

## Parkinson's UK Edinburgh Branch Newsletter January 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](mailto:Helen@edinburghparkinsons.org). We also remind you of the **wealth of information on the Parkinson's UK and Branch websites**.*

### Please Tell Us How We Are Doing

YES

NO

DON'T KNOW

Accompanying this issue is a Questionnaire which we ask you to complete by 15<sup>th</sup> February. The Committee would like feedback to ensure the Branch continues to provide the type of activities and information you appreciate. Several volunteers have worked hard on the design. We've tried to make it easy to complete yet still allow us to gather the information we need to help best serve you. Our intention is to analyse the responses in time to present the findings at the AGM on 12<sup>th</sup> March; so we do encourage you to respond by the February date.

### Branch 3<sup>rd</sup> WPC Symposium



On the 30<sup>th</sup> November, Branch representatives who attended the October World Parkinson's Congress bravely took to the stage in Bellevue Chapel to provide us with feedback. *Mo Morgan, Simon Wilkinson and Werner Remmele* spoke about the presentations and events that had greatest significance for them and gave us a sense of the buzz, enthusiasm and emotions expressed at the Congress. It was also an opportunity for Branch members to ask questions.

A more detailed summary of the day and the Symposium presentation slides are available on the Branch website via the *News: WPC Symposium* page. There will also be further opportunity for discussion about the Congress. Based on the team's feed-back, some of the more noteworthy issues included: the significant benefits of **patient-centred treatment** and use of **inter-disciplinary teams** (an approach our Branch Chairman, Patrick Mark, is keenly pursuing); **self-efficacy** and the benefits of becoming as involved and educated as possible in relation to your treatment; **non-motor symptoms**; and improvements in quality of life achieved through **regular exercise and activities**. Noted, was the success Dance for Parkinson's is having – check out our *Dance for PwP* classes.

*Fella Hammachi* (Centre for Regenerative Medicine) also attended the Congress and described the progress being made in understanding the pathways involving alpha-synuclein protein misfolding and aggregation and the impact on neurons in PD. Fella's slides are also available via the *News: WPC Symposium* page on the Branch website.

The team showed the Congress Grand Prize Video Competition Winner: ***Smaller, a poem about Parkinson's by Andy McDowell*** – beautifully composed in its simplicity but strong on stirring the emotions – see [www.youtube.com/watch?v=3n117vFWYaQ](http://www.youtube.com/watch?v=3n117vFWYaQ).

The next congress will be held in Portland, Oregon in 2016.

## Parkinson's UK Helpline

*"It was a joy for the phone to be answered by a real, live, person who immediately knew who best to transfer the call to. Both individuals were helpful and spoke in a calm manner that seemed genuinely friendly and helpful, with no hint of either the patronising tone that is often extended to someone who needs help, or of 'reading from a script' associated with call centres. Wonderful!"*

This is the feedback from a satisfied user of the Parkinson's UK Helpline, for which contact details appear on every publication that is produced by the organisation and the branches (see the foot of page 3 in this Newsletter issue). We thought you'd like to know more . . . . .

The Helpline is a confidential service not *just* for people with Parkinson's but *anyone* affected by it – carers, family, friends, colleagues, and is also available to pharmacists. It receives an average of 25,000 enquiries a year and is staffed by trained advisers with access to specialists best equipped to provide relevant advice where necessary. Queries are diverse. Many are about the condition but others include seeking information about local services, peer support, emotional support, requests for publications, specialist help on benefits and employment issues, and how to raise complaints about NHS services.

User surveys are carried out twice a year with recent surveys yielding excellent or good overall ratings from well over 90%. These surveys are also used to highlight areas where improvements can be made so that the service goes from strength to strength.

## Side by Side



Yet again the feedback for the latest Side by Side course (held in October and November) proved extremely positive. The course is Branch funded to provide relevant information to those close to someone with Parkinson's and involves weekly sessions over a 6-week period. It ranks highly among all attendees for the information provided by visiting specialists.

A recent addition to the programme is a session on **relationships**, led by Anne Chilton, Head of Professional Practice for Counselling with *Relationships Scotland*. Anne was previously involved with *VOCAL (Voice of Carers Across Lothian)* and has 30 years' experience in relationship counselling and particular experience in counselling involving carers. If you attended a Side by Side course before this aspect was included and are interested in the topic, you can attend this session in a future Side by Side course. The next course will be held in the Spring. For more details, please use the link on the *Regular Activities* page of the Branch website or contact **Cathie Quinn, 0131 557 6438**.

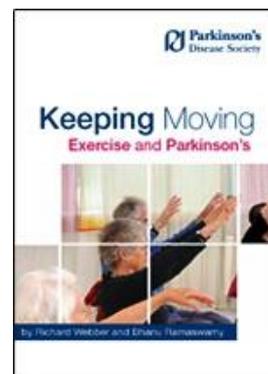
## RAAP

The **Rehabilitation at Astley Ainsley for Parkinson's** programme has been run by the neurological rehabilitation outpatient team since 1999. This is a 7-week programme preceded by a 1-2-1 assessment. Each week involves an exercise session led by a Chartered Neurophysiotherapist aimed at finding ways for participants to maintain general fitness and mobility. Then a refreshment break provides a social element before a group discussion is led by a specialist on a different aspect of Parkinson's. Topics include signs, symptoms and drug management, emotional and lifestyle issues, diet, sleep and body regularity, speech and communication, and finally disability aids. The specialists who provide information and facilitate the discussions include occupational therapists, nurses, dieticians, psychologists, and speech and language therapists.

The programme usually runs twice a year with a maximum of 10 participants each time. Application is via referral by Parkinson's nurses, GP's, consultants, physiotherapists and it is also possible to self-refer. Participant evaluations are usually very positive with regard to the exercise component, the specific information provided, the peer support element and enjoyment level. The next programme is likely to be in Spring 2014. If you are interested, please let your clinician know or get in touch with **Irene Nicol, Outpatient Coordinator, Astley Ainslie Hospital, irene.nicol@nhslothian.scot.nhs.uk, 0131 537 9065.**

## Keeping Moving Exercise DVD and Booklet

Available *free* from Parkinson's UK, this programme is intended as an exercise regime for those in the early stages of PD to improve and maintain physical function including postural control. It was devised in consultation with physiotherapists having an interest in PD, involved in research and with experience in running exercise classes for people with Parkinson's. The **DVD** includes work on postural *awareness*, techniques to correct poor posture, help with control of movement, and exercises for weight transference and balance. The **Booklet** can be used on its own, however the DVD (45 minutes) provides the added dimension of a physiotherapist talking you through the movements while 3 participants perform the exercises – makes it seem as though you're taking part in a class. Instructions are clear and the pace is slow/relaxed. Order via the Parkinson's UK website – search for *Keeping Moving* or telephone on **0845 121 2354.**



## Jubilo Choir

The Choir, which has selected Parkinson's UK Edinburgh Branch as its charity for 2013/2014, raised a splendid **£480** on 17<sup>th</sup> December while carol singing at Sainsbury's in Blackhall and afterwards at an outdoor carol party in India Street Gardens. A few days later, the Choir, together with the Edinburgh Players collected in the region of **£700** at a packed Carol Concert in St. Cuthbert's Church. The evening featured some beautiful baritone solos by Benjamin Ellis and a joyous and entertaining selection of carols and Festive pieces. Jubilo's next event is a **Baroque Concert in St. Cuthbert's on 5<sup>th</sup> April.**

## Festive Concert



This was a truly celebratory and uplifting event organised by Parkinson's UK Scotland Office in the inspirational setting of Greyfriars Kirk, with its established reputation as a major arts and concert venue. The *Singing4Fun* group surpassed all expectations with their performance of carols and festive songs – the weeks of learning part harmonies, conquering lyrics and coming together as a vocal team well and truly paid off. Their performance out of the way, members were then able to enjoy the remainder of the evening featuring the Edinburgh Junior Chamber Choir, Sangstream, the Vale of Clyde Pipe Band, and violin and piano pieces from the Rasaratnam Family. The event raised in the order of **£4000** for Parkinson's UK research in Scotland.

**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](mailto:hello@parkinsons.org.uk).

## More Fund-raising



Organised by Cathie Quinn, the **Biscuit Quiz** raised just short of **£140**. It seems that many spent long hours racking their brains, surveying supermarket shelves, Googling and working in team-mode with family and friends to identify the biscuits but there was only one outright winning submission (full marks), from Louise Ogilvy and a colleague. There was one runner-up – Annette McLeod. Well done! Here are the answers: Classic, Viscount, Rich Tea, Wagon Wheels, Jammie Dodger, Yo-Yo, TUC, Time Out,

United (or Club or Twix), Lemon Puff, Hobnob, Trio, Royal Scot, Penguin, Taxi, Shortbread, Break Away, Cream Crackers, 5-4-3-2-1, Brandysnap, Gold, Abernethy, Nice, Digestive, Gingernut, Double Decker, Morning Coffee, Kit-Kat, Caramel Log, Iced Gems.

**Race Night** on the 27<sup>th</sup> September, the first major event organised by the Branch's Fund-Raising Sub-Committee, raised **£1,705**. Well done to the team and their helpers for their sterling efforts and thanks to all who attended and made the evening a success.

The **Annual Quiz Night** held on 25<sup>th</sup> October once more proved popular and raised **£329**.

## People with Parkinson's Living on their own

We believe a number of people with Parkinson's who live on their own are interested in meeting with others in a similar position. Branch Committee Member, **Eileen Blackwood** will be organising something informal in the near future. If you haven't yet registered your interest and would like to do so, contact Eileen on **[e.e.bwood@gmail.com](mailto:e.e.bwood@gmail.com)**.

**Dates for Your 2014 Diary** (more details on Branch website or to follow)

**Research Interest Group: 8<sup>th</sup> February:** Dr Carl Counsell, University of Aberdeen, will give a talk on "*What changes over time for Parkinson's patients and their carers.*"

**Monthly Meetings: 12<sup>th</sup> February** – Dr Richard Davenport on "Current Parkinson's Developments;" **12<sup>th</sup> March** – AGM; **9<sup>th</sup> April** – to be announced.

**6<sup>th</sup> March:** a "**Moveable Feast Event**" involving three different courses in three different restaurants in the centre of town. See [www.parkinsons.org.uk/content/moveable-feast-edinburgh](http://www.parkinsons.org.uk/content/moveable-feast-edinburgh).

**26<sup>th</sup> April:** Coffee Morning, Craiglockhart Parish Church Hall.

**15<sup>th</sup> May:** annual Edinburgh Parkinson's Lecture at the Royal College of Physicians, Edinburgh. The lecture will be given by Professor Anthony Schapira, University College London on "*Recent Advances in the Cause and Treatment of Parkinson's Disease.*"

## And Finally

**UCanDoIT** is a charity that teaches people with disabilities how to use computers in their own homes and on their own computers, with particular focus on Internet and email skills, Charges depend on disposable income. Trainers are available in Edinburgh. To find out more, ring **020 8673 3300** or email, if able, to **[enquiries@ucandoit.org.uk](mailto:enquiries@ucandoit.org.uk)**.

**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](http://www.parkinsons.org.uk).

**Parkinson's UK Edinburgh Branch**, [www.edinburghparkinsons.org](http://www.edinburghparkinsons.org), Mrs. Pat Stewart, Hon. Sec., tel. 0131 449 2705, [Honsec@edinburghparkinsons.org](mailto:Honsec@edinburghparkinsons.org).