PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. Parkinson's UK Edinburgh Branch Newsletter August 2014

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 – please get in touch with Helen Harris, Helen @edinburghparkinsons.org. We also remind you of the **wealth of information on the Parkinson's UK and Branch websites.**

Branch Summer Lunch

FIND A CURE. JOIN US.

On 25th June, this last major event in the Branch Calendar once again proved highly successful in bringing members and their partners together socially, before the onset of summer trips and holiday commitments. Just over 60 people came to the Ellersley House Hotel where the weather proved perfect for pre-prandials in the garden, the menu worked well and staff were duly attentive. Thank-you Branch Secretary, Pat Stewart, for your hard work in organising the event.

Glasgow 2014 Queen's Baton Relay



On June 14th over 100 Baton Bearers took the Baton to communities throughout Edinburgh. The event included the Scottish Parliament where our *Singing4Fun* group led by Wendy Carle Taylor, together with singers from Wendy's *Scots Music Group* and members of *Còisir Dhùn Èideann* (Edinburgh Gaelic Choir) had the honour of performing the specially commissioned song

"Here's to All Our Common Wealth." The singers did themselves proud, first in the Garden Lobby before the Presiding Officer, Rt. Hon. Tricia Marwick MSP, and Baton Bearer, Lynne McNicoll, and then outside the building as the torch exited en route for Holyrood Palace. This was a superb opportunity to help raise awareness of Parkinson's, the Branch and people's ability to cope while remaining involved in community activities. Afterwards, Scottish rugby legend, Gavin Hastings joined the singers for an impromptu chorus of songs in English and Gaelic! Thanks to all who participated and to *Estelle Morali-Silver* for photographing the performance. We will be posting captured moments on the website soon. For now, here's a link to a video clip: *www.youtube.com/watch?v=Tzp2qSrWrXk*.

Recycling

May we remind you about Parkinson's UK recycling facilities. Almost £35,000 has been raised from recycling of donated items. These include mobile phones, toner/inkjet cartridges (except Epson, Epson-compatible or damaged cartridges), MP3 players, iPods, CD's, DVD's, satnavs, digital cameras and hand-held games consoles. Send items in an envelope to Recycling Appeal, Freepost NAT 22768, Parkinson's UK,



Falkirk FK2 9EG or ask Branch Secretary, Pat Stewart (contact details foot of page 2) for a bundle of pre-printed envelopes which you can also pass on to family and friends. To recycle larger items, email *info@recyclingforgoodcauses.org* or call *0800* 633 5323. To recycle your old car, consult *giveacar.co.uk/charities/parkinsons-uk*.

The Importance of Exercise



One of the aims of the Branch is to provide a range of activities for members that will contribute to improving their quality of life. Group exercise features strongly because exercise is increasingly being recognised as a way of helping to alleviate and delay PD symptoms while working in a group adds a social element. But our classes don't suit everyone. There are other ways of taking exercise to help with the condition whether facilitated in a group, on a one-to-one basis or with self-motivation at home, even while doing chores.

Bob Raeburn (aged 70 and diagnosed with PD in 2003) is an Edinburgh Branch member now living near Sheffield where he is also a member of the Sheffield Branch. Bob recently authored a paper entitled *RIPE: Realistic Improvement in Parkinson's through Exercise*. In the article Bob describes a variety of approaches to exercise and how these can help to ameliorate the symptoms of PD and improve quality of life. You can download the article from the Branch website News page and we encourage you to do so, especially if in need of motivation.

Recently, Bob wanted to address his feet dexterity as falls were happening more often. Bob's now taken on boxing training exercises, which have resulted in him being able to move his feet sufficiently fast that if he trips, he can regain his balance and not fall. Bob's just written about this aspect of his regime in another article *My Boxing Training*.

Ronnie's Kayaking



While Bob Raeburn uses a variety of exercises in his management of PD, another of our Branch members, Ronnie Blyth resorts to kayaking, a sport he learned in his early teens. Ronnie was diagnosed with Parkinson's 13 years' ago at the age of 50. Kayaking provides good exercise for the whole body with the technique involving rotation of the trunk

matched by pressure from the legs, while the arms provide the link between this power source and the paddle. Co-ordination and balance are also key factors.

Although it doesn't offer the regularity that is easier with indoor exercise, Ronnie's sport provides the opportunity for him to embrace the sea air, escape city bustle and apply long-learned skills, knowledge and experience paddling in tidal waters and in the company of kayaking friends. The elements aren't always as kind as on his most recent trip round the Ross of Mull – Paps of Jura in the background! Of significant note is that Ronnie has long recognised his symptoms seem to disappear whenever he's in the kayak, no matter what has gone on just before.

Bob's and Ronnie's achievements are beyond the scope of many but there *are* activities on offer through the Branch that feature exercise at a gentler level. We encourage you to give them a try if you have not already done so and to take note of the Drop In article next.

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.

Monthly Drop In



The Drop In is on the first Friday of the month 2-4pm at the Pollock Pavilion, 227 Ferry Road, EH6 4SP. It provides an opportunity for People with Parkinson's, and anyone they wish to bring along, to socialise and share experiences. We also like to include an activity or invite an informal speaker. On 5th September, a member of *KICC Active Lothian* will visit to tell us about their **self-management exercise programmes** aimed at those with long-term health conditions. KICC runs a variety of classes throughout the region. Their website is *www.kiccactive.org.uk* where our Branch Committee Member, Heather Robertson is beautifully featured (as here) in one of the Gallery photos.

On 3rd October *Roisin McVie* from *Health & Social Care Gateway* will visit. Gateway is an **information and advice support service** for those with neuro progressive conditions, aimed particularly at help with **decision-making**. One-to-one sessions are available. If you can't make this Drop In date and would like to know more, Gateway has organised a FREE information session at Firhill Centre, 257B Colinton Road, Edinburgh EH14 1DW on 27th August, 9.30-11.30 am. Contact Roisin McVie at *roisin.mcvie* @edinburgh.gov.uk or on 0131 441 7162.



On 4th June, music producer, composer and conductor James Morgan collaborated with Parkinson's UK to present this evening at the Royal Albert Hall involving some of the finest voices, funniest comedians, a symphony orchestra and a choral ensemble. James was diagnosed with young onset Parkinson's at the age of 42 and together with his partner Juliette Pochin (producer, composer and mezzo soprano), conceived the idea of the event – to help raise awareness of PD, to show that it *is* possible to continue to work and live life to the full after diagnosis and, of course, to raise funds. Our Branch Members Liz and Bill McBain were invited as guests of P-UK and reported that it *was* the evening of music and laughter that was promised. It raised £125,000. For links to photos and videos relating to the event: *www.parkinsons.org.uk/content/symfunny*.

Branch Calendar

The calendar for the coming Branch year is enclosed with this mailing. We encourage you to take note of the **regular events that are on offer and their start dates** but do also access the Branch website for the latest news and updates and in particular the *Events Calendar*. You will see that on the back page, there is a new address for the **Scotland Office** which is now located in **Perth**. The move is to more economical yet more spacious premises, supporting the expansion of the Scotland Office's role. At time of going to print, a phone number was not yet available.

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 that their call is confidential and the person listening understands Parkinson's. It is available Monday, Wednesday & Friday 9.00am – 8.00pm, Tuesday & Thursday 9am – 7pm, Saturday 10.00am – 2.00pm, FREEPHONE 0808 800 0303 (calls are free from UK landlines and most mobile networks), *hello@parkinsons.org.uk*.

Fund-raising & Donations

The annual **Ceilidh** held on 24th May raised £600. A huge thank-you to Lou Ogilvy for her hard work in organising the event and to all who helped make the evening run smoothly. The *Ceilidh Caleerie Dance Band* proved an excellent choice with their playing skills, selection of dances and the relaxed yet encouraging approach of the caller. The band grew out of the Scots Music Group and now plays regularly for community and charity ceilidhs – we highly recommend them.

The Branch contributed nearly £110,500 from donations and legacies to support Dr. Tilo Kunath's **research project** F-0902 "Investigating the impact of too much alpha-synuclein" at the University of Edinburgh. The latest project update will be posted on the Branch website in the next week or so.

The **Water of Leith Pram Race** collected over £330 for the Branch. A tremendous effort was made by all competitors with their fancy dress as well as in the race itself. "Pram" variations included a shopping trolley, a bogie (plank of wood on 4 wheels) and an eclectic mix of the more familiar baby transport. Thank-you to all who took part in this annual fun event which collects for a number of charities.



Gavin McBain raised over £1700 (plus Gift-Aid) for the Branch by running the Paris marathon in April. Gavin completed the run in 3hrs 50mins.

James Mark raised over £500 (his target) for the Branch by running the Edinburgh marathon in May. James completed the run in 3hrs 45 mins. You can still donate at www.justgiving.com/James-Mark14.

Well done both and a thank-you for the hours of training, for your efforts on the day and for dedicating donations to the Branch.



The **Dalkeith Rotary Club** raised £1000 at their June bucket collection at Dobbies Garden Centre.

The **Jubilo Choir** rounded off having the Branch as their 2013/14 charity with a delightful *Choral Pops at Lunchtime* concert at the end of May. Throughout the year Jubilo has raised £1600 for the Branch with more to come and for which our sincere thanks and for the pleasure brought to those attending their events.

Silver Line

Silver Line is a confidential helpline for older people, open 24 hours a day, every day of the year and launched late 2013 after a successful pilot. The organisation developed as the result of an article by Esther Rantzen, describing her feelings about being on her own as a widow at the age of 71. The aim is to provide advice and information to older people and their supporters, as well as **befriending opportunities**. Silver Line Scotland is run in conjunction with Age Scotland. Phone *0800 4 70 80 90* (free from landlines), the website is *www.thesilverline.org.uk*. If appropriate, do have a look and see what is on offer.