

Inspirational December ERIG Meeting

On Saturday 2nd December, at the MRC Centre for Regenerative Medicine, Dr Tilo Kunath, gave a talk entitled "Cell Therapy for Parkinson's: where are we now?" For the first time, ERIG recorded the meeting on video and Tilo's presentation can be viewed via the Branch website Research Interest Group page under *Reports from Past Meetings* (do follow the Notes for best viewing). If you want to learn about Tilo's work and positive progress with stem cell therapy we encourage you to view the recording – you won't need a scientific or clinical background to follow it.



After Tilo's talk, Leona Braund from Inverness told of her journey so far with PD. Leona at the age of 33 noticed something wasn't quite right but wasn't diagnosed with PD until 5 years' later. She spoke of how taking up cycling, challenging herself and learning to be mindful in the moment have helped her develop coping strategies and take ownership of her condition. It was an inspirational 15 minutes well worth viewing (it begins just over 46mins. into the recording).

We encourage Branch Members who have not yet attended an ERIG meeting or signed up for their newsletter to consider doing so. Speakers provide hope for the future, know that attendees don't necessarily have a scientific or clinical background and the meetings end with a sociable sandwich lunch. Contact Ken Bowler, 0131 669 8961, or ken@edinburghparkinsons.org.

Local Adviser Appointed



The aim of the Parkinson's UK Local Adviser service is to provide client focused information and support (including social care, welfare and benefit entitlement issues) that enables and empowers people to take control of their lives living with PD. A new Local Adviser (for Edinburgh, East Lothian and Midlothian) is now in place following Betty Thomson's retirement. We look forward to introducing you to **Abenet Tsegai** at the February Branch meeting. We were delighted Abenet was able to attend the Christmas Lunch on 13th December at Boroughmuir Rugby club where we took this lovely photo. You can view more photos reflecting the joviality of the event via the Branch website News page, 13th December entry.

Members' Journal Article Recognition

The joint paper by three of our Members (Alison Williams, Ken Bowler and Bill Wright) published in the *Journal of Regenerative Medicine* entitled "Adventures with Parkinson's: empowering Parkinson's patients to become active partners in research and treatment" has reached the list of top ten papers in 2017 published by the journal. Well done to Alison, Ken and Bill. The paper can be viewed via a link on the Branch website News page 3rd November entry.

Parkinson's Monthly Café Established

After the initial trial we're continuing with this new venture in a dedicated area of the Festival Theatre Café to encourage people to find out about the Branch, ask questions and meet existing Members. Our Cafés are on the last Tuesday of the month, 1–3pm, so forthcoming dates are 27th February, 27th March, 24th April, 29th May, 26th June. We would like existing Members to come and help create a relaxed convivial atmosphere. More details are on the Branch website or contact Liz Hume, honsec@edinburghparkinsons.org or 07594 481175.



Branch Meeting News



Our first meeting of 2018 featured a presentation by **Anne MacColl**, co-opted in 2016, elected in September 2017 as **Trustee**, Parkinson's UK in Scotland. Anne's husband was diagnosed with PD four years ago aged 50. Anne spoke of the role of Trustees, her areas of interest and concern, current areas of focus, progress in P-UK and her eagerness to learn of issues we want raised with the Board. It was a lively meeting with good exchange between the speaker and the floor. Anne's PowerPoint slides can be viewed on the Branch website News page 10th January entry.

Before Anne spoke, Ken Bowler demonstrated his **Path Finder shoe attachments** developed by a tech start-up company, Walk With Path Ltd. They project a laser line on the ground in front of the wearer at a set distance from the feet, giving the person a visual cue to step across, so acting as an external stimulus to trigger walking. The attachments are intended to help people with unsteady and irregular gait including FoG (Freezing of Gait). You may remember we were first introduced to the concept in Bastiaan Bloem's Edinburgh Parkinson's Lecture 2016. Find out more via the Branch Website News page 10th January entry.



Inspired by Ken's demonstration at the January meeting, we want to encourage other Members to tell us about **tech aids** they have found successful so we will provide a demonstration slot at every Branch Meeting for anyone who wants to bring something along.



At the next **Branch Meeting on 14th February**, 2-4pm, Tilo Kunath and John MacPhee will reprise their Edinburgh Fringe CODI (Cabaret of Dangerous Ideas) show "Eradicate Parkinson's." This is a highly entertaining, clever and expertly executed TV News spoof not to be missed, and well worth a second viewing if you saw them at the 2017 Fringe.

The **Branch Meeting on 11th April** will include a presentation from the Parkinson's Nurse Specialists and a presentation from Gill Murray on postural awareness. Gill is a physiotherapist with specialist knowledge of neurological conditions and is based at Slateford Medical Centre.

We would like to remind you about the **Young Parkinson's Network** which supports PwPs of "working age." Members meet in a relaxed atmosphere at The Steading, EH10 7DU on the first Thursday of every month 6.30/7pm and also organise a variety of outings. Contact Scott Wilson, 01899 220 827, scott@edinburghparkinsons.org for more information. In 2018 we will be working to build stronger ties between the main Branch and the YPN.



Ignore the Weather & Give Nordic Walking a Try

Using specially designed poles to help you move forwards, Nordic Walking makes you exercise your arms as well as your legs and allows you to walk faster and more steadily while taking the weight off the lower body joints. It helps with posture, mobility, cardiovascular fitness and co-ordination, plus it gets you out into the open air. The class features in a new P-UK video (see the New Activity article next page for information).

Our sessions are run by a qualified Nordic Walking instructor, Trevor Jones, in the Meadows, Bruntsfield, Thursdays, 12 noon for an hour. In addition to the feedback on our website from Member, Bill Wright, others who have been making use of our sessions comment:

“Nordic walking has improved my walking pace and balance considerably, and gives me a regular exercise opportunity. I also appreciate the social side of the activity and enjoy being able to talk to PwP's whilst exercising at the same time.”

“The Nordic Walking sessions are a great way of socialising and getting fresh air, while improving posture and walking. The special walking poles and technique help with correcting bad posture and walking difficulties. Our instructor, Trevor, is an excellent teacher who is well-qualified, friendly and patient. The class is suitable for a range of abilities as Trevor encourages everyone to go at their own pace.”

See the Branch website for more information or contact Bill Wright, 0131 281 6880, 07981 948402 or bill@edinburghparkinsons.org.

Glasgow Visit by Edinburgh Dance for Parkinson's Group



Each year, when Scottish Ballet opens its Christmas production in the Festival Theatre, its enormous Tramway rehearsal room is left empty – not for long! On 11th December the Dance for Parkinson's Glasgow and Edinburgh classes took over the space and all 60 of us danced the afternoon away. Our hosts plied us with tray bakes, tea, mince pies, smiles and banter – overheard, an Edinburgh dancer looking for a partner: *Are you dancing?* Glaswegian response *Nah, it's just the way I'm standin'* – true West Coast humour and hospitality!

Tramway and Dance Base teachers together led the class and kept everyone (more or less) under control. Many of the Glasgow contingent had been through to Edinburgh the previous Friday for the dress rehearsal of Scottish Ballet's "The Nutcracker" – a magical and moving evening – so they are starting to be well-kent faces. At the end of the evening, it was on the bus again, a snooze all the way back to the Grassmarket and home. Another wonderful way of getting into the festive spirit – roll on next Christmas! (Report from Member, Alison Williams)

Something for our Car Windows – Thinking Caps on Please!

We want to reach out to potential new members. We now have the Parkinson's Café. Another approach is to design a sticker for the car window that will draw public attention to the existence of the Branch. Before we design and print the item we need a short phrase to display with our website details. We need words that are **meaningful**, **catchy** and **inviting** encouraging others to find out more about us. We recorded some phrases from attendees at the recent Branch meeting but we would like others to put forward their creative suggestions. The Committee will consider all submissions in the next few weeks. Entries to helen@edinburghparkinsons.org. Chair, David Adams says "The chosen phrase will get a huge hurrah at the AGM!!!"



A New Activity for Your New Year?

We began this Newsletter with encouragement to consider trying out an ERIG meeting. We would like to remind you about *all* our participatory activities and to think about trying something new for 2018. On the exercise front, we have drawn your attention to dance and Nordic Walking but there are many more physical activities on offer: gentle forms of exercise at Portobello Swim Centre and the Thistle Foundation group, indoor bowling, Tai Chi, and Pilates. The success of our Pilates sessions (Mondays and Fridays) means we are able to make a small charge for these and invest the money elsewhere. Although the Monday sessions are currently full, our instructor, Sasha Baggaley can organise a taster session for individuals when she knows a regular participant won't be attending.

We also have Branch affiliation with Edinburgh Leisure for a Get Active Card allowing use of their facilities for a small fee. We established this to encourage Members to swim but card holders can use any of the Edinburgh Leisure facilities. P-UK has just launched a new video entitled "Parkinson's and Exercise" which can be viewed on their *Facebook* page or at www.parkinsons.org.uk/information-and-support/exercise. Member Bill Wright is in a number of clips and our Nordic Walking sessions also feature.

To complement physical activities there's the twice weekly singing sessions, the art group and our QL (Quality of Life) group, so please make the most of what we have to offer in helping to keep you active and socially involved. We also encourage care-partners to try out the monthly Carers Support Group.

More details of all activities are on the Branch website and printed in the Branch calendar and do let us know of any others you would like us to consider.

News in Brief

Side by Side Course Feedback: In the autumn our Side by Side with Parkinson's Course again proved much appreciated by the care-partners who attended. See the Branch website under Training & Care Programs for the glowing comments and information about the course.

Indoor Bowling: The Parkinson's Bowlers enjoyed their annual Christmas Lunch on 18th December at their usual venue of Meadowmill Indoor Bowls. The general consensus was "great food and excellent company."

Ginormous Teddy Competition: We have extended the closing date to 14th March (Branch AGM). This is to guess the birthday date for the 53in. teddy bear (named Arthur II) donated by Mrs Mair whose husband was a Branch Member. £1 a try – select a day/month from the diary at most of our regular events, or contact Lou Ogilvy via lo4parkinsonsfundraising@gmail.com.

Parkinson's Awareness Day: 11th April 2018 – focus is on a day rather than a week this year.

Volunteers needed

If you have a particular skill, expertise or experience you would like to offer to the Branch in a volunteering capacity do get in touch with Chair, David Adams, chair@edinburghparkinsons.org, or 0131 557 5979. You may also have a family member or friend who has something to offer.

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