

PARKINSON'S<sup>UK</sup>
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

**Newsletter: January 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: <u>communications@edinburghparkinsons.org</u>

A belated Happy New Year to you all. We hope that the festive season was enjoyable. Many we know are still recovering from the invasion of children and grandchildren! Many though have had a quieter time, which we hope was restful and restorative.

As is typical in winter, there are incidents and losses. We know some people have had falls in the period where it was incredibly icy. We hope all the broken bones and bruises are healing!

We also know some of us will have lost loved ones. We were very saddened to lose a key member of the Branch, Committee Member David Wilson. Dave was a huge asset to the Branch and we will miss his contribution greatly. Our condolences were sent to Dave's family, and the Branch was represented at Dave's funeral by Branch Chair, David Adams.

#### **Branch AGM**

A date for your diary – the Branch AGM is to be held on Wednesday 15th March 2023, at 2pm.

While we still have to finalise the venue, it is very likely that it will be an in-person event, held at Inverleith St Serf's, Clark Road (near Goldenacre).

# **Monthly Branch Get-Togethers**

We hope to restart the monthly Branch Get-Togethers in February. The venue again is likely to be Inverleith St Serf's, though we have the potential to alternate with Liberton Kirk Halls.

We aim to have a guest speaker at most meetings. Do you have any suggestions, or aspiration for a particular speaker, or topic we could cover? It needn't be related to Parkinson's, it can be any topic. We are hoping to have Kenny Williamson (who runs the Monday Bowling) come and talk about his forthcoming new book on steam railways, which is due for publication in July 2023.

You can <u>read an article</u> Kenny wrote in 2018 about one of his ancestors, who sadly passed away at the young age of 9 years old.

If you would like to talk at the Branch Meeting, we would be very happy to facilitate this. It's an intimate and relaxed forum, and would be a great opportunity to share experiences.

#### **Table Tennis**

If you are wondering what new activity to take up this year, why not join our table tennis group?

It's a fun activity for people of all abilities and we can also look forward to experienced Table Tennis Scotland coach, Billy Gibbs popping along from time to time to give us some tuition. Billy can give you top tips for improvement which will help you to enjoy your game more, whether you want to compete in future Parkinson's Table Tennis Scotland competitions or just have some fun on a Saturday afternoon.

Not only that, Lis Kirkness, one of our players says that since taking up table tennis only a few months ago, her dexterity and speed of reactions have improved greatly.

For more info see the <u>Table Tennis</u> dedicated page on our website. Or contact Scott (<u>scottwils180@gmail.com</u> Tel: 07835 820898), or Gina (<u>gina@edinburghparkinsons.org</u>)

### **Parkinson's Medicine Supply Problems**

Our Parkinson's UK Scotland team have advised us of medicine supply issues which you may be affected by.

Two types of Parkinson's medicine have been affected. This might mean that you can't get your usual tablets from the pharmacy for the next 3-4 months.

Products affected are:

- Selegiline (Eldepryl) 5mg and 10mg January to April 2023
- Stanek (various strengths) December 2022 to March 2023

Alternatives are available for both medicines and Parkinson's UK Scotland are working with NHS Scotland to make sure that these are easily available for everyone who needs them.

To get the latest information on these supply issues and what to do, use these links:

parkinsons.org.uk/news/selegiline-supply-issues parkinsons.org.uk/news/stanek-supply-issues

# **Parkinson's Medication Care (in case of emergency)**

Did you know that there is a handy sized concertina card available for you to list the medication you take, the doses and the timings, plus an emergency contact?

It also emphasises the necessity for you to get your drugs on time. It neatly folds up to business-card size and is available free of charge from Parkinson's UK.

To order, simply click on this <u>link</u>.

# **Art Exhibition: Lindsay McDermid**

A reminder that our Art Group leader Linsday McDermid's new exhibition of his work, is still showing at Dance Base. The exhibition runs until March 2023. For more details check out a previous News Item. You can contact Linsday directly, his contact details are in the News Item.

# **Focus on Health & Wellbeing**



#### Tai Chi

The December Newsletter incorrectly stated Tai Chi was only delivered online. Huge apologies, the face-to-face Tuesday delivery resumed some time ago! A reminder of the details:

Where: Barclay Viewforth Church, 1 Wright's Houses, Edinburgh EH10

When: Tuesdays 11am – 12pm (may overrun slightly)

If you prefer to do Tai Chi online, weekly Zoom class are on Wednesdays from 11.30am 12.30pm.

To join these sessions please contact Kevin via 01506 845 498 (please leave a message if out), or email: kevin@chi-flow.co.uk

### **Punching with Parkinson's**

Port O' Leith Boxing Club is a new family run boxing club based near Newhaven in Edinburgh.

They are starting classes for People with Parkinson's, at 11am on Wednesdays.

You can attend the class for between 30 – 60mins. The Port O' Leith Boxing Club is based at 83 Craighall Road, EH6 4RR (Right next to the Sainsbury's at Trinity – next to Victoria Park).

We have some additional information on our website as a News Item.

To find out more, please feel free to call the club on: 0131 563 8333. Or if you prefer, email: <a href="mailto:info@portoleithboxing.co.uk">info@portoleithboxing.co.uk</a>

# **Singing for Fun**

Our Tuesday afternoon class at Marchmont St Giles remains well attended. Song leader Penny Stone can always have more in the group, and the adage the more the merrier definitely applies!

We do need more people for Wednesday evenings, at Pollock Pavilion, Ferry Road.

We have a new volunteer (Lis Kirkness) who helps to facilitate the group. The song leader is Sally Jaquet, and Sally is happy for anyone to come along and join in. So you can bring a friend. You don't have to have Parkinson's, if you are a care partner and want to come along with your friends, that is fine. More details a on the <a href="S4F">S4F</a> website page.



(We ask for a small contribution, to help cover costs of venue, and the professional song leader).

## **Exercise Drumming**

Have you experienced the thrill of exercise drumming? If not, perhaps you should! Online Zoom session take place Monday's at 11am and Thursday's at 2pm. No special equipment needed, and you can do seated or standing. Full details are on our website in a <u>News Item</u>.

# Focus on Parkinson's & Research



## **Edinburgh Research Interest Group (ERIG)**

We have an active research focus within the Branch. If you are not already a member of ERIG, you may want to register. This will allow you to receive direct communications about talks. These events attract some very interesting speakers, from the Parkinson's research professionals.

The objectives of the Group are:

- To provide opportunities for members with an interest in Parkinson's research to meet, communicate, work together and generally further the cause of research.
- To encourage and develop all members' interest in research.

As with the Branch, membership of ERIG is free. Your details are never passed to any third party and communications are kept focussed and limited in quantity.

If you haven't already done so, please check out **ERIG** dedicated website page.

### **ERIG: Online Meeting**

The next ERIG event is an online one and will take place on Saturday 28 January 2023.

The speaker is Amber Roguski who is a Research Assistant in Sleep Disorders and Neurodegeneration at the Centre for Clinical Brain Sciences, University of Edinburgh.

Amber will talk about her plans for a clinical trial to alleviate obstructive Sleep Apnoea in Parkinson's Disease.

We will put the details on the website soon, on the dedicated page for Local Research Events.

# **World Parkinson's Congress**



Edinburgh Branch are 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 website)

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

The closing date for Bursary applications is 15<sup>th</sup> January 2023. (For the Congress itself, you need to register by 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: <a href="mailto:treasurer@edinburghparkinsons.org">treasurer@edinburghparkinsons.org</a>

# **Focus on Volunteering**



#### **New Branch Chair**

We are very fortunate to have provisionally secured a new Chair, who we hope will be confirmed at the AGM in March.

Stephen Brannan has a terrific range of experience that makes him a real asset for the Branch.

Some of his background includes Lay Member of Court for Edinburgh Napier University. He has a background in IT and Business Operations. His experience of Financial Services, Marketing and Business Management will be very important for the future security of the Branch.

(Photo Attribution: Edinburgh Napier University)



#### **New Volunteer Introductions**

Our outgoing Chair David Adams has been working hard to secure some additional volunteers who will join the Branch Community Development Group.

Diane Kennedy will chair the group, and alongside Anne Chalmers, Gina Allen and Stephen Brannan, we have been lucky to have Precila Jose and Claire Stevens join us. We will give more details of the group in a future Newsletter.

#### **Fundraiser Needed**



As we previously announced, Louise Ogilvy our Fundraiser is stepping down.

Would you, or somebody you know like to take on this role? Or maybe just focus on one type of fundraising – one event that may be annual, or could run a couple of times a year?

The sort of things we have done previously and might like to do again are:

Ceilidh, Summer Themed Afternoon Tea Event, Coffee Morning/Sale of Work.

Things we haven't done, that maybe you have experience of are Race Nights, Quiz Nights, Raffle, Auction. We need an ideas person to coordinate – we know from past experience we can get volunteers to help out.

If you could help, please let us know. In an ideal world we could have a small group who could help plan a series of events, which could help us rebuild our community within the Branch.

## **Focus on Carers**



We know that it's very common for people in caring roles, not to think of themselves as a carer. Whether one is a parent, a spouse, a family member or a friend – you can still be a carer for the person that may be your son, wife, sister, husband, daughter, nephew etc.

Carers often focus a lot of energy on the person they care for – and can let their own needs, interests and health take a back seat. As a Branch we have two key ways to support you:

### **Monthly Carer Group**

This group provides an opportunity for care partners, family or close friends of people with Parkinson's to meet, share, support, and learn from each other's experiences. Occasional talks are arranged on relevant topics.

The Group meets at Pollock Pavilion, 227 Ferry Road, EH6 4SP, on the last Wednesday of every month, from 10.30am–12.30pm

More details can be found on our website: Carer Group

## **Side by Side with Parkinson's Course**

The course is intended to help those who know/live/work with someone with Parkinson's and who want to learn more about the professional help, drugs, benefits and support available. Th course is run once or twice a year. The last finished in November 2022. We hope to start a new one in Spring/Summer. The course takes place one afternoon per week for six weeks. The course covers topics such as:

- The role of the Parkinson's Nurse Specialist and information on prescribed drugs
- The role of the Parkinson's UK Local Adviser and the help offered.
- Multidisciplinary therapists available, i.e. Speech, Physio and Occupational.

More details can be found on our website: Side by Side Course

#### **External Carer Resources**

#### **Care for Carers**

Care for Carers (C4C) is a voluntary organisation providing a range of support services for carers, including local events and short breaks (which are really enjoyable and fun). They cater to <u>all carers</u> regardless of the age or disability of the person they care for. Their services provide opportunities to share experiences with other carers, get practical information and find out you are not alone. C4C is extermely supportive of the Edinburgh Branch, regularly sharing our information. They are based at Meadowbank, in St Margarets House (within the Edinburgh Palette art building).

#### **Vocal**

VOCAL differs in the sort of services they provide. They support <u>unpaid carers</u> in Edinburgh and Midlothian through individual support, information, training and access to services. Some of what the Parkinson's Local Advisor role does, is covered by Vocal. Their website has some useful and practical information. They are based at 60 Leith Walk.

## **Focus on Fun**



We have shamelessly 'recycled' the guiz from the January Fife Branch Newsletter 🧟 (We have a dedicated part on our website for the Fife Newsletters)



#### **How Well Do You Know Our Bard?**

(Answers at bottom of page)

- 1) Which of these creatures did Burns not write an ode to?
- a) Mouse b) Cat c) Louse



- 2) What Burns' work provided the title for a Ken Loach directed film?
- a) Ae Fond Kiss b) Birks of Aberfeldy c) Halloween
- 3) Where is Burns buried?
- a) Dumfries b) Ayr c) Aberfeldy
- 4) Which British astronaut took a miniature book of Burns' poetry into space?
- a) Tim Peake b) Helen Sharman c) Nick Patrick
- 5) How many children did Burns have?
- a) 9 b) 12 c) 7
- 6) Which US city has a life-size replica of Burns' first home in Alloway, South Ayrshire?
- a) Chicago b) Atlanta c) Boston
- 7) Which of these is not a nickname Burns was known by?
- a) Bard of Ayrshire b) Deil of Words c) The Ploughman Poet
- 8) What job did Burns do before becoming known for his poetry and song?
- a) Stonemason b) Labourer c) Carpenter
- 9) What former republic or sovereign state featured Burns on a stamp?
- a) Soviet Union b) Yugoslavia c) Czechoslovakia
- 10) How old was Burns when he died in 1796?
- a) 28 b) 37 c) 42
- 11) Which of these is not formally toasted at a Burns' supper?
- a) Haggis b) Whisky c) Lassies
- 12) What was the horse in Tam O'Shanter called?
- a) Maggie b) Meg c) Molly

[Quiz Answers: 1 b); 2 a); 3 a); 4 c); 5 b); 6 b); 7 b) 8 b); 9 a); 10 b); 11 b); 12 a) & b)]