EDINBURGH BRANCH PARKINSON'S UK NOVEMBER 2017

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

People Dancing & Birds in Your Hair





People Dancing is the UK development organisation and membership body for those involved in creating opportunities for people to experience and participate in dance. Members believe dance can change lives and transform communities. The second International People Dancing conference was held in Glasgow in October. The programme focused on areas that reflect innovations and current participatory dance practices, one of which was dance for people living with Parkinson's. Branch Member, Alison Williams was part of a discussion panel which, she says, evolved into a lively conversation with the entire audience about what was truly important about dance to people with Parkinson's.

Alison writes, "We discussed what quality of life means, how the dance teachers and the participants influence each other, what is the place of creative dance in the classes – and what does *that* mean. We ended with a determination to continue exploring the topic, and for the panel to meet up before Christmas to carry on the conversation. The panelists included

Bethany Whiteside who has just completed an evaluation of our Edinburgh dance class." We will be able to find out more from Bethany at our Branch Meeting on 14th March next year when she features as the speaker. In the meantime, you might like to read Alison and fellow Branch Member Julia Melton's blog on the People Dancing website in praise of dance volunteers, whom they refer to as their *bird-scarers*. It's a profound yet humorous piece of writing. (See *www.communitydance.org.uk/news-and-views*).

The Edinburgh Parkinson's Annual Lecture 2017

Almost 300 people attended this year's lecture at the Royal College of Physicians given by Professor Andrew Lees MD, FRCP, FMedSci. This proved an informative, thought-provoking yet entertaining talk with Professor Lees describing his path through qualifying as a physician, then specialising in neurology, developing a particular interest in Parkinson's, becoming a researcher, and finally his deepening interest in William Burroughs, satirist writer and heroin addict, and the influence Burroughs' writings had on his research.

Available on the Branch website are overhead slides and photographs from the lecture, as well as details of how to order a DVD of the event. You can also access a summary written by your Newsletter Editor which can be read on its own but is also helpful in pulling together the various strands of the lecture after watching the DVD. You may also consider reading Professor Lees' book (which he referred to as his *emanation*) "Mentored by a Madman, the William Burroughs Experiment." In the words of James Grauerholz, literary executive of the Burrough's estate and who wrote the Foreword, "it is a compelling, unpredictable and quirky life-review."

Parkinson's Voice Information and Development Sessions

Mary Ellmers, Service Improvement Adviser and Tanith Muller, Parliamentary and Campaigns Manager, both from P-UK Scotland Office are organising information and development sessions for PwPs and care-partners interested in becoming Parkinson's Voice's to help with service improvement and campaigning work. Mary and Tanith want to use your experience to inform decision-makers and service providers (MSPs, NHS, health and care professionals) about what needs to change to make life better for you.

They have organised two events for those interested: Edinburgh on Thursday, 23 November, and Glasgow on Thursday, 30 November, both mid-morning to mid-afternoon, lunch provided. Exact times and locations are yet to be confirmed. Everyone is welcome. They want to involve people with a wide range of backgrounds and those at every age and stage of Parkinson's.

The ultimate work could involve being part of a consultation group to give your views on how changes in Scottish government policy might affect PwPs and their families, as well as working with Mary and Tanith to raise issues in the media and directly with councillors. MSPs, MPs and officials. They are also looking for people who are willing to join the Parkinson's Excellence Network in Scotland to work alongside the Network's health and social care professionals to identify service improvement issues and take forward improvement projects.

To sign up or find out more, please contact Mary via *mellmers* @parkinsons.org.uk or 0344 225 3723, or Tanith via *tmuller* @parkinsons.org.uk or 0344 225 3726.

And, **urgently**, if you haven't already done so, P-UK would like you to complete their *2017 Your Life, Your Services Survey* by 17th November – access it via the Branch website News page.

Betty Thomson Retires

We are sorry to report that as well as losing the support of Gina Allen, Betty Thomson, our Parkinson's UK Local Adviser for Edinburgh, East and Midlothian has announced her retirement. Betty took on the role (then entitled Community Support Worker) in Spring 2010 with "responsibility for providing client focused information and support aimed at empowering people to take control of their life living with PD." Many in the Branch are indebted to Betty for her abilities at helping them understand their rights and options, navigate health and social care systems and make appropriate choices. But what Members comment on most of all is the skill with which she put people at ease, engendered a sense of trust, impressed that nothing was too much for her and left people with a positive feeling about the future. The Branch Committee is particularly indebted to Betty for her support in our dealings with respite care, her contributions to our Side-by-Side courses and on a lighter note, her wonderful cakes and meringues donated to our Coffee Mornings. Betty, you will be sorely missed but we wish you well in your retirement.

Strictly for the Adventurous

Committee Member, Bill Wright, met one of the pilots who run the *Walking on Air* charity established for over ten years to bring the enjoyment of flying gliders to the disabled. Said pilot is enthusiastic about giving PwP's the opportunity to fly – he already has one person with PD whom he takes flying with great success. A trial lesson is available after checking that an individual's condition still allows him/her to fly safely. The charity is supported by grants and donations and enjoys the use of volunteers for all instructing, equipment maintenance as well as additional help, so fees ultimately charged cover just the cost of launching plus maintaining and insuring the glider. If you would like to find out more, see *www.walkingonair.org.uk*.

Swimming for Members



"Swimming is the only thing you can do from your first bath to your last without hurting yourself. When you're in the water, you're weightless and ageless," so said Esther Williams, the champion swimmer and film star of the mid-20th century. Not only does the buoyancy when swimming protect our skeleton, the exercise involved

can help improve circulation, lower blood pressure, expand lung capacity, build muscle strength and improve flexibility. And for PwPs it is ideal as it takes place in a safe environment – the water. The facility we offered at Braidburn Hydrotherapy Pool just once a week was no longer viable due to falling numbers but we want to encourage regular swimming for Members with PD and their care-partners. To this end the Branch is affiliating with the Edinburgh Leisure Community Access Programme.

Anyone with Parkinson's may apply for a Get Active Card (valid for six months and renewable for a further three months). Card holders may swim in any Edinburgh Leisure pool for just £1 as long as they can access the pool without staff assistance. A care-partner who accompanies the card holder has free entrance. You can apply for a Get Active Card by completing an application form, obtainable from our Hon Secretary, Liz Hume, *P.O. Box 17482, EH12 1NQ* or on *07594 481175* or at *honsec*@edinburghparkinsons.org. The card also allows you to use the other facilities at Edinburgh Leisure Centres but we hope many of you, who have perhaps avoided swimming for some years, will soon get splashing *PPPPPPP*

Tai Chi for Parkinson's

We want to encourage people to give Kevin Brown's classes a try (Tuesdays, Barclay Viewforth Church, EH10 4HR). In studies, Tai Chi time and again comes out as proving of benefit to people with Parkinson's. Kevin understands the problems PwPs can have with posture and balance and tailors his classes to the needs of everyone attending, with chairs available if needed. If you have no previous experience of this type of energy work, Kevin explains just enough of the philosophy behind it for people to grasp the concepts. Background music accompanies the exercises to help set a relaxing atmosphere but by the end of the class your body will still feel it has been exercising. For those who want to carry on at home, Kevin provides guidance and videos of himself doing the moves. You do not have to commit to attending each block of classes, people can drop-in and the classes are free. To find out more, please contact Kevin on *01506 845 498* (do leave a message) or email, *kevin@chi-flow.co.uk*.

Berlin Marathon Run by James Mark



Vice-President Patrick Mark's son, James, has again run a marathon to raise money for P-UK, this time close to £400. It was the BMW Berlin Marathon on 24th September which was also the day of the German national elections. This is one of the Abbott World Marathon Majors which unites the six most significant marathon races in the world: Berlin, Boston, Chicago, London, New York and Tokyo. James' time on the flat looping course was 3hrs 36mins despite heavy rain and humidity that lingered around 90 per cent. Conditions meant that the anticipated new world record set on the same course in 2014 (at 2:02:57) didn't happen but the winner, Kipchoge was acknowledged as having set a "rain world record" at 2:03:32.

News in Brief

Indoor Bowling: The Annual Bowls Match against Fife Branch was held at home on 28th August and the Edinburgh Branch won comfortably by 53 shots to 22. It was another very enjoyable event, players being well rewarded with a great lunch. The Branch now has a discounted membership with Meadowmill Indoor Bowling Club easing our administration. Those registering with the scheme pay £3 as before but others can still drop-in to a session for £4.

Edinburgh All-Ability Bike Centre: The pilot scheme for Branch Members and care-partners to attend on Tuesday mornings has now ended. It has been decided that rather than have a dedicated session, people can attend any of the *open* sessions during the week and be assured there will be adequate supervision and volunteer help to get safely pedaling on the rich variety of bicycles available. The Centre closes for the winter at the end of November but we will be reminding and encouraging people to get outdoors and on a bike when it reopens in March.

What We Do Document: To complement the Branch Calendar publication we now have a document entitled "What We Do" which explains all our activities in more detail. It is aimed at new Branch Members but we have enclosed a copy with this Newsletter for existing Members. It can also be accessed as a pdf file via the Branch website where it will be kept up-to-date.

Parkinson's UK Christmas Cards: These can be purchased at the imminent Branch Meeting (8th November), Singing4 Fun sessions and please also look out for them at charity outlets.

Ginormous Teddy Competition: Mrs Mair whose husband was a Branch Member has very kindly donated a 53in. teddy bear (named Arthur II) to help raise funds for the Branch. Guess Arthur's birthday date for a £1 a try at most of our regular events, or contact Lou Ogilvy via *lo4parkinsonsfundraising@gmail.com*. Closing date is the Christmas Lunch, 13th December.

Parkinson's Café: We held three monthly sessions in a dedicated area of the Festival Theatre Café with some people new to the Branch coming along to find out more and meet existing Members. Further dates will be announced in the New Year.

Singing4Fun: Earlier this year our Tuesday Singing4Fun group took part in a fund-raising promotional video for Marchmont St.Giles, where the group meets 2-4pm. You can watch the relevant lively extract on the Branch website S4Fun page under Regular Activities. If you've not yet given this activity a try we hope it will encourage you to pop along one Tuesday, or if the day and time don't suit, we have an equally lively session on Wednesday evenings at Grace Baptist North in Logie Green Road. To find out more please see the Branch website page or contact Cathie Quinn, *0131 557 6438* or *cathie* @edinburghparkinsons.org.

Branch Meetings

September: Julie Jones, Robert Gordon University, told us about a community-based exercise programme she is developing in Deeside. Julie would ultimately like to see this rolled out across Scotland and involving physiotherapists and fitness instructors.

October: We heard about and discussed patient involvement schemes to help train health professionals. Anyone interested in taking part in these schemes, please contact Kirsty Egan, Edinburgh Patient Partnership Supporting Assessment & Teaching, via *kirsty.egan*@ed.ac.uk or 0131 242 6535.

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