Parkinson’s UK Edinburgh Branch Newsletter March 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. We also remind you of the ***wealth of information on the Parkinson’s UK and Branch websites.***

ParkinsonNet Seminar 22nd February led by Patrick Mark, Hon. Branch Chairman

Background

It is now internationally accepted as “best practice” that people with Parkinson’s (and those with other neurological conditions) should have ready access to multi-disciplinary teams of physiotherapists, speech and language therapists, occupational therapists and more, all with specialist training and experience in PD. This is currently not a feature of the health service throughout the UK. There *are* some examples of good practice but for many in the Lothians, the situation is poor. As elsewhere in *Scotland*, NHS Lothian has groups working to identify and implement new and improved working methods for neurological conditions. Patrick Mark has consistently campaigned on behalf of those with Parkinson’s in the Lothians and played a part in encouraging NHS Lothian to appoint two more Parkinson’s Nurses in 2010. He represents us on a number of these development groups:

- *Lothian Parkinson’s Service Advisory Group* founded in 2007 by Parkinson’s specialists to co-ordinate and develop services for people with Parkinson’s and chaired by Dr. Conor Maguire.
- *Lothian Neurological Improvement Group* established by NHS Lothian in response to the introduction of the Clinical Standards for Neurological Health Services (2009) by Healthcare Improvement Scotland.
- *Lothian Neurological Voices* which prepares people with neurological conditions and their carers to get involved in planning and improving neurological health services; it comes under the *Neurological Alliance of Scotland* launched in 2004, an umbrella of organisations and groups representing people living with, or affected by a neurological condition.
- The *National Neurological Advisory Group* set up in 2012 to oversee and support NHS boards in Scotland as they implement improvements and with its *Operational Management Group* focussing on local operational issues within Scottish NHS boards.

So, on the face of it there is much activity in terms of forums for discussion and exchange of information but since the introduction of the Clinical Standards in 2009 no serious headway has been made in improving neurological services and in particular, Parkinson’s services in the Lothians. Yes, there has been some improvement in recent years. But, if we try and draw a schematic of how and what services *are* provided for people with PD in the Lothians, it becomes obvious just how large and unwieldy a structure is involved. Co-ordination is poor and integration is a long way off, with no hint in sight of access to multi-disciplinary teams of specialists.

What might be done to achieve much needed improvements?

There are a number of models for integrated healthcare being tried world-wide but the most encouraging in terms of results with PD is ParkinsonNet in the Netherlands.

The driving force behind this healthcare system is ***Professor Bloem***, Neurologist at Radboud University Nijmegan Medical Centre. Prof. Bloem has also worked in the USA and the UK. ParkinsonNet was described and discussed in a 2012 teleconference hosted by Parkinson's UK. The tele-conference, which includes visuals, was played at the Branch Seminar and can be accessed on request (see end of this article).

Here is a summary of Professor Bloem's key points:

Motivation to take a different approach (Netherlands perspective):

- After some years, PD becomes not just a dopaminergic condition but increasingly a non-dopaminergic one, for which patients don't have medication – PD *cannot* be managed by neurologists alone.
- Many different disciplines can be involved in the care of patients and their families but with no effective care structure, referrals can be *ad hoc* and there can be under-treatment and sometimes over-treatment.
- Many therapists treat only a few people with PD each year, these therapists are insufficiently trained and are not aware of what *other* professionals can also do for their patients.
- Referrals tend to be inadequate or inappropriate, with those professionals involved not communicating with each other.
- When surveyed, patients want patient-centred care that includes emotional support, relevant and helpful information, shared decision-making, expert professionals and transparent choices.

Development of ParkinsonNet

Prof. Bloem and his team began in 2005 with the catchment area of a single hospital. They identified all physiotherapists treating PD but most were treating just one to three people with the condition each year. The team selected a small number of physiotherapists to cover the catchment area equally, gave them specialist training, promoted communication using Internet facilities, and made them visible to referring physicians and patients. The outcome – these physiotherapists attracted a large volume of patients so they gained valuable experience and became even better at treating people with Parkinson's. The system developed from there.

By 2012, ParkinsonNet had nationwide coverage in 19 disciplines relevant to PD (physiotherapy, occupational therapy, dietetics, speech and language therapy, psychiatry, geriatrics etc.) and involving over 1800 specialists. Each year there is a symposium where these experts are brought together to listen, learn, exchange information and make face-to-face contact with those professionals they might have "met" only via the Internet.

Because the system is Internet driven, patients can choose their specialists based on location and expertise – the patient effectively builds his/her own "regional hospital." Those unable to, or not confident in using the Internet, usually have family and friends to help. ***The computer network system is robust and built with safety and security in mind***.

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*.

Identified advantages

- Patients deal with their problems at their own pace and are able to prioritise their complications.
- *Shared* decision-making, not clinician-driven (because the clinician feels most comfortable with a particular treatment).
- The system brings patients and professionals closer together.
- It promotes exchange of information with blogs, a discussion forum and a mechanism for therapists to share information and find solutions for individual patient problems, based on the experience of others in the network.
- It allows delivery of high-quality care from *specialists*, with fewer disease complications (e.g. hip fractures) and reduction in hospital admissions.
- Because of the information exchange including that of unusual patient circumstances, it provides a good structure for innovation and research by the seven universities that are part of ParkinsonNet, with better trials and faster availability of results which can then be clinically implemented where appropriate.
- Because each "regional hospital" is given a fixed income, there is an incentive to keep well within this and make a profit, while still having to fulfil quality control criteria. This has encouraged development of programmes to keep patients as healthy as possible despite their condition, e.g. through physical activity and good nutrition, so maximising potential profit.
- Transparent monitoring – a Consumer Quality Index is maintained and vetted through the eyes of the *patient* which also provides a good benchmark for improvements.
- Annual costs of care within the Parkinson's budget in Holland have been significantly reduced.

The system has now spread over the border to Germany, similar networks for other disorders are being explored and schemes to assist family carers are being developed.

Can we use ParkinsonNet to influence improvements in NHS Lothian services?

The general consensus from the Seminar roundtable discussions after the presentation was highly favourable for the ParkinsonNet approach. While recognising there are structural differences between the Netherlands Health Services and NHS Scotland the consensus was that such a system *could* fit into the NHS Lothian Strategy. (A summary of the views is available via the Research Interest Group page on the Branch website.) The most important aspects were that it is patient-driven, involves specially trained therapists, provides integrated consistent services, and promotes information flow and *exchange* of information. There was resounding approval for the Branch to promote its concepts.

If you were not able to attend the Seminar, and would like to listen to the teleconference, or to listen again, please contact Ken Bowler via the Research Interest Group page on the Branch website. **We encourage you to make your opinions about ParkinsonNet and its relevance to you known to the Branch and to your health professionals.**

Branch Questionnaire

Thank-you to everyone who completed the questionnaire. The results were presented by Sheila Edward after the Branch AGM on 12th March and a documented report on the analysis is enclosed with this issue. We are pleased to see the general consensus is that we are providing activities that members appreciate but there is still scope to improve. We have decided to set aside the next Branch Meeting (9th April) to open up the discussion among members as to the way forward from here. *More details on the enclosed Events page.*

Younger Parkinson's Group

The Group provides an opportunity for those with Parkinson's and of working age to socialise on the first Thursday of the month. The venue is the Steading, 118 Biggar Road, EH10 7DU, 6.30-9pm, with the conservatory usually set aside to provide a relaxed private setting where participants can drop in at any time, stay for as little or as long as they like and order a meal if required. Outings and other events are arranged by agreement with members. A highly successful Burns Supper was organised on behalf of the Group on 25th January. "Never been to a Burns supper before, but this was excellent, can't wait for the next one" was the parting comment from a happy guest! If you haven't yet been to a YPG evening, why not give it a try and experience the warm, friendly, supportive and laughter-filled atmosphere? Contact Scott Wilson, *scottwils01@btinternet.com, 07835 820898*, to find out more.

Fund-raising

Once again, **Gavin McBain** (son of Liz and Bill) will be fund-raising for us. This time it's his first marathon – the Paris one on 6th April. Starting on the Champs Elysées, Gavin may take in many historic and romantic sites - Notre Dame, the Bastille, the Eiffel Tower, the Louvre and follow the banks of the picturesque Seine much of the way but it's still a challenging 42km (26 miles) before finishing in site of the Arc de Triomphe. Please donate via *www.justgiving.com* and put *Gavin McBain* in the *Support a Friend* search box or send a cheque made out to *Parkinson's UK* to Mrs Liz McBain at 119 Craigleith Hill Avenue, Edinburgh EH4 2NB.

Carol Mott, a Tuesday Singing4Fun group regular will be trekking the Annapurna Circuit in Nepal in October. This challenging 23-day event includes crossing the Thorong La Pass at 5416m. Carol is raising funds for the Branch. Please sponsor her via *www.justgiving.com* (put her name in the *Support a Friend* search box). We hope she will be singing all the way!

Art Group

This activities group meets on Mondays fortnightly, 10.15-12.15 with two of the members who have professional experience, Christine Ellis and Lindsay McDermid giving advice and guidance. Participants can do their own thing or work according to the topic highlighted for the day. It is also an opportunity for participants to share their experiences and help each other. Some have submitted their work for *The Mervyn Peake Awards*, a celebration of the talents of people with Parkinson's in memory of the late Mervyn Peake, a much-admired artist and writer who had PD. All standards are welcome. The aim is to seek enjoyment from being creative and to socialise with fellow artists. The cost is £1 towards refreshments. Please contact Liz McBain, *Liz@edinburghparkinsons.org* or *0131 315 2493* for details of this venue.