

A New Year and New Activities

The Branch Committee sends its very best New Year wishes to Members and Friends. We begin 2019 with a number of pilot ventures to add further diversity and choice in helping those with Parkinson's and their care-partners to a better quality of life.



Tandem Cycling: Sessions for PwPs are now up and running (should that be revolving?). The tandem is stored at Cockenzie House in East Lothian, EH32 0HY so participants need to make their way there (26 Lothian bus going to Seton Sands will take you). Brian Moore who is appropriately qualified to pilot the tandem has already had a number of successful outings. After an inaugural session one participant reported "I slept the best I have done in ages" and "I don't feel any aches and pains." Cockenzie Links have proved a safe traffic-free practice area for those who want to get used to tandem riding before venturing on to public roads. Sessions are free and arranged at a time to suit Brian and participants. We are grateful to Walker Group (Scotland) Ltd for funding the tandem and to Edinburgh Bicycle Cooperative for funding support equipment. To find out more, please contact Brian at brian@edinburghparkinsons.org.

Chess: We have begun a pilot of free monthly chess sessions at the Maitland Bowling Club, 96 Main Street, EH4 5AB. After an early February session, the next ones are Wednesdays, 6th March and 10th April, 2-4pm. As the venue is not available during the bowling season, sessions will begin again on 9 October if there is enough interest, but we hope that attendees will also arrange their own chess get-togethers between the Maitland Bowling Club dates. If interested, please contact Kenneth Williamson on 0131 336 4088 or via trainbuff1@virginmedia.com.

Neurodynamic Exercise: Our Pilates instructor, Sasha Baggaley has been running a formal 10-week trial with six pre-assessed participants. The format, exercises and approach are being developed by Sasha based on her training and experience in Neurophysiology, Pilates and the PD Warrior Programme. Sessions are highly energetic and demanding of concentration with cognitive as well as physical challenges *and* participants have to work at home. But, based on published research, Sasha is hoping for significant positive outcomes for participants' quality of life. Depending on results, we would aim to establish the programme for those who pass a pre-assessment with regard to coping with the high intensity challenges and commitment needed.

Adaptive Yoga by Jean Itier: These classes are being piloted at the Steading, 118-120 Biggar Road, EH10 7DU, the regular meeting place of the Edinburgh Young Parkinson's Support Group but the sessions are open to the Branch as a whole. They begin on 18th March, will run fortnightly, 6-7pm and are free during the trial period. Jean is an experienced Yoga teacher with specialised training in Yoga Therapy, has taught in care homes and run classes to cater for a range of injuries and disabilities. Attendee numbers will be limited to allow focus on individual needs. To find out more, contact Jean via 07985 528839 or jean@yogatherapyedinburgh.com.

Wu-style Tai Chi: These classes for PwPs and care-partners are being trialled in the Seminar Room at the Scottish Centre for Regenerative Medicine, 5 Little France Drive, EH16 4UU, Wednesdays, 5.30-7.30pm (classes start at 6pm) and are free during the pilot period. Wu Style Tai Chi concentrates on the slow repetition of clearly defined movements which build in time into a sequence that can enhance both physical and mental states. The class is a mixture of individual work and work in pairs. Sessions are free during the trial period but must be booked via Eventbrite because of access to free parking and security issues. To find out more, contact Philippa Hope, who leads the sessions, via 07720 674924 or phobinder@aol.com.

The Dukes of Uke on the Road for Parkinson's



Saturday, 16th March at 7pm in The Steading, Biggar Road, Edinburgh, EH10 7DU. With this special show Scotland's Biggar-based nine-piece ukulele band will be performing songs from their extensive "On the Road" songbook to raise funds for Parkinson's UK and the Edinburgh Young Parkinson's Support Group. The band says these are songs you love and know, so do come and sing-along, dance-along, or just sit back and enjoy. Tickets, £12.50 which includes a cold buffet supper at the interval, can be bought via www.thedukesofuke.org.uk, from *The Steading* or from *Scott Wilson*, 07835 820898, scottwils01@btinternet.com.

P-UK Self-Management Programme on Hold

This news came as a shock to the Branch Committee as experience of the programme by our volunteers and participants has been positive and well valued. Hon. Chair, David Adams, says "Self-management, and everything it implies for optimising personal health and wellbeing with Parkinson's, lies at the core of all we stand for as a Branch, and we do not wish to forego any opportunity to continue to offer this well organised, well proven and effective programme to people with Parkinson's Edinburgh Branch feels strongly that it has the volunteers and potential to continue it for the great benefit of people with Parkinson's and their care-partners." The Committee will be looking for a positive way forward in the coming months.

Poster Abstracts Accepted for World Parkinson Congress

June in Kyoto is creeping nearer and once the programme of speakers is published our Branch representatives attending the congress will be meeting to discuss priorities with regard to booking into presentations. In the meantime, we are delighted to announce that three abstracts have been accepted from Branch Members outlining the topic they would like to display as a poster at the Congress. Posters show what the presenter is doing and allow viewers to discuss the work displayed, offering a chance for exchange of ideas and possible collaborations. Member, Alison Williams successfully presented a poster about our Quality of Life Group at the last Congress (co-written with Bill Wright and designed by Lindsay McDerimid). Abstracts go forward to a panel for approval for poster development. The accepted abstracts are:

- *"Where's the 'feeling better' box?" Beyond PDQ39* by Alison Williams [PDQ39 is a questionnaire assessing how often people affected by Parkinson's experience difficulties across 8 dimensions of daily living.]
- *Creating a virtuous cycle of PwP support* by Bill Wright, Judith Shepherd, Alison Williams.
- *Parkinson's smell levels, symptom management and empowerment: When Joy met Alison* by Joy Milne, Alison Williams.

Blister Packs Inspire Andrew's Creativity



Member, Andrew Guest, had a 10-day exhibition of his ceramics in the window of his local pharmacy, Smith's in North Berwick. The exhibition was featured in the East Lothian Courier. Over a 3-year period Andrew kept a sample of the used blister packs for every type/brand/strength of pill he took, eventually making ceramic pots from each of these. The pots are made by creating plaster moulds of the packs, making clay casts from the moulds then the pots are assembled, fired and glazed. Andrew's 34 pots are based on packs from everyday painkillers, herbal extracts, antibiotics and the first drugs he was given after being diagnosed with PD. Andrew says "As well as witness to the simple properties of plaster and clay, the work is a tribute to the advanced technology of drug manufacture and delivery that the blister pack represents and the ordinary beauty of the empty pack. It is also a picture of one person's dependency on this method of treatment."

One viewer said of the display "Elegantly arranged in the chemist's window they become a record of what we need to stay well, to get better, or to cope with pain. The repetition of the familiar shapes is a visual re-statement of the daily demands of illness that unite patient, medical staff, pharmacists, all working together towards good health." We love the originality and creativity related to this story. Might others be inspired? If you want to find out more about Andrew's pots, please contact him at andrew.guest2@btinternet.com.

Highly Critical Report from P-UK in Scotland about Services

P-UK in Scotland has published a report highlighting the struggle by health and social care services to meet the needs of Scotland's growing Parkinson's population. Publication of the report was announced in a press release in the first week of February so you may already have seen articles relating to this in the press. "The report, backed by leading clinicians, makes 13 recommendations that need urgent action if Scotland is to meet the health and social care needs of the growing Parkinson's population. . . . The report highlights unacceptably long waiting times for diagnosis and the nationwide shortfall in Parkinson's nurses as major concerns. It also recommends the establishment of multi-disciplinary Parkinson's teams to provide a more holistic, comprehensive and person-centred approach to Parkinson's care" – the Edinburgh Branch has been encouraging this for a number of years.



The newly appointed P-UK Trustee for Scotland, **David Allan**, says "Parkinson's isn't going away any time soon, not for me and the community and not for the NHS either. With numbers significantly increasing in the coming years it's vital that Scottish Government, NHS Boards and Health and Social Care Partnerships face up to the challenges that Parkinson's presents and ensure that specialist recruitment is increased and services re-shaped to make them fit for purpose." The Committee welcomes David's appointment as Trustee for Scotland.

This is the link to the press release, with a download of the full report available at the end of the release: www.parkinsons.org.uk/news/parkinsons-services-scotland. How timely it is that we have Annie Macleod, Director Parkinson's UK in Scotland speaking at the next Branch Meeting – see next page.

Forthcoming Branch Meetings, 2-4pm, Bellevue Chapel, EH7 4EL

13th March: AGM followed by Annie Macleod, Director Parkinson's UK in Scotland.

10th April: Education of Occupational Therapy, Physiotherapy and Social Work Students – creating a workforce that is fit for the future. Dr. Jane Hislop from the School of Health and Social Care at Edinburgh Napier University will be talking about the new multidisciplinary programmes being developed at the university. Some readers may remember Jane as a staunch supporter of the Branch while at Queen Margaret University, before leaving for the States for a couple of years. We are pleased to see Jane back in Edinburgh. Sasha Baggaley will also be giving us some feedback re the Neurodynamic Exercise trial – see page 1.

Other News

Parkinson's Café Dates: The café continues to thrive, introducing new people to the Branch and cementing relationships between existing members. Dates for the rest of the year are 26 March, 30 April, 28 May, 24 September, 29 October, 26 November. If you can place A5 flyers anywhere to draw attention to the Branch and encourage people to find out more, please get in touch with your Newsletter Editor or pick up some flyers at a Café or Branch Meeting. Similarly, if you can place our A5 "What We Do" flyer somewhere useful, do ask for copies.

Patient and Public Involvement: Members, Alison Williams, Ken Bowler and Bill Wright share their experience of PPI and what it means to them in a PPI Newsletter (published 2018). "Being involved keeps us mentally, emotionally, physically and spiritually healthy, and significantly enhances our quality of life regardless of our physical state We build new proactive relationships with our health professionals and share our lived experience of Parkinson's. We participate in training sessions and videos for doctors, medical students and care assistants, and much more." Read the full blog and perhaps be encouraged to participate in PPI – go to <https://medium.com> and search for *Adventures with Parkinson's*.

WPC Winning Song: We now have a video of the Singing4Fun group performing our song. Go to the Regular Activities – S4Fun page on the Branch website – it's not just the singers facing the camera – graphics and subtitles reflect the sentiments and help you remember the words.

Glowing Feedback from 2018 Side by Side Course Participants

"I would recommend Side by Side with Parkinson's course, very informative, A good range of topics and speakers, with a relaxed and friendly atmosphere."

"I would recommend this course, a carer's course, very early on one's journey, to meet the valuable advisers, therapists and pamperers (head massage, reflexology etc). All knowledge and information was available guided by Cathie with her extensive knowledge and insight."

"I have been helped enormously by this course both mentally and physically. Now, I am able to contact various people i.e. professionals we had the chance to meet. The atmosphere has reduced the stress I was feeling as a carer. Sometimes carers can feel inadequate to help their partner – where do I go next?"

"The final session was fantastic – introductions to ways we can 'pamper' ourselves and maybe follow up with our Parkinson's partner."

To find out more contact Cathie Quinn, cathie@edinburghparkinsons.org.

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