lining for the Branch.

The funding for Dance for Parkinson's Scotland comes from a funding stream that is continuing, so for at least one more year, the weekly classes can continue.

Like most things however, they will only continue if there is demand. So please consider attending classes if you don't already. The classes are excellent, for all abilities and are great fun. The Summer term dates have just been announced, running from April 19th – July 19th 2023.

Focus on Awareness

Fundraising at Craigleith

We have the first of our fundraising slots for the year, scheduled for Friday 14th and Saturday 15th April 2023. As usual the 'can shoogle' will take place at Craigleith Retail Park.



We need help from people to hold cans for passers-by to donate money.

We now have cash card readers, so not carrying cash is no longer a draw-back for potential donors. We promote both the Branch and Parkinson's awareness. We all have our own experiences, and that is perfect for informing people when they ask about Parkinson's. We can inform them how important it is to fund research for a cure and provide support to those impacted by Parkinson's.

The slots we are looking for are:

 10am-Noon, Noon-2pm and 2pm-4pm on Friday and Saturday. If you can help us even for an hour that would be much appreciated.

Our outgoing Fundraiser Lou has kindly offered to coordinate the rota for one last time. Please email lo4parkinsonsfundraising@gmail.com if you can help with any of the days/times. (Feel free to bring along a friend or family member for support, or company).

Light up blue for Parkinson's

Did you know that World Parkinson's Day is 11th April every year?

Parkinson's UK have asked for people to "Shine a light on Parkinson's" this World Parkinson's Day, by lighting up blue.

They suggest we can light up our own home blue or ask a business in your local community to do so. This could be the village hall, local shops or cafés or where any of your group activities or meetings take place (11th April is a Tuesday if that helps). Maybe you can get your neighbours involved, could you aim to turn your whole street blue?

The picture is from the Parkinson's UK website and shows just how spectactular it can be when a building is turned blue. Natwest in Edinburgh are partcipating this year (George Street and Glasgow Road).

For more information please see the Parkinson's UK website page: <u>Link</u>

If this is something you might like to participate in and

have any questions or need any advice, email: worldparkinsonsday@parkinsons.org.uk



ACTIVITIES/SOCIAL OPPORTUNITIES

There are many opportunities facilitated by the Branch, and also some external opportunities, for People with Parkinson's and care-partners to improve their wellbeing and provide the opportunity to socialise. These are listed below.

To find out more, including contact details for some of the classes, you need to access the Branch website "Activities and Events" page or use the 'search' option.

Weekly Activities Timetable

Monday

Indoor Bowling

Noon–2pm at Meadowmill Indoor Bowls, Tranent.

Tuesday

Tai Chi

11am-12noon, Barclay Viewforth Church EH10.

Singing4Fun

2-4pm at Marchmont St Giles (school term dates).

Yoga for Parkinson's

4-5pm on Tuesdays (delivered online).

Wednesday

Pilates via Zoom

10.30-11.30am (seated and standing options).

Dance for Parkinson's Scotland

11.30am–1.30pm at Dance Base, Grassmarket.

Pilates

2-3pm at The Fisherrow Centre, Musselburgh.

Neurodynamic Exercise

9.30-10.30am at The Fisherrow Centre. (Registration with Sasha is required)

Singing4Fun

7-9pm at the BB Pollock Pavilion, Ferry Road.

Wu-style Tai Chi Chuan

Class normally starts at 6pm, though check with Philippa Hope (who takes the class) via the website. Delivered online via Zoom.

Thursday

Nordic Walking

Noon-1pm. Meet at Jawbone Walk, the Meadows.

Art Group

1.30-3.30pm at Botanic Cottage, Edinburgh.

Pilates via Zoom

3-4pm (seated and standing options)

Neurodynamic Exercise

3-4pm at The Fisherrow Centre (with Sasha)

Friday

Neurodynamic Exercise

8-9am at The Fisherrow Centre (with Sasha)

2-3pm at Morningside Parish Church (until June).

(Again, registration in advance is compulsory).

Pilates

3-4pm and 4-5pm at Morningside (until June).

Saturday

Table Tennis

1.15-3.15pm at North Merchiston Club, Watson Cresc.

Monthly Activities Timetable

Monday

Social Café

Monthly 10.30am (2nd Monday of month) at Butterflies Café, Marchmont St Giles.

Walking Group

Monthly 10.30am (last Monday of the month). Meet at the chosen start point.

Wednesday

Carers Support Group

10.30-12.30 (Last Wednesday of the month), BB Pollock Pavilion, Ferry Road.

Branch Get-Togethers

These normally take place on the second Wednesday each month at 2pm. They run from September to June (though in June we typically have a summer lunch instead). We rotate between two venues (Goldenacre and Liberton).

We email details of Get-Togethers in advance.

Thursday

Quality of Life Group

For People with Parkinson's. Meetings are always held at 2pm on the first Thursday of the month.

Edinburgh Young Parkinson's Support Group

Monthly from 6.30pm (first Thursday of month) at The Steading, Biggar Road.

External Activities

These are activities we support but are *not* organised or run by the Branch. Some are delivered by other Parkinson's UK groups, some by our existing class providers and some by other charities. For more details, access our website and search for the activity or search directly for the organiser, if given.

Boxing

Wednesdays at 11am at Port O' Leith Boxing Club, Craighall Road, Edinburgh.

Exercise Drumming

Online Zoom sessions take place Mondays at 11am and Thursdays at 2pm. No special equipment needed. Can do seated or standing.

Indian Dance for Carers

Delivered by Theiya Arts, in partnership with Eric Liddell Centre. Classes are Fridays 11.00–12.00, both in-person and online.

Guided Meditation

Delivered by Theiya Arts, these Yoga Nidra sessions are delivered online on Tuesdays 13.00-13.30 and Thursdays 18.00-18.30.

Re-Connect: Gentle Movement Class

'Re-Connect' is a gentle movement class for older people aged 65+. Class is Mondays from 10.30am— 12.30pm at DN Studios, 9B South Gyle Cresc.

Yoga

Theiya Arts run an asana practice that focuses on movement with breath and finding steadiness and comfort in longer held postures. Mondays 19.15-20.15 (£7 per class).

Annual Activities

Summer Lunch

We try to have a lunch in June. For the last few years we have used the Leonardo Murrayfield and this has proven popular.

Christmas Lunch

In December we have our festive lunch, and once again we tend to use the Leonardo Murrayfield.

Branch AGM

Generally, in March we have the AGM. This is an ideal time to review the activities of the Branch and for the Committee to inform the Members of the financial position and our aspirations for the future.

Fundraising

Can Collections

We are fortunate to be able to carry out three sets of fundraising at Craigleith Retail Park. We very much depend on volunteers from within the Branch membership to come along and 'can shoogle'. One or two hours, three times a year makes a huge difference to our fundraising.

Fundraising Suggestions

As you may know, our long-term fundraiser Louise Ogilvy has stepped back after many years of service to the Branch.

We would very much welcome offers of help to plan/organise/run some social types of events where we can fundraise.

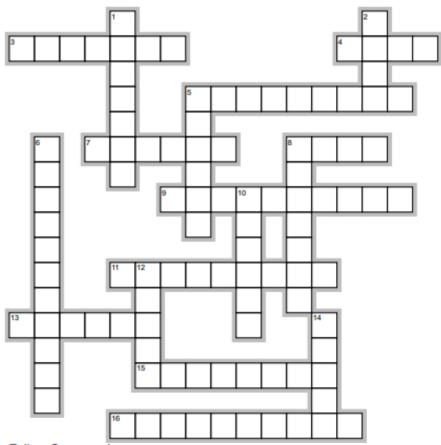
Do you have experience from somewhere else you can bring to us, to help organise a sale of work, a ceilidh, beetle drive, themed afternoon lunch?

Please do come forward – we feel the Branch needs a fresh perspective to help us improve engagement and social opportunities as well as opportunities where we can raise funds to keep offering all of the activities you have just read about. If you can help please email: chair@edinburghparkinsons.org

Focus on Fun

Have you read the Newsletter fully? If you have, you should have no problem with *most* of the crossword below. (Answers will be on the website from 31st March, as a News Item from this Link)

Edinburgh Branch Knoweldge Test



EclipseCrossword.com

Across

- 3. Our most prolific regular activity
- 4. Our Treasurer Weirs favourite pastime
- 5. Month of the Edinburgh Parkinson's Lecture
- 7. Surname of ERIG Chair
- 8. Name of our communication volunteer's dog
- 9. Where the Bowlers play
- 11. Where the World Parkinson's Congress takes place this year
- 13. Our Branch Secretary's first name
- 15. Where the Young Parkinson's Support Group meet
- 16. Area of Edinburgh our AGM took place

Down

- 1. New Chair's first name
- 2. The title of Alison Williams Video for WPC competition
- 5. One of the main reasons we go to the Carers Support Group is for Cathie Quinn's...
- 6. Name of the cafe where we hold our monthly social café
- 8. Where our Nordic Walking begins
- 10. Where Paul Mayhew-Archer's vicar lived
- 12. Outgoing Chair's last name
- 14. Christian name of the Professor who delivered our very first Edinburgh Parkinson's Lecture