

Christmas Lunch

Thursday 13th December is the date for our annual festive get-together. This year we will be at **Kingsknowe Golf Club** in Lanark Road, EH14 2JD. We're looking forward to experiencing the catering facilities of Food Creations, an award-winning catering company. The philosophy of their team leader is that great catering is about more than just the food, it's about the occasion, the ambience and the smooth running of the dining experience. If you would like to join us, we encourage you to make your reservation now – early booking greatly helps our administration.

Winners! World Parkinson Congress 2019 Song Competition



We are cock-a-hoop about our Branch Singing4Fun group winning the original lyrics plus melody category. Our Tuesday session song leader, Penny Stone, encouraged willing members to get together and submit an entry for the competition. She did an amazing job of sparking the group's creativity, resulting in the "Side by Side" song which will be sung by the WPC Choir at the opening of the 2019 Congress in Kyoto.

The submitted essay about the sentiments behind the song is on page 3 of this Newsletter and the lyrics are enclosed with this mailing. Both items are also on the Branch website where we hope very soon to have a video performance by the Tuesday Singing4Fun group. And rest assured, we will be teaching the song to Branch Members at every opportunity, including the 14th November Branch Meeting (2-4pm, Bellevue Chapel, EH7 4EL) when Penny will be popping in at the start to have us "side by side singing in harmony, side by side singing in tune" as the lyrics say.

The main feature of the November meeting is Dr Richard Davenport speaking on "**When the Going Gets Tough: Managing Advancing PD.**" This was a topic scheduled for last year but from which Dr Davenport digressed to report on aspects inspired by the 200 year anniversary of James Parkinson's "The Shaking Palsy" essay.

Branch Indoor Bowling Win



On 29th August our indoor bowling team won the annual match against Fife Branch, held this year at the Abbey View Bowling Club, Fife. It was just as well we were the winners as the team had forgotten to take the trophy, won last year. Thank-you to Fife for your hospitality and to the two players who swapped sides to make up Edinburgh's numbers.

Edinburgh Parkinson's Lecture 2018



The lecture on 17th September by Professor Giovanna Mallucci on “The Road to New Treatments for Dementia and Parkinson’s” was expertly pitched to the mixed audience of Branch Members, clinicians and researchers. Professor Mallucci talked about her research into brain cell protein misfolding in neurodegenerative conditions and the possibilities for slowing the process, even reversing it. There was also time to cover research aspects of how to protect our synapses, with much of the lively question and answer session focusing on this. A video stream, lecture summary and photos (courtesy of David Goldthorp) can be

accessed via the Branch website. A DVD is available – a donation of £5 is suggested to cover costs – please email Ken Bowler, ken@edinburghparkinsons.org.

World Parkinson Congress 2019 Branch Representatives

WPC is considered the most significant and diverse international forum for stimulating and sharing information and for energising networks with regard to PD. In response to expressions of interest, the Branch will be represented at the Kyoto Congress next June by Hagop Bessos, David Adams, Alison Williams, David Melton, and Julia Melton. Their trip will be partly funded by Branch bursaries on the basis that the information, connections and understanding gained can feed renewed value and impetus into Branch work and activities. Our representatives will submit a written report to the Committee on their experience and learning from the Congress, and participate in a 2019 autumn Branch seminar to share the experience and knowledge with other Branch Members. Kathleen Bessos will travel to Kyoto in a totally self-funded support capacity.

Online P-UK Self-management Groups

In addition to face-to-face groups, Parkinson’s UK is running their self-management programme **online** at various times throughout the year. It is for anyone affected by Parkinson's – people with the condition, partners and carers. Online groups combine self-guided workbook activities with group video calls over 6 weeks. Video calls last an hour and may take place in the evening. Getting set up is very easy and P-UK guide participants through it. To find out more and/or register interest, go to www.parkinsons.org.uk and search under *self-management*.

Monthly Drop-in Café



September had record numbers attend despite having to find a last minute alternative venue – thank-you City of Edinburgh Methodist Church Café for your accommodation and Festival Theatre staff for re-directing people. The last date for this year is **Tuesday, 27th November** in the Festival Theatre Café, Nicolson Street, EH8 9FT. Do join us there, otherwise on 29th January, 2019.

Hints and Tips

Based on a Hints 'n' Tips workshop at the annual Young Parkinson's event in Stirling this year, some members of the Edinburgh Young Parkinson's Support Group have compiled a document with much useful information on all manner of topics to help make life easier for PwPs. To find out more, please contact Scott Wilson scottwils01@btinternet.com. We also remind you that the Quality of Life group has hints 'n' tips available via its Edinburgh Branch website page.

Tandem Cycling



Research studies continue to demonstrate the benefits of exercise for PwPs, including cycling. The Branch is aiming to launch a pilot of tandem cycling on interesting safe routes in Edinburgh and East Lothian for those unsure of their ability and/or confidence on a bike. An additional factor in using a tandem is to gently force increased intensity for the rear partner, with its associated health benefits. Sessions will be run by Brian Moore who has a lifetime commitment to cycling and its positive impact on health. Brian has completed Tandem Cycle Training with the Edinburgh All-ability Bike Centre, Volunteer Induction with Parkinson's UK and holds a current PVG certificate. An independent family charitable trust known to Brian is funding the tandem and appropriate hi-visibility clothing. We are finalising a suitable start point where the tandem can be stored and which has a practice area as well as access to quiet, relatively flat, roads and off-road tracks (with coffee shops). If interested, please contact the Newsletter Editor (*see end of Newsletter*).

Background to Creating the Song "Side by Side" (Submitted Essay)

We are a singing group run by the Edinburgh Branch of Parkinson's UK with some 35 members who are people with Parkinson's, caregivers and friends. We call ourselves Singing4Fun and meet weekly throughout much of the year to do just that – sing for fun. Our song leader, Penny Stone, begins with physical warm-up exercises and games for the voice then we sing all sorts of music from all sorts of places. We often sing in 3 part-harmony (occasionally more!).

In a nervous sort of way we wanted to try, despite our inexperience, to write a song for the World Parkinson Congress 2019 so a number of us met to see what we could create under Penny's guidance. Who would have known we could put a musical composition together and have such a good time doing it?! We began by finding words and phrases to express how we felt about Parkinson's but that were well balanced by our awareness of all our positive feelings about the singing group and the community we have around us – Branch Members, family, caregivers and friends. Out of these the verses began to take shape. Then a few notes began to emerge from our various hummings. By our second session we had a melody for the verses. Then emerged a chorus which we wanted other people, the attendees at the Congress for example, to be able to sing easily. The chorus and the title of the song have been inspired by the Side by Side course run annually by the Branch to provide information and support for those who know, live, or work with someone who has Parkinson's.

With some work by Penny on a 2-part harmony and final tweaking at a Singing4Fun session we feel we have a song that very much reflects the positive community spirit of the singing group and the Branch as a whole AND we like to think of Congress attendees heartily joining in at the chorus. Whatever notes come out at Singing4Fun we always see it as 'singing in harmony.'

Other News

Well-deserved Praise: Branch Art Group members have kindly donated £530 to the Branch from sales of their work at the Bon Papillon café/gallery during their successful Art Exhibition throughout September. New members are always welcome by the group which meets at the Botanic Cottage, RBGE on Thursdays 1.30-3.30pm throughout the year. All levels are welcome. And well done to our **Hon Secretary, Liz Hume's son** for raising £430 for Parkinson's UK by taking the Forth Bridge Abseil challenge and to **Kevin Brown**, our Tai Chi instructor, for raising £560 for the Branch in the Edinburgh half-marathon earlier in the year.

NHS Lothian Website: Dr. Gordon Duncan has asked for feedback from Branch Members about the revamped web pages covering Parkinson's Services. The pages should be live by the time you read this and accessed via services.nhslothian.scot/ParkinsonsServices (no www).

Patient and Public Involvement (PPI): We remind Members to consider participating in this scheme which encourages the participatory process involving patients, carers, researchers and healthcare professionals working together for improved healthcare. The organisation now has a newsletter to share feedback on the outcomes of PPI input and keep people up-to-date on the programme. More at www.ed.ac.uk/usher/edinburgh-clinical-trials/patient-public-involvement.

Privacy Notice: In adherence to GDPR (General Data Protection Regulation) we draw your attention to the notice which can be accessed below the Main Menu on the Branch website.

“What We Do” Flyer: We now have a single page A5 flyer identifying our regular activities based on our 4-page *What We Do* more detailed document. The flyer can be left in suitable venues to help make the wider Edinburgh public aware of the Branch and what it has to offer. If you know of places where you can leave these, please pick up a handful at our Branch and ERIG Meetings or Singing4Fun sessions or contact the Newsletter Editor (*see foot of page*).

Listening Book Service: This is a UK charity providing an audiobook library service for anyone who finds an illness, disability or mental health condition impacts their ability to read. The charity has free membership available for people who would like to join but may not be able to cover annual membership (£20–£45). To find out more, see www.listening-books.org.uk or phone 020 7234 0522. It may not be applicable to you but you may know of someone who would benefit.

Boxing Exercise and Chess Sessions: We are currently investigating these as possible Branch activities. If you are interested, please contact the Newsletter Editor (*see foot of page*).

Roseburn House Charity of the Year: The residents have nominated the Edinburgh Branch to be their charity of the year for the next 2 years.

A-level Design Project: It has been a delight to have student, **Daniel Brown**, at Branch Meetings gathering information about the effects of PD on use of everyday products and which he will use in his project. We look forward to hearing about his final design project submission.

ICE: We encourage Members to flag up *In Case of Emergency* numbers in their mobile phone.

Carers Support Group: If you are a care-partner and have not yet tried this group which meets last Wednesday of the month, 10.30am-12.30pm, Pollock Pavilion, 227 Ferry Road, EH6 4SP we encourage you to come along and experience the benefits of the sharing and discussion.

Newsletter Editor: Helen Harris via helen@edinburghparkinsons.org.