

Parkinson's UK Edinburgh Branch Newsletter November 2012

Welcome to the re-launch of the quarterly Branch Newsletter. Our aim is inform Branch members about forthcoming events, to encourage participation in our regular activities, to foster a sense of community and

*to feature your efforts. We would love your feedback and suggestions – please contact Helen Harris, Helen@edinburghparkinsons.org. We also want to remind you of the **wealth of information on the Parkinson's UK and the Branch websites.***

Therapies Residential Event

For the last week-end of September, the Branch took over much of Peebles Hydro to host this event, attended by 56 Branch members. Activities included hydrotherapy, singing, line dancing, painting, card making, Ronnie Gardner Rhythm Movement (RGRM) and yoga.



There were presentations on lifestyle management, speech therapy, and exercise while various one-to-one therapies were on offer and a group experience of sound therapy. The opportunity to meet, chat and make new friends during meals and free-time was just as important. Feedback suggested the benefits to individuals were many and varied but the general consensus was the event was very worthwhile and the activities programme had been well chosen. Huge appreciation was expressed for the organising team: **Liz McBain, Cathie Quinn, Heather Robertson and Pat Stewart.**



Festive Concert, Parkinson's UK

**Friday 23rd November, 7pm, St. Mary's Cathedral,
Palmerston Place, EH1 3JD**

Come help us celebrate the lead-up to Christmas with a joyous fund-raising concert in Scotland's largest cathedral, a masterpiece of Victorian Gothic architecture, with its magnificent high altar, one of the finest organs in Scotland and Eduardo Paolozzi's stunning stained glass windows.

The evening will be hosted by Radio and TV presenter **Kaye Adams** and guest **Gavin Hastings**. Performers

include The Lothian and Borders Police Choir, The Academy Junior Chamber Choir, flautist Fiona Kelly, St. Mary's Music School, singer Wendy Carle Taylor and our own "Singing4Fun" group (*featured in next article*). Tickets are £5, under 12's free. Because of the vastness of this splendid venue, please come wrapped up warm.

To book, please download the booking form at www.parkinsons.org.uk/festiveconcert or contact Emma Wilson – Community Fundraiser on 0844 225 9857 or email her at rf.scotland@parkinsons.org.uk.



“I don’t sing because I’m happy, I’m happy because I sing” William James, American Philosopher & Psychologist, d.1910

“Health choirs” are becoming all the rage thanks to the BBC and choirmasters like Gareth Malone. The Natural Voice Practitioners’ Network promotes the idea that singing is everybody’s birthright. Research in recent years has suggested that human beings sang before we could speak. If you listen to the babblings of a baby you should recognise that it’s more akin to singing than speech. For millennia, civilisations have sung to express joy as well as grief,

accompany work, support devotional rituals, foster a sense of community and aid healing. They’ve done so without worry of whether any one individual had a good voice, got it right or harmonised.

Here’s what singing can do for us:

- ♪ Improve our **breathing**, exercise the **vocal chords** and tone the **facial muscles**
- ♪ Release **endorphins**, our pain-relieving and feel good hormones
- ♪ Help **tone the diaphragm and abdominal muscles**, which in turn helps the digestive system and circulation
- ♪ **Focus the mind** away from everyday worries and concerns.

These are the benefits for everyone but for those with Parkinson’s they relate to areas often affected by the condition. When we sing in a group we have the added benefits of improved listening skills, mutual support and friendship, and if we don’t take it too seriously, a great source of fun and laughter.



The Branch recognised the beneficial effects and established the “Singing4Fun” group in 2009. It’s run by Branch members, **Cathie Quinn** and **Heather Robertson** with professional singer and voice coach **Wendy Carle Taylor**. Ask any regular member about the benefits and you shouldn’t need further convincing. Anyone can join, which may provide an incentive for people who shy away from gatherings involving just those with Parkinson’s.

No matter how well or poorly *you* believe you sing you’ll be warmly welcomed. Participants learn by call-and-response, no need to read music. The group tackles all manner of music genres, languages, rounds and harmonies. The odd piece of percussion may even be thrown in. Wendy is such a master of encouragement, patience and persistence (all with a glorious sense of humour) that, in the last year, the group has performed at the Branch coffee morning, a Bonnyrigg community gathering, the Parkinson’s Specialist Nurses Information Afternoon and with other singers in the Usher Hall. Participants don’t need to take part in these events, but many do because they can see just what’s possible when all manner of voices blend. The group will be participating in the **Parkinson’s UK Festive Concert** mentioned earlier.

If you want to join us, see the “Regular Activities” section for venues. If you don’t feel ready yet, do please **sing in the bath**, the **shower**, the **kitchen**, or **wherever it takes your fancy**, **carers included**, and **watch for the benefits**.





Guy Deacon Running the Florence Marathon

The editorial team know Guy through the “Singing4Fun” group. He’s enthusiastic about singing and understands its benefits to those with Parkinson’s. On 25th November he’ll be running the Florence Marathon on behalf of the Cure Parkinson’s Trust and will cherish your support. We wanted to know more about the man himself. . .

Guy is an Army Colonel and currently Chief of Staff at the Army Personnel Centre in Glasgow, making the daily commute from Edinburgh where he lives with his wife and two teenage children. He returned to the UK after being involved with the United Nations’ peacekeeping mission in the Democratic Republic of Congo for which he received an Operational OBE in 2011 – something we found out through research, not an attribute about which he’s forthcoming. If you want to learn more, Google *guy deacon scotsman obe* for the Scotsman article published at the time – Guy’s contribution and the OBE citation are a very worthwhile read.

Although Guy played rugby, was a keen rower and ran the Paris and London marathons a decade ago, he doesn’t regard himself as currently fit (he’s 50); so this marathon is a significant challenge for him as he was diagnosed with Parkinson’s early in 2011. He says he finds running exceedingly boring and admits if he hadn’t developed the condition he wouldn’t be running yet another marathon. What spurs him on is **his passion to support Parkinson’s research** by helping to raise money for the cause. Just as important is **increasing awareness of Parkinson’s among the general public**. He also knows that improving his fitness can play a significant role in helping him manage the condition.

Guy began training in July taking a fairly relaxed approach similar to the regime he followed for his previous two marathons but **our** support is key to his progress for, in his own words, *“every time somebody sponsors me, I feel I must get out and train harder.”* Guy’s i-Pod, playing mainly rock music, helps keep him going and provides a rhythm for him to work with and drive him forward. Fortunately, he has no problem keeping his balance on the road unlike when on a treadmill. Getting changed and ready to run is one of the most tedious parts of the exercise for him.



Florence was chosen with the enticement of sight-seeing *after* the event and even in November the weather should be clement. The route is stunning, taking runners through lush parks, past the Duomo, across the Ponte Vecchio and along the River Arno. Guy will be running with two friends; Fee Tanner has never run a marathon before: for James Moberly it will be his fifth and in his fifth decade. Both are supporting Guy in collecting for the Trust and raising awareness of Parkinson’s; so we hope you’ll agree, they too firmly deserve *our* support.

To sponsor Guy, please go to www.justgiving.com/Team-Deacon.

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.

Confused About the Various Parkinson's Organisations?

The following are the organisations most relevant to the UK. (*Contact details at the end*)

Parkinson's UK

The organisation has been established as the **major support and research charity for the UK** for more than 40 years, changing its name from the *Parkinson's Disease Society (PDS)* in April 2012. If you haven't spent time on the website, we encourage you to have a look at the wealth of information available which includes access to free publications and downloads. In addition, research news, advice and topical items are published in the members' quarterly magazine "The Parkinson." The twice-yearly "Progress" covers more detailed information about research grants and advances and is sent on request. There are 13 Regional Offices, Scotland being one with 10 regional Information Support Workers (ISWs) and 44 Branches or Local Support Groups. There is also a **Helpline** (see Page 3).

Edinburgh Branch of Parkinson's UK (run by volunteers)

The Branch was the first to be formed in Scotland (in the early 1970's) and the second in the UK. It was established by *Prof. John Gillingham*, a distinguished neurosurgeon specialising in Parkinson's. The Branch provides a local network of support and, via the Scotland Office, a means for raising awareness of people's needs with local health services. We currently have over 300 members. You're likely to be a member and have received a wealth of information and documentation on joining. If you haven't, please contact us – we would like to hear from you. There is also the **Edinburgh Younger Parkinson's Group** – see the "Regular Activities" section.

Cure Parkinson's Trust (CPT)

CPT was founded by a group led by *Tom Isaacs*, who was diagnosed with Parkinson's at the age of 27. Tom raised significant sums of money from his various fund-raising challenges. These included walking 4,500 miles round Britain's coastline in 2002-2003. The aim of the charity is to raise and award funds for "research that will build momentum towards a cure for Parkinson's."

The European Parkinson's Disease Association (EPDA)



The EPDA, founded in 1992, represents 45 member organisations across Europe. Their objective is to become the leading voice for Parkinson's in Europe, **sending a clear message to policy makers** within member states about investment in advancing the treatment and management of Parkinson's. It also aims to promote sharing of practice among member organisations and to provide information and resources to the treatment industry, healthcare professionals and the media. **The UK member is Parkinson's UK.** The EPDA logo features the **James Parkinson Red Tulip** which became the official world symbol of Parkinson's Disease in 2005. The cultivar was developed by a Dutch horticulturist who had Parkinson's.

Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. 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.

Cure Parkinson's Trust, tel. 020 7929 7656, www.cureparkinsons.org.uk.

European Parkinson's Disease Association: www.epda.eu.com.

PARKINSON'S UK EDINBURGH BRANCH SCHEDULED EVENTS

Annual Quiz Night – A Fun evening and still time to book

Friday 16th November at Stewart's Melville Sports Pavilion, 523 Ferry Road, EH5 2DW. Contact *Liz McBain*, 0131 315 2493, Liz@edinburghparkinsons.org.

Branch Meetings – Contact *Pat Stewart* 0131 449 2705, Honsec@edinburghparkinsons.org
Held 2.00–4.00pm, *St James Thistle Hotel (Trinity Suite)*, 107 Leith Street, EH1 3SW.

Wednesday 14th November – Dr Connor Maguire, “Developing the Parkinson’s Service in Lothian.”

Wednesday 12th December – Christmas Lunch, Boroughmuir Rugby Club, Meggetland.

Wednesday 9th January 2013 – Dr Richard Davenport, “Current Parkinson’s Developments.”

Wednesday 13th February 2013 – Hamish Coghill, “You’ll Have Had Your Tea!”

Edinburgh Research Interest Group

Saturday 1st December – “Genetic Parkinson’s: Studying the Few to Treat the Many,” **Dr Miratul Muqit**, 10.30am–12.30pm followed by sandwich lunch, Scottish Centre for Regenerative Medicine, 5 Little France Drive, EH16 4UU. Contact *Ken Bowler*, 0131 669 8961, ken@edinburghparkinsons.org.

Regular Activities

Swimming – Braidburn School Hydrotherapy Pool, 107 Oxbgangs Road North, EH14 1ED, Mondays 6.15–7.15pm, TERM TIME ONLY. Contact *Liz McBain*, 0131 315 2493, Liz@edinburghparkinsons.org.

Indoor Bowling – Portobello Indoor Bowls and Leisure Centre, 20 Westbank Street, EH15 1DR, Tuesdays 1.45–3.00pm. Contact *Liz McBain* – see above.

Gentle Exercise – Drylaw Parish Church, Groathill Road North, EH4 2RG, Thursdays 1.30–3.00pm. Contact *Liz McBain* – see above.

Gentle Exercise at Portobello Indoor Bowls and Leisure Centre, 20 Westbank Street, EH15 1DR, Wednesdays 11.30am–12.30pm. Contact *Liz McBain* – see above.

Art Group – Christine Ellis and Lindsay McDermid, private location, Mondays Fortnightly, 10.30am–12.00 noon. Contact *Liz McBain* – see above.

Dance For People With Parkinson’s – Dance Base, 14-16 Grassmarket, EH1 2JU, Wednesdays Fortnightly, 11am–12.30pm. Contact *Mo Morgan*, Mo@edinburghparkinsons.org.

Singing4Fun – Marchmont St Giles, EH9 2DW, Tuesdays, 2–4pm AND Gillis Centre, EH9 1BB, Wednesdays, 7–9pm, TERM TIME ONLY. Contact *Cathie Quinn*, 0131 557 6438, Cathie@edinburghparkinsons.org.

Drop In Centre – Pollock Pavilion, 227 Ferry Road, EH6 4SP, 2–4pm, 7th December, 4th January, 1st February, 1st March. An opportunity to meet and share experiences. Contact *Cathie Quinn* – see above.

Carers Support Group – Pollock Pavilion, 227 Ferry Road, EH6 4SP, last Wednesday of every month, 10.30am–12.30pm. Contact *Cathie Quinn* – see above.

Young Parkinson’s Network – meets first Thursday evening of the month. Contact *Scott Wilson*, 01899 220 827, scott@edinburghparkinsons.org or *Gina Allen*, 0844 225 3725, bvso.southscot@parkinsons.org.uk.

Young Parkinson’s Carers Support Group – meets first Tuesday evening of the month. Contact *Joyce Quiletti*, 01573 410 363, Joyce@edinburghparkinsons.org or *Gina Allen* – see above.