PARKINSON'S<sup>UK</sup>
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

# Parkinson's UK Edinburgh Branch Newsletter September 2013

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.

## 3<sup>rd</sup> World Parkinson Congress

The WPC in Glasgow in 2010 proved a significant event in the Branch's development, not the least of which was the establishment of the Research Interest Group. We want to use this year's event in Montreal in October to further enhance the work of the Branch. To this end we have awarded bursaries to three highly suitable candidates to attend the congress on our behalf: (in alphabetical order)



**Mo Morgan** was a key player in the founding of the UK "Dance for Parkinson's" network as well as establishing and running the Branch's "Dance for People with Parkinson's" classes (featured in our March Newsletter). Mo has been involved with performing arts and teaching for many years and is well known to many branch members. Her mother was diagnosed with Parkinson's in 2008. In 2012 Mo conducted a joint research project concerning dance and people with Parkinson's (see next article).

**Simon Wilkinson** is a Police Officer in Police Scotland, with over 20 years' service and extensive experience in carrying out investigations, compiling reports, logistics planning and briefing presentations. Simon was diagnosed with Parkinson's 8 years ago at the age of 38. He is a participant in the on-going Transeuro Project, a collaborative European clinical study on the treatment of PD patients using a cell therapy approach, co-ordinated by Professor Roger Barker, Cambridge University

**Werner Remmele**, a member of the Fife Branch has collaborated with Edinburgh Branch through his research interests. Before retiring, Werner spent many years as a researcher and manager within the IT & Communications industries including those involved with Artificial Intelligence and Neural Networks. Werner was diagnosed with Parkinson's three years ago. He was involved in the recent Branch workshop on *Pain & Parkinson's*.

Our three representatives will attend lectures and workshops in agreement with the Branch and be responsible for reporting back to members in the form of web updates, documents and at a **WPC Branch Symposium** on **30**<sup>th</sup> **November** (please mark the date in your diary). In the meantime, via a link on the *WPC Montreal 2013* page of the Branch website, members can see Mo, Simon and Werner's provisional attendance choices, as well as their personal statements. We encourage you to advise the team on topics you would like to hear about – send suggestions for session attendance via their listed email addresses.

With Mo, Simon and Werner's combined knowledge and experience of Parkinson's, interest in research and approaches to treatment (clinical and holistic), organisational, planning, communication and presentation skills and ability to handle digital media, we believe we have put together a **formidable team** on your behalf.

#### **Research Poster for Montreal**

In April 2012, *Mo Morgan* and *Beata Michalska* conducted a research project, which formed part of Beata's Masters in Neuro-Psychology at the University of Edinburgh (supervised by Dr. Sharon Abrahams). The project involved participants from the East Lothian Support Group and investigated whether or not weekly participation in a dance class could improve cognitive functioning in people with Parkinson's. The classes followed the *Dance for Parkinson's*® format over a period of 10 weeks. Although the group was small, the outcome was positive and sufficient to justify presenting the results in poster format at the 2013 International Congress on Alzheimer's and Parkinson's Disease in Florence in March. The poster has also been accepted for presentation at WPC Montreal and Mo will be monitoring response and interest in the results while at the congress.

### **Garden Party and More for Liz and Bill**



Liz McBain joined the Branch Committee at the same time as current chairman, Patrick Mark. As they walked across the car-park that evening in 1999 Liz and Patrick realised they shared similar ideas in wanting to make a wide-ranging choice of activities available for Branch members. Liz has long been an advocate of the benefit to those with PD of keeping physically and mentally active. Although diagnosed with Parkinson's in 1996, since she joined the Committee Liz has expended much of her own energy in establishing a range of regular classes – **Art, Indoor-Bowling,** 

**Swimming, and Gentle Exercise**. Liz has also been instrumental in organising the annual Ceilidh and Quiz Night, as well as regularly contributing to the organisation of the Coffee-morning. She finally managed to introduce the highly successful Branch Therapies Weekend in Peebles last year, an event Liz had wanted to take place for some time.

Husband Bill has been a stalwart in the background, quietly supporting Liz in ensuring all these events keep going and run smoothly, with daughter Kirsty providing support in recent years and son Gavin raising significant sums of money through his triathlon and similar efforts. We're pleased that Liz has now handed over responsibility to other Branch members for some of the annual events so that she can find more time for herself. Liz and Bill were invited to the Queen's Garden Party, Holyrood Palace on 2<sup>nd</sup> July in recognition of their outstanding work.

Golden Wedding Anniversary 2011





Shame it poured with rain at the Palace but nothing seems to dampen Liz's positive attitude and her enthusiasm for life. This beams through in her broad smile, so familiar to Branch members, many of whom have found respite in her strong moral support in difficult times. It's a smile that's often seen in publications and on the web as Liz doesn't shy away from being an active voice on

behalf of the Branch and the Parkinson's community. We are now pleased to announce that Liz's monumental contribution has been further recognised with the recent award of **Honorary Life Membership of Parkinson's UK** presented to her by previous Branch Chairman Ron Partington at the Branch Meeting on 11<sup>th</sup> September. (*Photo – Liz and Ron*)

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.

#### **Scotland Office**

Parkinson's UK has developed from a one-room office in Putney in 1969 to a UK-wide network with 13 regional or country teams supporting over 350 local groups. The charity set up an office in Scotland in 2001. Although the office is still tiny the charity's presence in Scotland has grown from one member of staff to over 20, full and part-time and nearly all home-based. *Katherine Crawford*, Country Director has managed the team since 2010. The team provides: **information and support on a one-to-one basis** for people, their families and carers; **support to local groups and over 1000 volunteers** in Scotland; **education courses for health and social care professionals**; and staff work with local health and social care organisations to **strengthen and develop services** for people affected by Parkinson's. The charity **campaigns** vociferously to ensure the voices of the 10,000 people affected by Parkinson's in Scotland are heard by the Scotlish Government. It has a Fundraising Manager to develop **fundraising** for Parkinson's UK in Scotland, and additionally, Emma Wilson was appointed as the Office's first *Community Fundraiser* in 2013. Emma has been working closely with our newly established *Branch Fund-Raising Sub-Committee* whose first event is the imminent Race Night (see page 4).

Katherine says "It is very positive to work with a charity with such a strong sense of identity in Scotland. Our staff enjoy the opportunity to work alongside our many volunteers and feel that together we achieve a great deal for people with Parkinson's. However, we know there is so much more to do!" For more details about whom to contact in the Scotland team, the website link is <a href="https://www.parkinsons.org.uk/content/scotland">www.parkinsons.org.uk/content/scotland</a>.

### **New Venue for Branch Meetings**



We're delighted to have found a **new venue for our monthly meetings** and for the **Wednesday evening Singing4Fun** sessions. Bellevue Chapel (Rodney St, EH7 4EL) is an independent evangelical Christian church. The building was constructed around 1880 originally for a German Lutheran congregation. It's believed many were workers involved in the

construction of the Forth Rail Bridge. The building was then sold to a Brethren assembly who have continued meeting and worshipping there. We were immediately taken by the brightness, warmth and comfort of the venue, the availability of catering facilities and the ease of access in Cornwallis Place. There are disabled parking bays and meters close by in Bellevue Crescent and it's served by Lothian Buses 8, 23 and 27. By the time you read this Newsletter you may already have attended the first meeting of the season there.

The **9th October** meeting will include a talk by **Jim Wilson** on Yemen – the Place and its People. Jim worked there 1976-1982 and eventually published *Take One Three Times a Day, After Meals*, a memoir chronicling the lives of a small group of medical missionaries running a hospital in the town of Rada'a. It tells of the customs, superstitions and tenacity of the people of Yemen, one of the oldest centres of civilisation in the Near East. Jim has handed over his collection of Yemeni artefacts to the National Museum of Scotland where it is being catalogued and photographed for on-line access. Should be a fascinating talk!

The **13 November** Meeting will include a performance by **The Mercators** of their latest piece, *According to Oscar*, performed at this year's Edinburgh Fringe. The group is one of Edinburgh's longest established amateur drama groups (since 1936). In 2002 they began presenting dramatised readings in period costume celebrating the lives of famous writers. This year features Oscar Wilde, highlighting the often forgotten role of his wife, Constance. "So much in it with touches of brilliance," quotes one reviewer.

# Race Night & Fund-raising

If you haven't already bought your ticket for the Race Night on Friday 27<sup>th</sup> September at Inch Park Community Sports Club, EH16 5UD, **there's still time**. Race nights have been enjoyed by many for a number of years but those who've never been to one tend to wonder what's involved. The races are on film and were held in far flung places so no-one knows the results. On the night, you peruse the races and bet on your chosen horse



for a particular race (there will be 8 races) . . . if you pick a winner, you win a share of the race's takings. The evening will also include a raffle and as we've been given very worthwhile gifts from a variety of companies, we're also holding a mini auction. After a light buffet, the second half of the evening will be entertainment from **The Cobblers Bairns**, a local Scottish folk band.

If you would like a tickets (£5 entrance), please post the form received in the last Branch mailing together with a cheque for the relevant amount. If you don't have a chequebook, please email **Lou Ogilvy** at *lo4parkinsonsfundraising@gmail.com* stating how many tickets you'd like and they will be kept at the door for you. If you have a blue badge, you can park outside the venue; all others please contact Lou about a car permit for Cameron Toll Shopping Centre. A very short path leads right to the venue. And please remember to bring your wallet/purse/ chequebook – these are fun events and a most enjoyable way to help fund-raise – we look forward to seeing you there.

In June, **Sandra and Bill Neil** held their *Golden Wedding Anniversary* celebrations and suggested donations were made to the Branch in lieu of gifts which raised a splendid sum of over £700. Sincere thanks to the golden couple and all who donated.

The **Water of Leith Pram Race** was held in June and raised just over £350 in collection cans for the Branch. We had 6 prams entered, competing with competitors for the Royal Hospital for Sick Children and Marie Curie Cancer Care. Thank-you runners and pram occupiers for your splendid effort.

### **Respite Care**

Were you aware the Branch funds respite care given by Crossroads Caring Scotland? The scheme offers flexible short breaks for unpaid Parkinson's carers in Edinburgh and the Lothians. The service is available on any day including evenings, for a few hours on a weekly basis or for a concentrated block over a few days, up to a total of about 33 hours. There is no charge but users can donate if they wish, helping to make the service available to more people. To apply or find out more, please contact your Information and Support Worker: **Shona Lawson** for West Lothian, West and North Edinburgh, *0844 225 3727* or *Slawson @parkinsons.org.uk* and **Mrs Betty Thomson** for Midlothian, East Lothian and East and South Edinburgh, *0844 225 3771*, *Ethomson @parkinsons.org.uk*.

**Addendum:** Please put 25<sup>th</sup> October in your diaries for the **Annual Quiz Night** at Stewart's Melville Rugby Club Pavilion, EH5 2DW, 7pm – 10pm.

*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.