

Our aim is to inform members about forthcoming events, foster a sense of community, encourage participation in regular activities and feature your efforts. We welcome suggestions for the Newsletter – please get in touch with Helen Harris, Helen@edinburghparkinsons.org.

Parkinson's: Let's Get Moving

The *Annual Parkinson's Lecture* has been scheduled for the 11th October to accommodate the availability of our 2016 speaker, *Professor Bastiaan Bloem* of *ParkinsonNet*, the Netherlands (see our website for *Newsletter Issue March 2014* re his ground-breaking organisation). The later scheduling has provided us with space in the calendar to



organise an event on the **benefits of exercise** for people with Parkinson's and here we include exercising the voice as well as the body. Research and anecdotal evidence increasingly shows that a variety of forms of exercise can help PwPs manage symptoms and improve their quality of life. Research is also beginning to show that exercise can help *everyone's* neuronal activity.

For many years now, the Branch has organised a *range* of exercise-based activities for its members on the basis that people's needs and preferences vary. Most Newsletter issues have covered one or more of these, as does this issue. The Branch Committee decided the time is right to organise a whole day on this topic with a strong participative element as well as informative presentations. The flyer announcing the event is enclosed with this issue. We anticipate that it will be a popular event; therefore, we encourage early booking.

Burns Supper Success



"The night drave on wi' songs and clatter; And aye the ale was growing better" aptly describes the success of this year's Burns Supper. The event has now proved so popular (tickets sold out in four days) that its stalwart organiser, Lyndsay McDermid will be looking for a 2017 venue better able to accommodate the growing number of guests. Sir Geoffrey Palmer, highly respected for his knowledge and appreciation of Burns, delivered a witty and informative *Immortal Memory*. Burns was further

honoured in music and song by the classy performances of Torcull Kennedy and Wendy Carle Taylor. Ged Holmyard in *The Toast to the Lassies* performed a "miracle" by getting everyone singing an hilarious Ivor Cutlar song, but – he was equally matched in humour and originality in *The Response* from mother and daughter, Leonora and Anna Winstanley. We feel confident that next year *"the minutes will yet again wing their way with pleasure"* on what, thanks to Lindsay, has now become a regular event for the Branch.

4th World Parkinson Congress

This is being held in Portland, Oregon, USA, 20-23rd September 2016. The Branch has established a bursary to send two Branch representatives, David Adams and Alison Williams, so that they can feed back information and news from the event.

Art Group Exhibition

The Parkinson's Edinburgh Branch **Art Group** is having a public exhibition of their work from Friday 4th March to 3rd April at **Bon Papillon**, 15 Howe Street, EH3 6TE (closed Mondays and Tuesdays). The venue is a gallery of contemporary art with a regularly changing exhibition, a studio and a café. It is run by picture framer *Stuart Allan* and artist *Ingrid Nilsson*. The Group's show contains a vast range of diverse styles for you to view and perhaps purchase while enjoying the home-made delights of the café with Stuart's scones reckoned to be some of the best in town – your editor can vouch for that!

Mistaken Identity by Eileen Blackwood

We're delighted that Eileen has allowed us to publish her touching poem, written in response to a personal experience and recited at a 2015 Branch Meeting.

"Is that Parkinson's?"
said a man on the bus.
I wanted to turn but
I'm stiff and don't like fuss.
"Yes," said a woman
who seemed to know.
I wanted to turn and
tell them "No."
"It's Eileen, with Parkinson's
that you see.
I may have Parkinson's but
I'm still me!"

Pilates Sessions

The Branch is running a 10-week pilot to assess the possibility of one (or more) weekly pilates classes for members. **Core stability** is the foundation of pilates. It aims to promote strength, stamina, balanced muscle development, flexibility and increased range of motion for the joints. As your core strength develops so does stability throughout your entire torso, which can help with some of the mobility and postural issues of PD. Additionally, reducing the effort placed on the body during everyday activities can help reduce fatigue levels. We are fortunate to have **Sasha Baggaley** leading the sessions. As well as being a pilates instructor, Sasha is a neuro-physiotherapist with a particular interest in neurological conditions. The pilot completes in May when we will assess the viability of such a class(es) for the Branch. If you believe regular pilates may be of interest or want to ask about this form of exercise, please contact Sasha on 0131 620 3780. Sasha will be running a taster session at the *Parkinson's: Let's Get Moving Event* on 7th May (and is available for 1:1 Pilates sessions in your own home).



Movement and Dance for PwP

Dance Base and *Scottish Ballet* have successfully secured funding to deliver a **Dance for PD project** in partnership with a range of organisations. The year-long programme aims to address PD-specific physical and psychological issues through dance and music. The Branch sessions, run by *Jen Farmer*, will be incorporated into the project. Sessions will be weekly on Wednesdays AND will be free beginning 13th April. They will be held in the larger lower floor studio and run 11.30am – 1pm with free tea and coffee afterwards for half-an-hour for people to socialise. For more information please contact Jen via the *Branch website* or 0758 1308 9381.

The Parkinson's UK Helpline offers a 'listening ear' to anyone with Parkinson's or their families who need to talk to someone, safe in the knowledge their call is confidential and the person listening understands Parkinson's. It is available Monday to Friday 9.00am–7.00pm and Saturday 10.00am–2.00pm, FREEPHONE 0808 800 0303 (free from UK landlines, most mobile networks), hello@parkinsons.org.uk.

Branch Exercise Class at Thistle Foundation

The Thistle Foundation, located in Niddrie Mains, was established as a charity in 1944 by Sir Francis and Lady Isabella Tudsbery to provide housing and care for disabled war veterans and their families. Since that time the organisation has undergone many developments, handing over the housing activities to others and focussing on helping people with disabilities or long term health conditions to a better quality of life. It does this through a variety of courses, classes and provision of gym facilities, all with a person-centred approach (*see later*). Twelve years ago a number of Branch members attended Thistle's 10-week Lifestyle Management Course. It was such a positive experience, in particular the benefits of exercising at the venue on a regular basis, that the Branch set up a weekly exercise class there for PwPs running throughout much of the year.



Others have joined the class since the original group (*shown here*). The session is facilitator-led and begins with warm-up exercises involving walking, stretching and twisting. (Participants can be seated when the need arises.) Then follows much laughter with ball throwing activities which participants are well able to do – research shows that when the mind is focussed even tho' people are experiencing tremors, controlled co-

ordination *can* be achieved. Next, there are specific mobility exercises perhaps with some tai chi movements. Finally, a little mindfulness is used to help focus thoughts on the here and now helping individuals to feel in charge and in control. These sessions run on Mondays from 10.30am till 12.15pm and cost £20 per 8 weeks. The benefits are not just physical, the group support and sociability have a significant positive influence. To find out more, contact Kate Mark, 0131 663 3108 or Kate@edinburghparkinsons.org.

Thistle's main facilities include the Lifestyle Management Course (LMC), an Exercise-based LMC, a Nutrition-led LMC, movement and mobility classes, tai chi, pilates, mindfulness, gentle circuits, jogging or guided walks, as well as use of their gym with skilled staff on hand to help and support. People can self-refer or be referred by healthcare specialists. What is on offer is free or at very low cost. Do look at their website (www.thistle.org), or the dedicated page on the Branch website under *Training & Care Programmes/Lifestyle Management Courses*, or contact Emma Hollands, 0131 656 7346.

Festive Concert

Held on the 4th December in Greyfriars Kirk, this yet again proved a joyous way to begin the Christmas celebrations and our Singing4Fun group performed splendidly, as always ending on a humorous note. Income from the event was just under £2,800 but expenditure was over half that; so the Scotland Fundraising team has decided to give up organising the event. The Branch is looking at the feasibility of arranging our own 2016 Festive Concert because we believe this event is welcomed by members and their families *and* is effective in raising awareness of Parkinson's. Anyone interested in supporting us in such a venture, please contact Cathie Quinn, Cathie@edinburghparkinsons.org or 0131 557 6438.

Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. It is a charity registered in England and Wales (258197) and in Scotland (SC037554), tel. 0808 800 0303, www.parkinsons.org.uk. **Parkinson's UK Edinburgh Branch**, www.edinburghparkinsons.org, Mrs. Pat Stewart, Hon. Sec., tel. 0131 449 2705, Honsec@edinburghparkinsons.org.

More Forthcoming Events

Monthly Meeting: On **Wednesday, 13th April** **Fiona Morris**, Herbalist is returning to tell us more about the therapeutic benefits of herbs relevant to people with Parkinson's.

Summer Lunch & Ceilidh: see flyers enclosed with this issue.

Coffee Morning: Saturday 9th April, Marchmont St.Giles, Kilgraston Rd, EH9 2DW.

Home baking, books, bottle tombola, art corner and Young Parkinson's craft tables. Entry £2, payable at the door, includes tea/coffee and scone (or two).

Scottish Parliament (report from Member, Alison Williams)

As part of the P-UK "Get it on Time" campaign (to ensure PwPs in hospitals and care homes get their medication on time, every time), ten of our Branch Members attended an evening reception at the Scottish Parliament on 10th February to meet NHS professionals and MSPs and share experiences on this topic. Dennis Robertson MSP sponsored and hosted the evening. Parkinson's UK Hon. Life Member, Jean Ballantyne (for many years the distinguished Hon. Sec., Fife Branch) related the detailed and moving narrative of her husband Mel's experiences of hospital inpatient stays, ranging from first-rate on-time PD medication to "sanity-threatening psychosis" induced by lack of understanding and inability to depart from hospital logistics. Responding, the Scottish Minister for Sport, Health Improvement and Mental Health, Jamie Hepburn, emphasised the Scottish Government's active support of a pilot project in Raigmore Hospital and the South & Mid Highland region.

Katherine Crawford, Scotland Director Parkinson's UK, spoke eloquently about what P-UK and Branches were doing to raise awareness, lobby for changes and make training available. Over a hundred people from all over Scotland, PwPs and care partners, P-UK staff, health professionals and three other MSPs held great conversations, networked, commented, questioned, and learned. The noise levels were awesome!

Joy Milne at the AGM



Joy Milne from Perth gave a ground-breaking and highly motivational talk about "The Gaping Chasm in the Earlier Diagnosis of Parkinson's from the Carer's Perspective." Joy can detect Parkinson's through her acute sense of smell. She became aware of a change in Les, her husband's, scent 6 years before he was diagnosed with PD but didn't make the connection till some years later. Les died in June 2015. Her revelation at a Parkinson's UK meeting involving Tilo Kunath, P-UK's Senior Research Fellow at the Centre for Regenerative Medicine, Univ. of Edinburgh led to a small research project involving the Branch and its members. That has led to a much bigger project countrywide to find out why the scent changes and how the findings can be harnessed to develop a simple diagnostic test. In the meantime Joy and others, based on their experience as partners/carers, have been identifying a wide range of very early signs of PD that should be mapped and researched. See the Branch website for her presentation slides. We hope to follow up with an ERIG meeting.

PWPLA: Self-Carers' Group

The *People With Parkinson's Living Alone* group was established almost a year ago for people in this situation to meet in a mutually supportive environment. The *Quality of Life* group was established around the same time and this group now seems to be fulfilling most of the needs of those who attended the PWPLA meetings; so until a greater need is recognised there will be no further PWPLA meetings. Our thanks to Bill Wright for his time, effort and provision of a meeting place for the group during the last year.