

Edinburgh Parkinson's Lecture 2018

Enclosed with this Newsletter is the flyer for this year's lecture being held 17th September, 7.15pm, Queen's Medical Research Institute co-located with the Edinburgh Royal Infirmary, Little France. **Professor Giovanna Mallucci**, Cambridge University will talk about "The Road to New Treatments for Dementia and Parkinson's." Although the lecture is a little way off, due to the popularity of this annual event we encourage you to reserve a place using the form in the enclosed flyer or online at *Eventbrite* or via a link on the Branch website page for the lecture.

Rescheduled ERIG Meeting

Due to the adverse weather conditions in March the much anticipated presentation by Professor **W Gedroyc** (Imperial College) on "MR guided focused ultrasound of the brain" was postponed. The rescheduled date is Saturday 16th June, 10.30-13.30, Scottish Centre for Regenerative Medicine, EH16 4UU. Professor Gedroyc and his team are currently concentrating their brain focused ultrasound applications on motion disorders. Register online at *Eventbrite* for this free event or via a link on the *Research Interest Group* page of the Branch website.

Young Parkinson's Support Group on Facebook



The Group (previously referred to as *Young Parkinson's Network*) has established a Facebook Page with the mission statement "run for people with Parkinson's under the age of 65. We meet in the conservatory at The Steading first Thursday of the month. Our aim is to give support for people with Parkinson's of working age, whether newly diagnosed or diagnosed for a while. We can offer advice regarding all things Parkinson's related. If we don't know then we will endeavour to find someone who does." This is a Closed Group so only members can create and see posts (the public can see the group exists and who are members). Membership is growing and people are posting useful information. Do think about joining if you want to be part of this community – apply on the page to the Group Administrator.

Paul Mayhew-Archer: Incurable Optimist

We emailed Members some weeks ago about possible accommodation for Paul who has PD and is bringing his one-man show to the 2018 Edinburgh Fringe. Paul co-wrote the *The Vicar of Dibley* and other comedy series. Members may also have seen the 2016 BBC2 documentary *Parkinson's: The Funny Side* with Paul telling of his life with PD since being diagnosed five years earlier. We're pleased to announce that Paul has now arranged his accommodation. He was overwhelmed by the kindness of Members who got in touch. His show which is about the therapeutic power of comedy (title as above) is available to book via www.edfringe.com.

Self-referred Aquatic Exercise



We have access once more to Astley Ainslie Hydrotherapy Pool. Sessions for PwPs began in April and the intention is to continue throughout the year apart from holiday periods. The sessions are run by Physiotherapist and Hydrotherapy specialist, **Jackie Rochmankowska** supported by trained lifeguard, **David Waughman**, and Branch volunteer, **Kathleen Bessos**. We welcome David who has opted to join our band of Branch volunteers. The format is different to the courses run by the Branch before the pool closed for refurbishment. We are still trialling the sessions so things may change but for the moment, people self-refer (by completing an application form) and attend usually for 4 weeks at a time. We have use of the pool on Fridays, 2-4pm with participants working with Jackie in the water for half-an hour at a time. The aim is to help participants build strength and flexibility using the extra support the water provides. For the moment sessions are free, being funded by the Branch. To find out more, please visit the Branch website *Aquatic Exercise* page under *Regular Activities*.

Bearing in mind the buoyancy benefits of water, may we remind you of the Branch's affiliation with the **Edinburgh Leisure Community Access Programme**. This allows a Member with Parkinson's to apply for a Get Active Card (valid for six months, renewable for a further three). With it you can swim in any Edinburgh Leisure pool (or use any of a Centre's other facilities) for £1 if able to access the pool without staff assistance. An accompanying care-partner has free entrance. We already have a number of Members making use of this facility. To find out more please visit the Branch website *Swimming* page under *Regular Activities* or contact Branch Secretary Liz Hume via honsec@edinburghparkinsons.org or P.O. Box 17482, EH12 1NQ.

We also draw your attention to the facilities at **Braidburn Pool**, 107 Oxfangs Road N, EH14 1ED where we are welcomed by BackCare Lothian who hire the pool on Wednesdays 6-7pm in school term times. A lifeguard is on duty. This is a spacious pool with warmer water than normal. For insurance purposes, users must be BackCare members (£15 pa for pool use) and pool charge is £40 per 8 week block. A physiotherapist, specialising in pain management, provides free advice and suitable exercises at 2 sessions per block of 8. Newcomers are offered 3 trial sessions at £5 each. For more details, see www.backcarelothian.org.uk.

Branch Car Sticker

Below is the newly available vinyl strip for the back window of Members' and their families' cars. The aim is to give wider visibility to the Branch's existence so that more PwPs can benefit from what we have to offer. After some weeks of gathering suggestions for a phrase, in the end some Committee Members brain-stormed and the Committee finally decided on the phrase shown below. The vinyl is 50cms by 7cms and should be placed very close to the bottom of the inside back window so there is no obscuring of driver vision. We may come up with other designs in the future and we're considering a smaller sticker that can be used on bikes, wheelchairs, back packs, and walking aids. If you would like a vinyl (free) or have suggestions, comments, or feedback, please get in touch with Helen Harris via helen@edinburghparkinsons.org.

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Dance for Parkinson's Scotland DfPS



At the Branch Meeting 14th March following the AGM, Dr Bethany Whiteside, Royal Conservatoire of Scotland, reported her findings from a *Mixed Methods Evaluation of the DfPS programme*. It was based on data collected by questionnaire, observation and interview regarding the weekly Dance Base sessions in Edinburgh and Scottish Ballet sessions in Glasgow. The outcome suggests the programme is beneficial to

participants in a number of ways. Physical benefits include improvements with balance, co-ordination, gait, flexibility, fluidity, posture and confidence with movement. Cultural benefits include participants' growing relationship with dance, opportunities for self-expression, feeling the movement, and sharing and showing emotions, all while learning about the cultures of dance and ballet. Social benefits include a sense of community through shared determination to participate and feelings of responsibility for one another, as well as creation of friendships and social networks.

The Branch has been a strong promoter of the benefits of dance for PwPs for many years, having run its own sessions from 2010 based on the Mark Morris Dance for PD® model before the Scottish Ballet and Dance Base collaborative programme took over in 2015. It's good to now have an evaluative study justifying our long-established involvement with dance. The full report is available via our *Regular Activities: Dance for Parkinson's Scotland* page which also includes a link to the recent DfPS video. Wonderful news – the collaborative has received a further 3-year funding for the programme which will include expansion to other parts of Scotland.

Whether a PwP or a care-partner, if you have not yet given dance a try we encourage you to go along on a Wednesday to Dance Base in the Grassmarket 11.30am-1pm to experience some of the aforementioned benefits, then stick around for a social café in the studio afterwards.

Edinburgh Festival of Cycling 7th to 24th June

The festival is hosting a wide variety of activities – rides, competitions, art and cultural events, exhibitions, workshops, films, talks, and more. As part of the fortnight, the **Edinburgh ABC (All-ability Bike Centre)** at the Bangholm Outdoor Education Centre has organised open days, a ride to Cramond with adaptive bikes available, and a celebration of its third birthday on 17th June, 10am–1pm to which all are invited. There will be much activity with a truly impressive assortment of specialised bikes, trikes and pedal machines available. These adapt to a very wide range of physical abilities which participants can use at no cost. For more details about the festival see edfoc.org.uk or for more about ABC see the Branch website page under *Regular Activities* or contact David Glover at david.glover@cyclinguik.org or on 07500 069357.



While on the topic of cycling, **Leanne Owens** (who has Parkinson's) aims to arrive at the Scottish Parliament on Saturday 30th June at about 3.30pm to 'meet and greet' while on her **K977 Challenge** to cycle 977 miles around the UK in 11 days. She starts on 28th June and will visit the four UK capitals to raise awareness and funds for Parkinson's research. We hope some of you will manage to be there. If so, it will help if you let Scott Wilson of the Young Parkinson's Support Group know via scott@edinburghparkinsons.org.

Regular Activities: Other Exercise Options

We remind you of the **Parkinson's Group at Thistle** which includes a variety of activities to help co-ordination and mobility, with a little mindfulness and meditation to finish. Sessions are on Mondays, 10.30am–12.15pm and run by Chris Davies. See the Branch website page for more details or contact Chris on 0131 661 3366. Now that we are experiencing weather more in tune with the months we encourage you to get out into the fresh air and enjoy walking round the Meadows with the support and additional exercise benefits of **Nordic Walking** poles at our Thursday lunchtime sessions. For more details see the Branch website page or contact Julia Melton via julia@edinburghparkinsons.org or 0131 445 2500. Julia is taking over from Bill Wright as Branch contact for the sessions. We thank Bill for all his efforts to date.

Dundee-Edinburgh Parkinson's Research Initiative

A number of Members attended a public event in April in Dundee at which key members of this new initiative gave an overview of the scientific and clinical research on-going and planned between Dundee and Edinburgh. The vision is to become a centre of excellence for scientific innovation, patient-centred research and clinical care. Our Edinburgh Research Interest Group will be maintaining a watchful eye on progress and announcements from the initiative.

Other News

Pilates: Due to increasing demand for Sasha Baggaley's classes, we've introduced a fourth session which is aimed primarily at those new to Pilates. These are on Fridays 11am–12noon, Morningside Parish Church, 2 Cluny Gardens, EH10 6BQ. To find out more see the Branch website page or contact Sasha via sasha@edinburghparkinsons.org or 0131 620 3780.

Parkinson's Café: These continue to prove successful, bringing in new Members and providing the opportunity for existing Members to socialise at the Festival Theatre Café, 13/29 Nicholson Street, EH8 9FT, 1-3pm. Scheduled dates are 26th June, 25th September, 30th October, 27th November, 29th January 2019, and 26th February 2019.

Patient Involvement Schemes: A reminder that anyone interested in taking part in these schemes should contact Kirsty Egan, Edinburgh Patient Partnership Supporting Assessment & Teaching, via kirsty.egan@ed.ac.uk or 0131 242 6535.

Singing4Fun: Our Tuesday session song leader, Penny Stone, is available to spend 15 minutes after the session on a one-to-one basis with PwPs to explore what voice exercises would be good for each individual. Tuesday sessions are 2-4pm, Marchmont St.Giles Church Hall. The Wednesday evening sessions, 7-9pm with Ellie Logan will be returning to Bellevue Chapel in September after a break from the end of May.

Summer Lunch: details in the enclosed flyer. The change of venue last year proved a success so we're back there again for Members to wine, dine and socialise before the summer break.

Returning to Bellevue Location: As of September, Branch Meetings will once again be held in our long-established location of Bellevue Chapel. We were well served by Goldenacre Bowling Club as our temporary venue and we are most grateful to Goldenacre for their hospitality and help with setting up meetings there. We also thank them for their kind donation to the Branch.

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