

PARKINSON'S UK, EDINBURGH BRANCH

NOTE OF INAUGURAL MEETING OF RESEARCH INTEREST GROUP, ROGER LAND BUILDING, THE KING'S BUILDINGS, UNIVERSITY OF EDINBURGH, SATURDAY JULY 2, 2011, 10.30-12.30.

1. OUTLINE OF THE MEETING

Of the 24 people who had expressed interest in joining the group, 18 had said they would attend, and of these, 14 attended on the day. Participants included six people with Parkinson's, their partners and other interested parties, including Tilo Kunath, whose stem cell research premises provided a very flexible venue for the meeting, Emily Hughes from Parkinson's UK, and Claire Lamb, an occupational therapist with a strong interest in Parkinson's.

After a welcome from Tilo, who noted that his research team would be moving shortly to a site adjacent to the ERI at Little France, Patrick Mark explained that the impetus for setting up this group had come from the enthusiasm for the Glasgow World Congress last year and the very well attended feedback meeting which had followed. Lubna Arif and colleagues in SPRING had been informed of our intention to set up a local research group, which had not been done anywhere else before.

Ken Bowler then explained that the intention in setting up the group was to increase awareness of research into Parkinson's and to develop understanding of that research, but he stressed that the agenda should be driven by the membership. Following an opportunity for all participants to introduce themselves briefly and explain their motivation for attending, the meeting then divided into two discussion groups, led by Ken and Patrick respectively, to consider two broad questions:

What do you personally want to achieve?

What do you want the group to achieve?

In the closing plenary session, the group leaders summarised the discussion, which was further debated, and it was agreed that a further meeting would be held in September to finalise an action plan (see Section 3 below).

2. THEMES EMERGING FROM THE DISCUSSIONS

Participation in the Research Interest Group

The holiday season, fine weather and perceived inaccessibility of the King's Buildings meeting might all have contributed to the relatively small attendance, which did however encourage participation in the discussions. It was suggested that numbers attending future meetings might be increased by a postal mailshot to a wider range of members, and by giving information about the group's activities at the regular monthly branch meetings.

Potential scope to influence research priorities

Although all were agreed on the importance of scientific research on, for example, stem cells and foetal tissue transplants and also of research on care and coping strategies for people with Parkinson's, there was less consensus about which of these we might most usefully discuss. For many, day-to-day issues, such as nutrition, medication, exercise of body and mind and ways of being able to communicate to health professionals and researchers the realities of living with Parkinson's, were seen as more important than understanding advances in scientific research. To use the distinction made by Ken in his introduction, most participants would be satisfied with *awareness* of scientific advances, but sought more *understanding* of the day-to-day issues, and stressed the need for more research in this area. While there was limited scope to influence directly the decisions on which projects were funded by Parkinson's UK, Emily indicated that any priorities identified by the group would be listened to by those who set the research agenda.

Potential scope to tap into the experience of the group

A recurrent theme was the desire not only to understand more about coping with Parkinson's, but also to share experience, both with researchers and with other people with Parkinson's. One participant commented that on a visit to a research centre, he had been depressed by the things that the researchers did *not* know about Parkinson's, while another noted the value of making visits to speak to research teams as an opportunity to give them contact with people who know more about coping with the day-to-day realities of Parkinson's. The discussions also revealed a strong interest in sharing with other people with Parkinson's their understanding and knowledge of what had worked well for them. This broadened out into discussion of a 'Take Charge' event, which might focus on topics such as nutrition, exercise, dance, gym, or singing with a presentation from Lucille Leader, possibly incorporating evidence from members who had participated in the activities and could describe how they personally had found them useful.

Participation in research projects

Several people expressed interest in taking part in research projects. A few in the group already had experience of participation, and questions were raised about how information about such opportunities becomes available. There was also strong interest in visits to research projects, and in the list of research projects based in Scotland which is to be published by Parkinson's UK in a forthcoming newsletter.

3. ACTION PLAN

As noted above, an action plan will be finalised in September. This might include:

- A 'Take Charge' event, with a keynote speaker
- A 'Star Speaker Day' to increase awareness of scientific research particularly in the stem cell and genetic fields.
- Visits to research projects
- A Research Interest Group Newsletter, distributed to all members.
- A Medication Masterclass led by a PNS.

The September meeting will also discuss how the group might contribute to the monthly branch meeting scheduled for 12 October 2011.