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

# PARKINSON'S UK EDINBURGH BRANCH NEWSLETTER AUGUST 2016

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 – contact Helen@edinburghparkinsons.org.

#### **Annual Parkinson's Lecture**



In February 2014, we held a seminar introducing the concepts of ParkinsonNet, a successful integrated healthcare system in the Netherlands for PwPs. The seminar (reported in the March 2014 Branch Newsletter) was based on a teleconference hosted by

Parkinson's UK and involving *Professor Bastiaan Bloem*, lead developer of this best practice system. Afterwards, there was resounding approval for the Branch to promote ParkinsonNet concepts. We believe the time is right for Professor Bloem to present the Annual Lecture, which for reasons of availability, this year we delayed till the autumn – it's **11<sup>th</sup> October**. **Details will be posted soon in a mailed flyer and on the Branch website**. We encourage you to watch out for these then to book your ticket without delay to hear Professor Bloem speak about *ParkinsonNet: The Future of Parkinson Care*.

## 4<sup>th</sup> World Parkinson Congress

The Congress is being held in Oregon, USA, in September. Hon. Chair, *David Adams* and Member, *Alison Williams* will be attending on behalf of the Branch. **Enclosed with this mailing is a note of their intentions** and the major Congress topics. A Special Branch Meeting is scheduled for **Saturday 26th November** (in Bellevue Chapel) for Alison and David to present information, impressions and opinions from their Congress attendance. Do mark it in your diaries now and read the enclosed note, letting David know of any topics you especially want reported (his contact details are at the foot of the note).

As a result of its success the Branch's QL (Quality of Life) Group has had an information poster accepted for the Congress with the title *Quality of Life Group: Maintaining our mental, physical, emotional and spiritual wellbeing*. The poster explains how in the safe space of the Group's monthly meetings, PwPs can freely express thoughts and feelings, laugh and cry, free from judgement, criticism, advice or embarrassment and includes quotes from participants: "A joyous gathering, sharing our experiences and building trust in such a healing atmosphere" and "The feeling of understanding and companionship was heart-warming. My quality of life has already gone up!" as well as "It is great to talk about PD without fear of boring or worrying anyone."

WPC Posters are displayed during the Congress for attendees to view at lunchtimes. Having a poster displayed is a significant achievement and we congratulate Bill Wright and Alison for their work in putting it together and having it accepted. The intention is to encourage others to form similar groups. If you would like to know more about our QL Group, please contact Alison Williams, 07719 603321, 0131 557 5979, Alison @edinburghparkinsons.org.



## **Pilates for Parkinson's**

Thanks to the success of the Branch's pilot Pilates course and the interest and enthusiasm shown for the taster at our *Parkinson's – Let's Get Moving* event in May, we have now established regular sessions with neurophysiotherapist and Pilates Instructor, **Sasha Baggaley** at **two venues**. They are: most Fridays 2-3pm, Pollock Pavilion, 227 Ferry Road, EH6 4SP and from September, most



Mondays 2.30-3.30pm, Christchurch Morningside, 6a Morningside Road, EH10 4DD. The sessions are free. Please contact Sasha on *0131 620 3780* for more information or to register interest. Sasha will also be speaking at the Branch Meeting on 14<sup>th</sup> September.

#### **Branch Art Group**



The Art Group has been running successfully for a number of years, providing an opportunity for Members who like to draw, sketch or paint to meet and support each other. Skill levels and experience vary from beginners to those who have been using their artistic talents for many years – all levels are welcome. Professional help is available from Member, *Lindsay McDermid* who usually suggests a theme for the session.

The Group used to meet fortnightly in a Member's home but we are most fortunate to have been given a **delightful space in the Botanic Cottage** at the Royal Botanic Garden Edinburgh on a weekly basis (Thursdays, 1.30-3.30pm) for a trial period. The Cottage was originally situated in Leith Walk at the entrance to a mid-18<sup>th</sup> century existence of the Garden. After various uses it fell into disrepair until a project was established to move it stone by stone to its new location, with completion earlier this year. You can learn about the project at *www.rbge.org.uk*. To find out more about the Art Group and access to the Cottage, contact Liz McBain, *Liz@edinburghparkinsons.org* or *0131 315 2493*.

Lindsay McDermid will be running an *Art Workshop for Everyone* at the 9<sup>th</sup> November Branch Meeting. This is intended as a fun event when you just might realise you have more artistic talent than you thought, or at the very least, discover the joy of a little creativity. See **Branch Meetings** in the Branch Calendar enclosed with this mailing.

## A Baby for Jen



We are delighted to let you know that Jen Farmer, our much loved Movement & Dance for PwP leader gave birth to a boy, Buddy, just after 2 a.m. on Monday 18<sup>th</sup> July, weighing 7lb 4½ oz. Mother, baby *and* father are all doing fine. Very many congratulations! In the meantime, Jen's highly capable colleagues have been leading the

sessions (currently supported by Dance Base and Scottish Ballet) at the Festival Theatre during the summer months, resuming at Dance Base from 7<sup>th</sup> September.

*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. Secretary, 0131 449 2705, Honsec@edinburghparkinsons.org.* 

## Tai Chi for Parkinson's

Yet another positive outcome from the *Let's Get Moving* event was the interest in *Kevin Brown's* Tai Chi taster. Tai Chi fared well in the research covered in Professor Rochester's presentation that day and we have members who already practise the discipline and speak of its benefits. We are running a 10 week pilot course with Kevin. Sessions are Thursdays 11am-12.30pm, 15<sup>th</sup> September to 24<sup>th</sup> November (no class 20<sup>th</sup> October) at Marchmont St. Giles, 1a



Kilgraston Road, EH9 2DW. Kevin also teaches Chi Kung and is a Reiki Master. He is well used to managing classes involving participants of varying ability levels. To find out more about the pilot and to register interest, please contact Kevin on *01506 845498* or *07714 092626*. To learn more about Kevin's skills, look at his website, *www.chi-flow.co.uk*.

## The Branch Needs More Volunteers – from our Hon. Chair, David Adams

Thanks to our volunteers, Edinburgh Branch is one of the most active and successful in the UK. *Together* we are bringing more activity, quality of living, interest and fulfilling initiatives into our wonderful Parkinson's community. Our present team members are all people whose lives have been touched by Parkinson's – from having Parkinson's, to care partners, carers, relatives and friends.

We really value volunteers. Their input, time and practical support to grow, co-ordinate and maintain our range of activities and services create huge benefits. We could not maintain the Branch without them.

#### And we would like to do more!

Do you, or does anyone you know have a couple of hours a week to assist us in giving even better services to the Parkinson's community in Edinburgh? Please get in touch with *David Adams*, Hon. Branch Chair, *Patrick Mark*, Hon. Vice Chair, *Pat Stewart*, Hon. Secretary or any other Committee Members – their contact details are on the enclosed Branch Calendar and the Branch website. We would be delighted to hear from you!

#### Side by Side with Parkinson's Course

The next course is being held on Mondays, 26<sup>th</sup> September to 7<sup>th</sup> November (except 17<sup>th</sup> October), 10am-12.30pm, at the Faith Mission Centre, 548 Gilmerton Road, EH17 7JD. The course is aimed at people who know, live with, or work with someone with PD and would like to learn more about the professional help, drugs, benefits and support available. Feedback from these courses has always been very positive and attendees also feel they benefit from mutual support. For more information or to register, contact **Cathie Quinn**, *cathiequinn*@googlemail.com, 0131 557 6438, 07703 497354.



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*.

#### **Forthcoming Meetings**

Throughout this Newsletter we draw your attention to some of the meetings planned for the autumn. We encourage you to look at the other dates announced in the enclosed **Branch Calendar 2016/17** so that you can pencil those of interest in your diary now.

#### **Fundraising and Donations**

Members of the **Art Group** exhibited their work at Bon Papillon café in March and very generously donated £647 from their art sales. The **Coffee Morning** in April raised over £1250. Thank-you again to Committee Member, Annette McLeod and her team of helpers. The **Ceilidh** in May was thoroughly enjoyed by all and raised £260. A **Laughter for Health** event run by Jo Bluett at the Mound raised just over £200 in a bucket collection. Jo is a qualified Laughter Consultant and Trainer who facilitates group laughter therapy sessions to help people's mental and general wellbeing – more at *www.laughterforhealth.co.uk*.

The annual **Water of Leith Pram Race** on  $3^{rd}$  June raised £525 – that's a great deal of coin to count! Our Hon. Secretary, Pat Stewart was asked to judge the fancy dress and start the race. Since March other contributions and in memoriam donations have reached £1260. We express our thanks to all for their efforts and generosity.

#### Become a Parkinson's UK Volunteer Trainer

Elsewhere in this edition we expressed a need for more *Branch* volunteers. Parkinson's UK also have a need for a particular type of volunteer and Gina Allen, Volunteer Co-ordinator for the South of Scotland has asked us to include the following:

Parkinson's UK would like to expand their network of **volunteer trainers** to help them to reach a greater number of care staff across Scotland. Our aim is to help professionals to better understand Parkinson's and improve their practice. The role will suit someone who has an interest in Parkinson's, has good administration skills and is enthusiastic and confident in speaking to different audiences. Parkinson's UK will provide training to enable volunteers to plan and deliver a one-hour presentation on Parkinson's to groups of staff in their local area.

Previous volunteers have reported that the volunteer trainer role is very rewarding and worthwhile. "The greatest reward is knowing that as a result of something that you have said, life will be easier for someone with Parkinson's." Feedback from care staff attending the sessions has also been consistently positive and sessions are very much valued. For more information on how to apply and to request a role description, please contact Candice Dillen, Education Adviser Scotland, *cdillen@parkinsons.org.uk*, 0344 225 3701.

## **WPC Video Competition**

In advance of the 4<sup>th</sup> World Parkinson Congress, the World Parkinson Coalition has announced **The Top 12 Videos** selected from 75 entries from 20 countries. One British entry made it to the Top 12. It's by *Eros Bresolin* and features the song he wrote about his journey from diagnosis to acceptance and demonstrates how his positive attitude has helped him on what he considers an amazing journey. His and the other Top Videos can be viewed at *www.wpc2016.org/page/top12*. Winners of the Grand Prize Award and the WPC People Choice Award will be announced at the 4<sup>th</sup> WPC Opening Ceremony.