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

PARKINSON'S UK EDINBURGH BRANCH NEWSLETTER OCTOBER 2015

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. If there are new activities you would like the Branch to consider, please also let us know and if you are able to contribute time and effort to help get any ideas off the ground, so much the better.

Get Involved to Target Better Services

As part of the *Parkinson's UK Strategy for 2015-2019*, P-UK has launched a major survey *Parkinsons 2015 – Your Life, Your Services* to determine whether people affected by PD are getting the right health and support services. The intention is to identify where improvements are needed so that these areas can be targetted. **The Branch is keen for the survey to produce a realistic picture of what is needed in Lothian**. With this in mind, we enclose a printed copy with this mailing to encourage members to participate (with help if needed). Completing the survey will take 10–30 mins. You can also access it online at *parkinsons.org.uk/yourlifeyourservicessurvey*. Responses are required by **20**th **November 2015**. The aforementioned strategy document is available via the P-UK website as a download and as a printed version.

Get it On Time Campaign - Anecdotes Urgently Needed



In 2006 Parkinson's UK launched the *Get it on Time* campaign to ensure while in hospital, patients with PD are given their appropriate medications on time – every time. The P-UK Scotland Office has been and continues to be particularly active in this campaign as there are still significant short-comings in the administration of medications, both at the time of admission

and throughout inpatient stay. The focus is currently on getting local hospital trusts/health boards to put a **policy of self-administration of medication** in place for people with Parkinson's admitted to hospital.

Tanith Muller, Campaigns Manager, Parkinson's Scotland and long-standing Parkinson's campaigner, *Jean Ballantyne*, recently met the Scottish Government Health Minister, *Jamie Hepburn*, to explain the imperative need for people with Parkinson's to get their medication on time, every time, while in hospital. The Minister has asked for anecdotal evidence about the issue – the more reports we have, the stronger the case that can be made for the NHS, in our case NHS Lothian, to make the necessary changes. As Tanith will shortly be reporting back to Jamie Hepburn, Branch members who can share their experience in this matter are asked **to contact her ASAP** at *tmuller@parkinsons.org.uk* or *0344 225 3726*. More information about the overall campaign and progress in Scotland so far is available at *parkinsons.org.uk* and search for *self administer scotland*.

Branch Fund-raising and Donations

Recent **in memorium** and similar generous donations totalled over £14,000. In addition, the Murrayfield View Residents' Association made a donation of £1200 to the Branch and the Newbattle Golf Club a donation of £320. Our thanks to all those involved.

Forthcoming Events

Monthly Meeting: 11th November, 2-4pm, Bellevue Chapel, EH7 4EL – George Laing, a leading Festival Guide will tell us about History and Tales of The Edinburgh Grassmarket.

Quiz Afternoon: *Saturday, 14th November, 2-5pm*, Marchmont St. Giles church hall. Tickets are £8 which includes refreshments. There will also be a raffle. Quiz Nights prove light-hearted yet competitive affairs enjoyed by all who participate. This year we wanted to make it accessible to those more hesitant about venturing out of a winter's evening. To book, please email Louise Ogilvy at *lo4parkinsonsfundraising@gmail.com* or purchase tickets from a Committee Member at Singing4Fun.

Festive Concert: *Friday, 4th December, 7pm*, Greyfriars Kirk, EH1 2QQ. Organised by P-UK Scotland Office to raise funds for research in Scotland. Tickets £10 (accompanied under 12's free) – use the link on the Branch website *News* page or 'phone *Leah Cranney, 0344 225 3724*. Our Singing4Fun group will be adding their dulcet tones to the event.

Christmas Lunch: *Wednesday 9th December, 12.30 for 1pm*, Boroughmuir Rugby Club, EH14 1AS. See enclosed flyer for details and to book for this sociable festive event. Note, P-UK **Christmas cards** are now available to buy at Bowling Group and Singing4Fun sessions and at the 11th November Monthly Meeting.

Quality of Life and **People with Parkinson's Living Alone** Groups: If you were not already aware of these, do look at the Branch website. Scheduled dates: **QoL** (*Alison Williams, 0131 557 5979*) 19th November, 10th December 2015, 7th January, 4th February, 3rd March 2016 and **PWPLA** (*Bill Wright, 0131 281 6880*) – 5th November, 3rd December.

A Reminder about the Research Interest Group



We take this opportunity to remind members about the Branch RIG chaired by Prof. Ken Bowler. Not every talk, visit or activity may be of interest or at a level that suits but there may be some that are; so, if not already a member, we encourage you to look at the RIG page on the Branch website to see whether you would like to be added to that particular mailing list, or you may just like to keep an eye on the RIG pages. An objective of the Group is to **encourage** and develop ALL members' interest in research. The next meeting is on

Saturday 7th November 2015, 10.30am-12.30pm at the Scottish Centre for Regenerative Medicine on *Dopaminergic Neurons*. RIG members were recently emailed about a free online course from Future Learn entitled *Good Brain, Bad Brain, Parkinson's*. There are two further *Good Brain, Bad Brain* courses plus many more free online courses on a wide variety of subjects from reputable teaching organisations. See **www.futurelearn.com** – there might be some you fancy to keep those brain cells humming.

Change of Title for Betty Thomson

Formerly referred to as Information Support Worker (ISW), Betty Thomson's title is now **Parkinson's Local Adviser**. Betty's responsibilities are the same but the new title more accurately reflects the support role through the provision of confidential advice and information to people with Parkinson's and their carers.

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.

Bowling Activity

The Indoor Bowling Centre at Meadowmills, Tranent is used every Monday by our Indoor Bowling Group. Although this is a relatively new venue for the Group, members and their partners or carers have been meeting to play indoor bowls since 2000. Every year, Edinburgh faces the Fife Group in a challenge match, this time hosted by the Branch. After two consecutive years of defeat we're pleased to report that our



Group redeemed itself on Bank Holiday Monday winning 4 rinks to 2. A big thank-you to Jackie Calderhead and her team of organisers for the smooth running of the event.

Were you aware bowling is an ancient sport dating back possibly as far as 5,000 BCE? The oldest established club is in Southampton but it was Scottish bowlers who kept the sport alive when the English monarch, Edward III prohibited the game for common people in the 14th century because archery, essential to national defence, was being neglected. Scottish bowlers developed the present lawn game, establishing a set of rules by the late 19th century. Carpet bowls were introduced around the same time allowing people to set up a "rink" indoors by laying down a length of material. With modern materials technology and laser floor levelling techniques it became possible to design the equivalent of a full size green lawn indoors liked the one used at Meadowmills in the above photo.



At first glance, bowling seems a relatively low-key physical sport but the constant movement helps burn excess fat and the legs are being exercised as you walk back and forth between ends. As you roll the ball, the repeated flexing, bending, twisting and stretching tones the shoulders, arms, chest and leg muscles, whilst gripping the ball helps strengthen the hands. Your sense of balance and hand-eye co-ordination are also given a workout.

Yet all this can be achieved in a very gentle fashion, which is why **it is such a good activity for people with motor skill challenges as with Parkinson's**. Added to the benefits is the social aspect of these meetings; so if you're looking for an activity to help further improve your quality of life, we encourage you to give indoor bowling a try whether you've previously bowled or would be a total newcomer to the activity. The Group books 3 rinks (enough for 24 players) every Monday 12-2pm (charge is £3 per head). Contact *Kenneth Williamson* on 0131 336 4088 or *Marjorie Barker* on 0131 449 3450. If you are keen but getting there is an issue, please get in touch with the Hon. Branch Secretary, *Pat Stewart* on 0131 449 2705.

Movement & Dance Video

Branch Member, *Lindsay McDermid*, has compiled a tasteful short video demonstrating the types of movement involved in Dance for PwP and compiled from a number of PwP dance groups. We hope to add our own video to the compilation soon. You can access it via the Movement & Dance Group page on the Branch website.

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.

Successful Boat Trip

Thanks to the generosity of the *Seagull Trust Charity*, over 30 members of the Singing4Fun group experienced a joyous **canal boat trip** in September. They met for lunch first at the Bridge Inn at Ratho before boarding the three boats. The sun shone, familiar songs were sung and a family of swans glided by in appreciation.



Committee Member Liz McBain & Husband Bill



In the September 2013 issue we wrote about the outstanding contribution that Committee Member, Liz McBain had made to the development and success of the Branch (that Newsletter can be accessed on the Branch website). We also mentioned the sterling support of Liz's husband, Bill who has recently been diagnosed with PD; so after 16 dedicated years on the Committee while coping with

her own diagnosis of Parkinson's, Liz has decided to step down. She will be sorely missed by Committee Members but we appreciate that resigning will allow Liz to still remain involved with a number of the regular activities which she originally inspired. Bill remains active in the Branch but has also relinquished some of his responsibilities which have been much appreciated over the years, with special note of his involvement with the Bowling Group featured in this issue. This charming photo was taken at the recent canal boat trip.

Artlink Edinburgh & the Lothians



Artlink is an arts and disability organisation established in 1984 to increase opportunities for those who experience disadvantage or disability in the East of Scotland to take part in the arts. The *Arts Access* service is available for those who have difficulty getting out and about to arts events and venues. For each outing booked it offers a door-to-door service providing a volunteer driver and a companion. It may be to the theatre, gallery, museum, cinema,

historic building or sculpture park. There is an annual membership fee of £20 and an administrative fee of £3 per outing. You pay for your ticket but Artlink get the best available concessionary rate and pay for the ticket and travel expenses of the volunteer. There may be a waiting list to become a member but it could be well worth the wait for those who feel restricted by their PD in maintaining an interest in the Arts. Also worthy of consideration is Artlink's *Participants* programme which provides the opportunity to become involved in an Artlink project. To find out more, go to *artlinkedinburgh.co.uk*.

Respite Home in a Beautiful Setting



Our attention has recently been drawn to Leuchie House, an independent charity respite care home. The 18th century mansion set in the East Lothian countryside near North Berwick was designed by Sir Hew Dalrymple. You might want to make a mental note of the facility, perhaps for some future need. In the meantime you could visit their **Christmas Fair** on **Saturday 28th November**, **11am-4pm** to appreciate the facilities and the rural setting (£5 includes mulled wine and mince pie). More at www.leuchiehouse.org.uk.