EDINBURGH BRANCH PARKINSON'S UK APRIL 2022

PARKINSON'S^{UK} Change Attitudes. Find a cure. Join US.

World Parkinson's Day 2022: 11th April

This year Parkinson's UK is supporting two activities:

Light Up Blue for Parkinson's

Can you help Parkinson's UK (P-UK) make Light Up Scotland even bigger this year?

If you have suggestions for local landmarks or buildings they can approach to Light Up Blue, or if you would rather do it yourself, then P-UK would love to know.

Volunteer Karen McConnell would like to hear your suggestions, or to know that you are planning to approach venues yourself – email her at <u>lightupscotlandforparkinsons@gmail.com</u>. In the latter case, this will help her to avoid approaching venues that have already agreed or declined to participate, as well as to acknowledge everyone who's taking part.

All sorts of buildings can light up – castles, churches, lighthouses, village halls, post offices and even swimming pools. People can light up their home or business to show solidarity with the Parkinson's community.

We'd love for *all of you* to mark the day and share your pictures with us. Everyone can do something – we have seen it all, from ambitious illuminations to a single heartfelt candle!

And, if you've got a couple of hours a week between now and late April, Parkinson's UK are looking for volunteers to help us make this year's Light Up Blue bigger and better than ever. You'd be part of a small virtual team approaching new venues and helping us to co-ordinate our efforts across Scotland. <u>Find out more about this role</u>.

Poems for Parkinson's

Could you write a limerick or five line poem? Parkinson's UK is asking everyone connected with Parkinson's to write about their experience to help raise awareness.

Your limerick or poem can be happy or sad, positive or expressing some of the challenges of living with Parkinson's. You could think about symptoms, hobbies, treatments, how Parkinson's impacts you, connecting with others with the condition, and so much more

Whether you're a first-time poet or an experienced bard, why not get creative and have a go? Whether you have Parkinson's, are a relative of someone who does, or work, volunteer or live with someone affected by Parkinson's, P-UK want to hear about your experience of Parkinson's.

Poems may be shared online, in printed materials and press releases, and at a special event to raise awareness of the realities of Parkinson's. Entries can be made online until 3 April 2022.

This is the link to upload your poem: Poems for Parkinson's



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Edinburgh Parkinson's Lecture 2022

It has recently been announced to Branch Members via e-mail that this year's Edinburgh Parkinson's Lecture will take place on the evening of Wednesday 28th September at the Royal College of Physicians of Edinburgh.

The Lecture will be delivered by Julie Jones from the School of Health Sciences, Robert Gordon University, Aberdeen.



The title of Julie's Lecture is "The Importance of Exercise for People with Parkinson's: Evidence, Empowerment and Enablement."

First Steps

Sadly, we have had to postpone our initial delivery of the First Steps programme.

You may be aware there have been changes in the structure at Parkinson's UK, with Annie Macleod stepping down and a new Director for Scotland being appointed (see below). Their starting date for that appointment means the delay is likely to be a bit longer than we had hoped, but we are confident that by early summer we will be able to deliver the First Steps programme.

As a reminder, it is aimed at those with a recent diagnosis of Parkinson's. If you know someone in this category, please do check they know that First Steps is a brilliant course, delivered online by people with Parkinson's who can give invaluable advice and support.

Parkinson's UK New Director for Scotland



We were informed of the recent appointment of a new Scotland Director. James Jopling begins with Parkinson's UK on 19 April. His previous post was with the British Heart Foundation where he held a senior role.

James's knowledge, skills and experience shone through at the interview process which was run by David Allan (Trustee for Scotland), a range of volunteers (including our Treasurer, Weir Brown), and People with Parkinson's from around Scotland.

We wish James success in his new role and look forward to the same robust support for the Branch as his predecessors have given.

Social Café

Our next café will take place on Monday 11th April. Once again it will be at Butterflies Café, Marchmont St Giles Church, Kilgraston Road, from 10.30am. Please enter by the side entrance as indicated in the image.



Tea and coffee will be on offer in this spacious and well-ventilated venue. All People with Parkinson's and their Care-partners are welcome.

Please see our website for more details.

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Walking Group



The walks so far this year have been a great success. The fact that we had good weather certainly added to the enjoyment.

This photo is of some participants who joined a previous walk which was at Inch Park. We have a walk in March which will have taken place by the time this newsletter is published.

Details of <u>Walks</u> are on our website.

East Lothian Parkinson's Café

We were very happy to hear the East Lothian café was starting up again. It takes place on the last Wednesday of the month at 2pm at the John Gray Centre, Haddington EH41 3DX.

If you live in the east, you would be welcome to go along and meet other people with Parkinson's and their families. The next café on 27th April will have a Parkinson's Nurse attending.

Contact Chloe on 0300 123 3679 or at <u>scotland@parkinsons.org.uk</u> for further details.

Fundraising

Please support us at our 'Can Shooglin' which we do three times a year at Craigleith Retail Park.

If you can help to hold a can (we can't actually rattle them to avoid 'hard sell') for a couple of hours that would be hugely appreciated. The time slots on each day are: 10am to Noon, Noon till 2pm, and 2pm to 4pm.

- April: Fri 22nd and Sat 23rd (10am 4pm)
- August: Fri 12th and Sat 13th (10am 4pm)
- \circ November: Fri 25th and Sat 26th (10am 4pm)

If you could help, please contact Lou: lou@edinburghparkinsons.org.

Alternatively, come and do your shopping at the Retail Park and if you can donate any spare cash, it would be much appreciated. We also have card readers for those who don't carry cash.

Singing 4 Fun: Wednesday Evenings

The Wednesday evening Singing4Fun group takes place at the Boys Brigade (BB) Pollock Pavilion, Ferry Road, Edinburgh. Our song leader is Sally Jaquet.

The session runs from 7pm – 8.30pm with a short break for tea. Price is £3 plus a donation for refreshments.

All are welcome. For more information, contact Cathie: <u>cathie@edinburghparkinsons.org</u>.



Activities (details and contacts on our website)

We thought it might be useful to do a brief reminder of the days/times of our activities:

Art Group

Thursdays at Botanic Gardens. Currently numbers are restricted, though it is worth contacting the organiser for information.

Dance for Parkinson's Scotland

Every Wednesday from 11.30am – 1.30pm at Dancebase, Edinburgh.

Indoor Bowling

Every Monday Noon – 2pm at Meadowmill Indoor Bowls, Tranent. New members very welcome.

Neurodynamic Exercise

10 week programme, three or four times a year. Contact Sasha for information and to request to attend a future programme.

Nordic Walking

Every Thursday Noon – 1pm. Meet at Jawbone Walk, the Meadows. New walkers welcome. Poles can be provided by our instructor.

Pilates

The Wednesday face-to-face class is currently full. It is worth checking our website and contacting Sasha for further information. We expect more classes to return to in-person delivery soon.

Quality of Life Group

For People with Parkinson's. Group meets monthly on a Thursday from 2pm – 3.30pm.

Singing4Fun

Tuesdays at 2pm at Marchmont St Giles (during school term times).

Wednesdays at 7pm at BB Pollock Pavilion, Ferry Road (all year).

Social Café

Usually the second Monday of the month at 10.30am at Butterflies Café, Marchmont St Giles.

<u>Tai Chi</u>

Tuesdays, 11am – 12noon – currently still online via Zoom. New members very welcome.

Walking Group

Monthly – end of the month. Meet at 10.30am at the chosen start point.

Wu-style Tai Chi Chuan

The classes are taking place online, currently on Wednesdays.

Yoga

Classes are still being delivered online on Tuesdays 4-5pm.

Edinburgh Branch Hypnotherapy Pilot

This is a pilot to assess demand for the positive impact of hypnotherapy on your experience of living with Parkinson's. The pilot finishes at the end of June, but we hope to continue beyond that depending on interest. We still have a few places available for People with Parkinson's, if you would like to apply.



Anne-Marie Parham, a <u>GHR</u> registered and accredited clinical hypnotherapist is working with People with Parkinson's, creating bespoke treatment plans to meet individual needs. This can include relaxation techniques and addressing other lifestyle issues. You can self-refer by contacting Gina Allen <u>gina@edinburghparkinsons.org</u>.

If you live in any of these postcodes: EH1-EH30 or EH47-EH55, you can access up to 4 home visits from our hypnotherapist. Or you can access sessions via Zoom, as long as you live within the Lothian Health Board area. Each session is 1 hour. There is no fee for the duration of the pilot.

Hypnotherapy can help you to develop a mind-set that enables you to more effectively manage the emotional impact of living with Parkinson's. From diagnosis to ongoing symptomatic experience, Anne-Marie can help you to reframe your perceptions and responses, positively impacting upon your levels of wellbeing, confidence and self-efficacy. Hypnotherapy cannot cure Parkinson's but it may be able to mitigate its psychological impact.

If you would like more information about hypnotherapy, please click on this link.

Safety Checks

For our listed practitioners, we have carried out the necessary checks with regards to insurance, qualifications, health & safety, and safeguarding. Our therapists will also take tests to ensure they are free from Covid-19. They will contact you in advance to check that you have no symptoms and confirm with you they are symptom free.

Support Groups

We have two well established support groups:

Edinburgh Young Parkinson's Support Group (EYPSG)

Meet the first Thursday of the month at 6.30pm at The Steading, 118-120 Biggar Road, Edinburgh. The next meeting is 7th April. All are welcome, it's a friendly and nicely informal group. For more details contact Scott Wilson: scottwils180@gmail.com

Carers Support Group

This group for current and ex Care-partners meets last Wednesday of the month at 10.30am in BB Pollock Pavilion, 227 Ferry Road, Edinburgh. The meeting concurrently uses Zoom for those unable to attend in person. For information contact Cathie Quinn: <u>Cathie@edinburghparkinsons.org</u>.

Branch AGM

We held our Annual General Meeting on Wednesday 16th March 2022. This was our first meeting at Inverleith St Serfs, our future venue for Branch Meetings.

There are no changes to the Chair (David Adams), Vice-Chair (Patrick Mark), Secretary (Olivia Bell), and Treasurer (Weir Brown) – pictured right (not in order!).

Other Committee Members and lead volunteers are: Anne Chalmers, David Melton, David Waughman, David Wilson, Gina Allan, Iain Steele, Kirsty Low, Lou Ogilvy, Maggy Douglas, Nick Shelness, Scott Wilson, and Sheila Edward.

Our Chair has previously intimated he would like to find a successor, and our search continues. If you know of anybody who would be interested, please do let us know. The role is rewarding, and there is a great support network in place to make transition as smooth as possible.

Tanith Muller, Parliamentary and Campaigns Manager for Parkinson's Scotland, gave us an overview of activities in Scotland. The proposed <u>National Care Service for Scotland</u> will be introduced in Summer 2022. There will be a single assessment for anyone in need of care. New devolved benefits include an Adult Disability Payment rollout and more support for Carepartners. The Attendance Allowance will be replaced, and support will come from the UK DWP, for instance through Universal Credit.

The AGM was a fantastic time to reflect on the wonderful support the Edinburgh Branch is able to provide to People with Parkinson's, friends, family and Care-partners – and the wider community.

How can you help? We always welcome volunteers, but more so, we need people to support and attend our activities and meetings. If none are to your liking, please suggest the kind of things you would like us to offer. Our Branch always aims to evolve and adapt to your needs.

Covid-19: Update

Scotland currently has a very high infection rate. We want to keep as safe as we can, and request as follows:

<u>To attend any indoor in-person activity</u>, please ensure you have a negative Lateral Flow Test within 24-hours of each in-person event.

(If for medical reasons you are unable to take a test, and wish to attend, please let your activity organiser know in confidence).

Please do check our website, where we will post news items on the front page with any updates.

Herbert Protocol

We received information from Parkinson's UK about this, though it's not an entirely new initiative. It is a form that family members can complete in advance if they have a relative prone to wandering. It lists essential information, and can include a photo too so that this can be forwarded ASAP to police and emergency services should someone go missing.

For more information please visit the specific information on the <u>Police Scotland website</u> which includes a very useful video.





