

PARKINSON'S UK, EDINBURGH BRANCH

NOTE OF SECOND MEETING OF RESEARCH INTEREST GROUP, ROGER LAND BUILDING, THE KING'S BUILDINGS, UNIVERSITY OF EDINBURGH, SATURDAY SEPTEMBER 17, 2011, 10.30-12.30.

The meeting was attended by 19 people, including several who had been unable to attend the inaugural meeting in July. Ken Bowler welcomed the group, outlining the agreed objectives:

- 1. to provide opportunities for members with an interest in Parkinson's research to meet, communicate, work together and generally further the cause of research;**
- 2. to encourage and develop all members' interest in research.**

Ken then presented elements in the outline action plan which had been developed after the previous meeting, for discussion in turn.

A 'Roger Barker Day', to increase awareness of scientific research particularly in the stem cell and genetic fields

Patrick Mark suggested inviting Dr Roger Barker (Reader in Clinical Neuroscience, University of Cambridge), to present a lecture at a suitable central Edinburgh auditorium. This would probably be in early summer 2012, early evening on a weekday, in conjunction with Lothian Parkinson's Forum.

Tilo Kunath advised that joint sponsorship with the Institute of Stem Cell Research might be possible, if Roger Barker agreed to give a lecture for professional researchers at ERI earlier on the on the same day. The group agreed that this was an excellent idea, although there was some debate about whether the ERI site would be a more convenient and accessible venue for both events. Patrick, Ken and Tilo Kunath will take forward the planning of this, together with Dr Maguire (Chair of Lothian Parkinson's Forum).

The programme for the Branch Meeting on 12 October.

Ken apologised for not being able to attend, but the meeting would include a 20-30 minute presentation by Diane Wilsdon on involvement opportunities in Health and Social Care for people living with Parkinson's in Edinburgh; a presentation by Dave Lee on sound and movement; and up to three brief presentations by members of this group¹. Three members volunteered topics.

¹ Subsequent to the ERIG meeting, the agenda for 12 October has been amended to include a presentation by Patrick Mark based on the lessons from the World Parkinson's Congress in Glasgow last year on what best practice is for Parkinson's services worldwide, and how this relates to Lothian instead of the short contributions by members.

A Medication Masterclass, to be led by a Parkinson's Nurse Specialist.

Patrick reported that Alison Stewart had agreed in principle to do this, in a session from 11am-3pm, including a presentation from her, followed by lunch and a discussion / question and answer session. Volunteers were sought to organise the detail of the date, venue and structure: Marian McIntyre, Leonore Hislop and Liz McBain offered to take this forward. Because of Alison's professional involvement, it was likely to be held on a weekday.

'Take Charge' events, on topics such as diet, exercise and physiotherapy.

There was considerable debate around this topic and two models emerged from the discussion. Firstly, we could run events with invited expert keynote speakers, such as Lucille Leader on nutrition or Lyn Rochester on physio, possibly taking over sessions in the future Branch monthly meeting programme to provide slots. This option clearly aims to meet the *second* of the two objectives of the Research Interest Group as defined above. Secondly, we could 'take charge' by providing a chance for the group to engage with pre-arranged topics, reading up on recent research reports in *Progress* and other published sources to generate discussion within the group. This second option addresses the *first* of the defined objectives, providing a forum for interested members to communicate and work together to develop their understanding of research.

It was agreed that it should be possible to cater for both options, by providing a range of different meetings. Given that the Branch monthly meeting programme for this year is already fully arranged, and taking into account the additional events that are already being planned around Roger Barker and the Medication Masterclass, we agreed that the next meeting for the group would be on the topic of nutrition, on a date to be arranged in early December at the new premises at the ERI. Members would bring their thoughts, questions and readings on nutrition for discussion.

ERIG Web Page

Ken reported that a Research Interest Group web page had been set up since the last meeting and could be accessed via the menu on the Branch web page at <http://www.edinburghparkinsons.org/>. Thanks to Emily Hughes, a list of Scottish research projects funded by Parkinson's UK was now available and could be accessed via the new page, along with links to other research resources.

PAW Event

Ken reported that the Parkinson's UK Research Support Network (RSN) was planning a public event in Edinburgh during Parkinson's Awareness Week, 16-22 April 2012, with Tilo as lead speaker. Details were unclear at this stage but the principal organiser is Stacey Storey at HQ in London. Tilo confirmed that the precise date and time had not yet been agreed.

The Next Meeting

The date of the meeting in early December will be arranged with Tilo, after the move to ERI has been completed. Members were invited to let Ken know in advance about books, articles and ideas they want to discuss at the December meeting, so that other group members can also prepare for the discussion.

Sound and Movement

At the conclusion of formal business, Professor Dave Lee from the Department of Psychology at the University of Edinburgh gave a short presentation on his work on developing a therapy for patients with movement disorders such as Parkinson's. There was a practical demonstration of "Whoop" training. Further information can be found at <http://www.pmarc.ed.ac.uk/>