

*We aim to inform, foster a sense of community, encourage participation in events and feature your efforts. We welcome suggestions – contact Helen@edinburghparkinsons.org.*

## **Branch AGM**

**Election Results:** Hon Chair – David Adams, Hon Vice-Chair – Patrick Mark, Hon Treasurer – Kenneth Williamson, Hon Secretary – Liz Hume, Hon Assistant Treasurer – Frances Panton, Hon Auditor – Hazel Cavens, Committee Members – Cathie Quinn, Heather Robertson, Eileen Blackwood, Annette McLeod, Louise Ogilvy, Bill Wright, Judith Shepherd. We welcome Judith as a new Committee Member and thank Julia Melton for taking on responsibility for handling the Branch and Parkinson's UK literature earlier in the year. David Adams spoke of the work being done to define a Branch Strategy to help guide us forward with focus and intention under the broad headings of *Supporting Research, Personal Well-being and Interactive Community*.

**Ken Bowler** reported on **Edinburgh Research Interest Group (ERIG)** activities, highlighting involvement with the *Parkinson's: Let's Get Moving* event last May, the *Review of the World Parkinson Congress* and the *Annual Lecture* given by Professor Bastiaan Bloem (see also the STOP PRESS item below). Ken encouraged members interested in research to join the Group and stay informed about the latest developments. Joining the wider Parkinson's UK *Research Support Network* provides the opportunity to become **actively** involved in research. Members can also consider the possibility of becoming a lay grant reviewer for P-UK, as Ken is.

**Lindsay McDermid** spoke about some of the exciting creative activities the Art Group get up to and how therapeutic the Group members find the weekly Thursday sessions at the Botanic Garden Cottage, 1.30–3.30pm. Lindsay then entertained us with his expertly crafted video encouraging others to join the Group – no previous art experience necessary.

**John McPhee** gave an inspiring talk about his approach to being diagnosed with Parkinson's and his subsequent *Long Straight Walk* from Land's End to John O'Groats and the adventures that have followed. If you missed the AGM you can watch an equivalent version of the talk on the YouTube TEDxBruntsfield video *Walk Smarter – Living with Parkinson's*. You might also like to hear John talk about his use of the Beats App (to help his walking) on the YouTube video *How John MacPhee Challenged Parkinson's – Beats Medical*.

**See also later entry re *Cycling Pilot*.**

## **STOP PRESS – Edinburgh Parkinson's Lecture 2017**



The speaker for the lecture will be **Professor Andrew Lees** (UCL), internationally recognised for his work on PD. His topic is **The Quest to Find a Cure for Parkinson's Disease Mentored by a Madman: The William Burroughs Experiment**. Burroughs (1914-1997) was a writer and spoken word performer who drew on his experiences as a heroin addict and traveller, experimenting along the way with mind-altering substances. Professor Lees, in his recently published memoir, talks of his search for new molecules to relieve PD and his own self-experimentation. In this year of the 200<sup>th</sup> anniversary of James Parkinson's "An Essay on the Shaking Palsy" we are looking forward to an informative, thought-provoking and entertaining lecture. It will be held on 20<sup>th</sup> September (evening) at our old venue, the Royal College of Physicians. Please put the date in your diary – details will follow.

## Honorary Branch Secretary Retires



**Pat Stewart's** father had Parkinson's and was a founding member of the Edinburgh Branch. Pat became a Committee Member in 1980 eventually taking on the role of Hon Sec in 1999. Since that time there have been three Hon Chairs, Ron Partington, Patrick Mark and currently David Adams. It was Ron who made the retirement present-

ation to Pat at the recent Branch Meeting but all three Chairs acknowledge Pat's dedication, hard work, and countless hours contributed to the Branch and its Members, and all done in a voluntary capacity. Pat's professional skills, judgment, efficiency and sensitivity have helped create a highly effective administration for us and with an ever increasing membership (currently 330) it has been a demanding role. Added to this are the many hours Pat has spent chatting to Members and, at times, providing an empathetic ear to those in crisis and stressful situations. We owe Pat a great deal for her outstanding contribution but now look forward to seeing her at future gatherings where she can enjoy these purely for social and personal interest reasons.

## Liz Hume Honorary Secretary Appointment

After a responsible career in IT and latterly as Marketing and Projects Director and Company Secretary for a long-established firm of Edinburgh jewellers, Liz has been looking for something valuable and interesting to do. Some of you will know her from the Quality of Life (QL) group. We are pleased and grateful that Liz has agreed to take on the role of Branch Hon Secretary. We welcome her on board and look forward to getting to know her better as well as the opportunity to appreciate the talents we believe she will bring to the role.



## Learning About Falls Workshop

The event was held in Bellevue Chapel on the 10<sup>th</sup> March. Topics covered the Falls Services in Edinburgh/Lothians, advice from a physio-therapist and an occupational therapist about practical things we can do to help prevent falls, instructions about how to get up from a fall or how to help someone unable to get up, and available community alarm services. The day also covered Edinburgh Leisure's *Ageing Well* and *Steady Steps* exercise activities aimed at helping to maintain fitness and prevent falls. Participants joined in two sessions on the day.



Feedback from participants was predominantly very positive. What was apparent from the presentations is that there is a wealth of information and support available in Edinburgh and the Lothians to help with falls prevention – see [www.nhsinform.scot/healthy-living/preventing-falls](http://www.nhsinform.scot/healthy-living/preventing-falls). If you missed the workshop we recommend accessing the *Learning About Falls* page on the Branch website (via the News button). There are PowerPoint slides, pdf alternatives and short demonstration videos (taken by Ken Bowler) covering many of the salient points presented by the speakers – **all highly informative and helpful**.

## Cycling Pilot Programme



Branch Member, Lindsay McDermid enthused about the benefits of cycling at the *Parkinson's: Let's Get Moving* event last May. We took notice and invited recently retired Physiotherapist, **Julie Hooper** to the AGM to give a short presentation about the benefits of cycling, including for people with Parkinson's. Julie is a trained volunteer for the Edinburgh ABC (All-ability Bike Centre), EH6 4RJ. The Branch has launched a 12-week pilot cycling programme for 6 PwPs, beginning Tuesday 18th April, 11am to 12noon.

Care-partners are welcome to attend. ABC has a large safe cycling area, access to the well-paved cycle paths network and an impressive array of adaptive cycles that accommodate a wide range of physical abilities. These will be available for participants to use. Julie will be the facilitator, with other volunteers available to help. The Pilot is free but we ask that participants complete a short evaluation form at the end of the 12 weeks. To find out more or to book, please contact David Glover at ABC, [david.glover@cyclinuk.org](mailto:david.glover@cyclinuk.org) and copy Julie, [jehooper@hotmail.co.uk](mailto:jehooper@hotmail.co.uk). David can also be contacted on 07500 069357.

## Other News & Events

**Coffee Morning:** Saturday 8th April, 10.00.am to 12.00 noon, Marchmont St Giles, Kilgraston Road, baking, crafts, books and bottle tombola stalls, £2.00 entry (includes tea/coffee, scone) and can be paid at the door. If you have donations of books, DVDs, CDs or bottles (concealed in paper wrapping), please bring these on the day.

**Annual Ceilidh:** Friday 26th May, 7pm to 10.30pm, see enclosed flyer.

**Summer Lunch:** Wednesday 28<sup>th</sup> June. Details to be announced.

**Bowling:** Due to the popularity of the sessions we now have 3 rinks (instead of 2) on Mondays, 12noon-2 pm at Meadowmill Indoor Bowling, EH33 1LZ. Join the regulars for a good game as well as a snack lunch and chat in the café at half-time. For more information, please contact *Marjorie Barker*, 0131 449 3450 or *Kenneth Williamson*, 0131 336 4088.

**Dance for Parkinson's:** We are delighted to welcome Jen Farmer back from her maternity leave and express a big thank-you to Rhiana Laws for stepping in so ably during that time.

**Nordic Walking Pilot:** the 10-week taster programme is underway with instructor Trevor Jones at the Meadows, Edinburgh on Thursdays, 12noon till 1pm. These sessions are fully booked but you can register interest in future sessions – contact Bill Wright, [Bill@edinburghparkinsons.org](mailto:Bill@edinburghparkinsons.org). More details are on the Branch website under *Regular Activities*.

**Pilates:** we now have a *second session* running at Christchurch, Morningside – sessions are Mondays, 2.45 to 3.45pm AND 4.00 to 5.00pm. Both are bookable via [eventbrite.co.uk](http://eventbrite.co.uk) or Sasha Baggaley on 0131 620 3780. (The established Friday session, 2 to 3pm is at Pollock Pavilion.)

## P-UK Scotland Office Events

**Edinburgh Marathon Festival** – a variety of race options, 27<sup>th</sup> and 28<sup>th</sup> May with P-UK support of participants through their training and fund-raising. **Forth Rail Bridge Abseil** – the chance to abseil 165ft off the bridge with safe and expert guidance throughout. See [www.parkinsons.org](http://www.parkinsons.org).

**Annual Scotland Younger Person's Residential:** Stirling Court Hotel, 2–3 June 2017. The 2-day residential is free to attend and open to all who are 65 and under and affected by PD. It's an opportunity to take part in a variety of workshops and to network with peers and staff at P-UK. A full programme and booking forms will be available towards the end of March. If you are not already on the Office's distribution list, please contact Nicole, [nogundele@parkinsons.org.uk](mailto:nogundele@parkinsons.org.uk).

## Parkinson's UK Self-Management Programme



Parkinson's UK has launched a self-management programme to run throughout the UK. Trained volunteer facilitators lead each group of 12 PwPs and care-partners wanting to attend. Branch Committee Members, *Liz Hume* and *Bill Wright* are facilitators. The next Edinburgh programme begins in May but is already full. There will be another in the autumn. Find out more at the Parkinson's UK website. Although there are a good number who have already registered interest, if you would like to add your name to the list we encourage you to do so via the P-UK website.

While on the subject of self-management, we remind you that the Branch *Quality of Life (QL)* Group has a number of **self-help documents** available on the Branch website – see under the *Regular Activities* menu for the Group's page.

## Singing4Fun with Parkinson's



We are pleased to announce that we have appointed two new song leaders. *Ellie Logan* will lead the Wednesday evening sessions at Bellevue Chapel, 7-9pm and *Penny Stone* will lead the Tuesday afternoon sessions at Marchmont St.Giles, 2-4pm. We are excited at the prospect of what Ellie (left) and Penny (right) will bring to the sessions with their extensive and varied experience and look



forward to the joyous vocal times to come. If you would like to know more about these sessions, please contact Cathie Quinn, [cathie@edinburghparkinsons.org](mailto:cathie@edinburghparkinsons.org) or on 0131 557 6438.

## The Parkinson's Poems



Editor and poet, *Frank Ormsby* was brought up and educated in Northern Ireland and taught at the Royal Belfast Academical Institution from 1976 till his retirement in 2010. In 2009 he landed in hospital with heart failure and was also diagnosed with diabetes. Two years later Parkinson's was added to the list of ailments accompanying him into retirement. His time in hospital in 2009 and his diabetes didn't prompt poems but his experience with PD did. The result is this tastefully presented pamphlet of 14 poems, published in 2016 (£6 from *Mariscat Press*). Ormsby states "I wanted the poems printed here to embody a sense of the absurd, a refusal to mourn, and the impulse to good-humoured defiance that has characterised my experience of the early stages." At a reading in Edinburgh a teaching nurse from Queen Margaret University asked if she might use the poems for a class about neurological diseases. What resulted were 16 Haiku composed by the nurses and responding to the main points in Ormsby's poems. Food for thought – should this pamphlet and other artistic expressions by people with Parkinson's be considered more widely as informative aids for those learning to support PwPs?

And finally, **Parkinson's Awareness Week** is 10-16th April 2017.

**Parkinson's UK** is the operating name of Parkinson's Disease Society of the United Kingdom, a charity registered in England and Wales (258197) and in Scotland (SC037554), [www.parkinsons.org.uk](http://www.parkinsons.org.uk). The **Helpline**, Monday to Friday 9.00am–7.00pm, Saturday 10.00am–2.00pm, FREEPHONE 0808 800 0303, [hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk).