

Parkinson's UK Edinburgh Branch Newsletter March 2013

Our aim is to inform members about forthcoming events, foster a sense of community, encourage participation in our regular activities, and feature your efforts. We welcome suggestions –

*please contact Helen Harris, Helen@edinburghparkinsons.org. We would also like to remind you of the **wealth of information on the Parkinson's UK and Branch websites.***

Fund-raising Activities by Branch Members, Families & Friends

A **Branch Fund-raising Sub-Committee** has been established. Founding members are *Louise Ogilvy* and *Jennifer Wilkie* and the Scotland (Office) Community Fundraiser *Emma Wilson*. The aims are to identify and organise major new fund-raising events for Edinburgh Branch and, when requested, to provide support for Branch Members already involved in fund-raising activities. The ideas are already flowing.



In August 2012, **Gavin McBain**, son of Branch members Liz and Bill, raised **£1600** for the Branch by completing his 13th London Triathlon. Gavin began with the half-triathlon in 2000, a completely unknown challenge for him. He then took on the full triathlon – swimming 1500 metres, cycling 40 km and running 10 km. Gavin doesn't just contribute with triathlons – in the past, he has taken part in the Great London Swim (1 mile in the Thames) and a full marathon on our behalf. His earlier fund-raising activities contributed £5000 towards the Therapy week-end at Peebles Hydro last September. Participants at the week-end also donated over £3,500 towards the cost of the week-end.



Guy Deacon, who has Parkinson's, and his *Team Deacon* member, Fee Tanner, ran the Florence Marathon in November. They raised **£12,500** for the Cure Parkinson's Trust. On 17th March they will run the Barcelona Marathon having coaxed two others to join the team. Looks as though Florence might be the first of many – *"I have to keep doing these runs because I am utterly convinced that fitness in body leads to fitness in mind, and if you can think positively about Parkinson's, you*

are three-quarters of the way there." We wish Team Deacon every success with their efforts. **Donations:** www.justgiving.com/user/36235575.



Keith McLeod is the son of Annette and Tom (who sadly died towards the end of 2012). Keith rode from John O'Groats to Lands' End over ten days during the last Easter break. He endured horrendous and at times scary weather, but with the much appreciated support of many of his friends at various legs of the ride, he managed to arrive on time and raised **£2578** for the Branch.

The **Quiz Night** was held on 16th November. Our usual organisers, Liz and Bill McBain, were on a well-earned break overseas but left everything set up and in the very capable hands of their daughter, Kirstie with support from Marian McIntyre. The event was a sell-out with seventy-five participants, raising **£460** (tickets plus raffle). Sincere thanks to Eric Grigor, Quizmaster, for giving his services free-of-charge as well as helping with the fund-raising. Ken Cox and his All Male Team were the winners. ***Because this event is proving so enjoyable, we would like to know if we have your support for a twice-a-year schedule.*** Please let us know.

The **Ladies of Kingsnowe Golf Club** raised **£1081** for the Branch as their nominated charity for the year. Sheena Shepherd whose husband Dick had Parkinson's is a member.



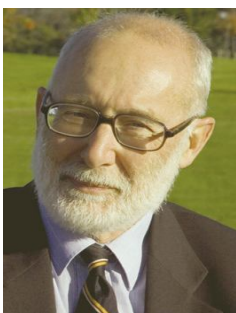
On 5th February the **Singing4Fun Group** enjoyed a special experience performing with the **RSNO Trio**, *Duncan Swindells, Jane Reid and Sarah Digger* in Marchmont St. Giles. The group performed a variety of songs to accompaniments specially arranged by the Trio who also played their own beautiful pieces. *The group can be seen here rehearsing with the Trio.* Branch Members, *Linda Remally* (voice), *Marysia Williamson* (flute) and *Sandy MacLean* (mouth-organ) made fine contributions with their solos and the audience sang along to a number of the songs. It proved a spirit-lifting event during the cold and wintry days of early February and thanks to purchases of donated tray-bakes, the afternoon raised **£300**. We are now delighted to announce **RBS Edinburgh Community Partnership** has donated **£8000** to help fund Singing4Fun. This generous donation will be handed over at the group's regular get-together on 5th March.

Finally, a total of **£2372** was contributed via **smaller donations/fund-raising activities**: in lieu of birthday gifts, Dr. Colledge (Liberton Hospital), Bayne's Bakers, Fairmilehead Parish Church Women's Forum, Mary Ward and Branch Members when renewing membership.

We wholeheartedly thank-you all. And, organised by the Scotland Office

The **Parkinson's UK Festive Concert** in November at St. Mary's Cathedral was a joyous success. It was a sell-out and raised **over £4,500** to help Parkinson's UK *research* projects in Scotland. The Singing4Fun Group did themselves proud with their performance.

Life Membership Honours



Patrick Mark, Chair of Edinburgh Branch and **Iain Young**, Chair of Aberdeen Branch, have been awarded Honorary Life Memberships "*in recognition of their longstanding, committed and substantial support for the work of Parkinson's UK.*" In congratulating them Katherine Crawford, Scotland Manager, states, "*It is utterly true that our volunteers are vital to our work, and Iain and Patrick are two of a number of people that we can always rely on for support and valuable, if at times, challenging opinions. We appreciate it and I am delighted that their work has been recognised in this way.*"

Patrick joined the Branch as a Committee Member in 1999. Soon after, he was elected for a three-year term as **Trustee for Scotland** of the Parkinson's Disease Society, working hard to establish a constitution for the **Scottish Council** as a forum to represent the views of the Scottish membership to the PDS Board of Trustees. He then chaired the Society's **Nominations Panel** for a number of years. This recommends the recruitment of appointed and co-opted trustees so the Board has the full range of skills and expertise it needs.

In the meantime, when the previous Branch Chair, Ron Partington retired in 2004, Patrick reluctantly took over. In canvassing opinions of those who've worked closely with Patrick since then, there are no doubts in people's minds about the enormity of his contribution to the local Parkinson's community. He has consistently applied his skills as a strategist and planner and coupled these with his career experiences, persistence and determination to relentlessly campaign for improvements in multi-disciplinary systems and a more streamlined service for people with PD in Edinburgh and the Lothians. One successful campaign included an increase in the size of the Lothians' PD Nurse Specialist Team.

Within the Branch, Patrick has applied the same qualities in working with highly motivated Committee Members and other volunteers to offer a wide variety of support activities, on the premise that we all have different interests, needs and capabilities. Just one significant

innovation has been the establishment of the Research Interest Group, led by Ken Bowler. The RIG had its genesis at the 2010 World Parkinson's Congress in Glasgow. Patrick and a number of others were later motivated to organise a Branch Symposium to discuss the lessons from the WPC and from this, the vision to establish the Group in 2011, fulfilling a need for Branch members with a specific interest in research.

On the award of his Honorary Life Membership, it seems an appropriate time to say on behalf of Branch Members . . .

Patrick, we are exceedingly grateful and appreciative of your efforts, commitment and time given to the Branch as well as to the wider Parkinson's community.

Side by Side with Parkinson's



This 6-week course, established and run by volunteer **Cathie Quinn**, is intended to inform those who live or work with someone with Parkinson's. A variety of professionals explain about drugs, medical investigations and clinical as well as general support. The sessions provide an opportunity for carers to offload, share experiences and receive some pampering on the last day. The most recent course was held October/November 2012 with consistent positive feedback from the six participants. Suggestions for future courses included: information about nutrition; possible benefits of complementary therapies for people with Parkinson's; and how carers can and should look after their own health. *Carers, if you've something to add, please get in touch or raise it at a monthly Side by Side Support Group meeting.* The next course will run after Easter – dates will be announced (these will be evenings). *Contact Cathie Quinn, 0131 557 6438 for information.*

Acupuncture and Parkinson's

Many people with Parkinson's find *complementary therapies* provide a positive experience, helping with relief from symptoms and an improved sense of wellbeing. In recent years there's been a growing interest in the possible benefits of **acupuncture** for those with Parkinson's. The medical and acupuncturist professions have been collaborating in clinical trials. Areas looked at include pain relief, difficulty swallowing, digestive discomfort, as well as examining the direct effects of acupuncture on the areas of the brain affected by PD. While some of these studies have shown encouraging results, they also indicate the need for further controlled and larger randomised trials. Currently, a study funded by the Michael J Fox Foundation and begun in 2010, is looking at whether acupuncture can help alleviate symptoms of severe fatigue. It's due to conclude in 2013 having involved 100 patients.

At the Branch Meeting on the 10th April (St. James Thistle Hotel, 2pm) **Caroline McGuire Physiotherapist in Neurological Rehabilitation** at the Astley Ainslie Hospital will be talking about "Acupuncture and Parkinson's." Come along and find out more.

Parkinson's Awareness Week

15-21 April 2013. This is our week to tell the world what life is really like for people affected by Parkinson's. It also gives us the chance to let people know about Parkinson's UK and what we do. Watch out for events.

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.



You won't be taught ballerina moves, hip-hop, disco, ballroom or ethnic dances at **Dance for People with Parkinson's (Dance for PwP)** but you will have the opportunity to experience the pleasure and direct benefits of specially choreographed movements to music. There is a powerful source of rhythmic knowledge in us all. Think of our heartbeat, our breathing, the way we walk, and the patterns of our daily lives which include waking, eating, working, relaxing. As we are all too aware, the impact of Parkinson's on movement and its knock-on effects on our rhythms of life can have devastating consequences.

Dancers know all about rhythm, movement, stretching, strengthening and toning muscles and about co-ordination and balance. They also understand how thoughts, imagination, seeing, listening and touching can influence control of body movements. *Dance for PwP* involves dancers *specially trained* to apply this knowledge in helping people to manage the condition better and improve feelings of well-being.

The concept arose from collaboration between the Mark Morris Dance Group and the Brooklyn Parkinsons Group in New York. This resulted in Dance for Parkinson's®. The UK network of practitioners and subsequent training development has been wholly supported by the UK-based Dance Umbrella and the Foundation for Community Dance. The Branch has been supporting the concept since 2010 with its *Dance for PwP* sessions. The dancer/performer leading the team, **Mo Morgan** is not only highly qualified and experienced, she also brings her direct involvement with Parkinson's to the sessions – Mo's mother has PD.

Classes are run fortnightly in a highly supportive environment at Dance Base, 14-16 Grassmarket. Some partners and carers also participate because the activity can be very therapeutic for *them*. A talented pianist provides the accompaniment, allowing flexibility in how the music can be used to encourage movement and development of sequences. The session begins seated, to provide a stable base for warm-up exercises then progresses to gentle choreographed movement around the floor, all with the aim of:

- **waking up stiff muscles** and improving **flexibility**
- encouraging **mind-body connection**
- improving **co-ordination** and **balance**
- increasing **self-awareness** and **self-esteem**

But just as important is enjoyment, creativity and mutual support; so if you're not already a regular, come and give it a try. Contact Mo to find out more and to let her know you are coming – mo@edinburghparkinsons.org.

We are delighted to announce **the Rambert Dance Company** will be visiting the group on the **10th April**.

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 to Friday 9.00am – 8.00pm and Saturday 10.00am – 2.00pm, FREEPHONE 0808 800 0303 (calls are free from UK landlines and most mobile networks), hello@parkinsons.org.uk.