

**Prospective All Party Parliamentary Group for Parkinson's Disease
Inaugural meeting
5pm, 3 June 2008; Committee Room G, House of Lords**

Attendees:

Lord Ashley of Stoke, Paul Burstow MP, Russell Brown MP, Jeremy Browne MP, Rt Hon Kenneth Clarke MP, Lord Clement-Jones, Baroness Finlay, Baroness Gale, Nia Griffith MP, Earl Howe, Baroness Howells, Mark Hunter MP, Madeleine Moon MP, Andy Reed MP, Baroness Shephard, Phil Willis MP, Baroness Wilkins

Karen Rose, Marion Wale

Steve Ford, Val Buxton, Dave Clark, Helen Kirrane, Clare Moonan, Anjuli Veall - Parkinson's Disease Society

1. Welcome

Baroness Gale, as host of the meeting, welcomed and thanked parliamentarians for attending. Attendees were briefed on the background to the setting up of the Group, including discussions held between a cross-party group of Parliamentarians on 4 March 2008.

Baroness Gale thanked the Parkinson's Disease Society for their support in organising the meeting.

2. Apologies

Apologies for the meeting were noted (see attached).

3. Purpose and activities of the prospective All Party Parliamentary Group on Parkinson's disease

Baroness Gale referred to the proposal paper tabled at the meeting outlining the aims of the Group. The remit was agreed as follows:

It is proposed that the Group's remit includes:

- To keep Parkinson's disease on the political agenda
- Investigate, monitor, report on, provide a forum for discussion and exert pressure on issues relating to implementation of relevant Government initiatives, with the ultimate goal of ensuring equal access to recommended and appropriate health and social services to all people with Parkinson's and their carers
- Provide regular briefings to Parliamentarians in order to ensure awareness of the needs of people with Parkinson's and their carers
- Ensure policy-making is evidence-based and focused around the needs of service-users.
- To liaise with members of the devolved administrations within the UK in order to share best practice

A discussion took place on whether the Group should take the form of an All Party Parliamentary Group or an Associate Parliamentary Group. It was agreed to form an All Party Parliamentary Group.

4. Election of proposed officers

The following elections took place:

- Chair: Baroness Gale (Lab) - nominated by Madeleine Moon MP (Lab), seconded by Baroness Howells (Lab)
- Vice Chair: Mark Hunter MP (Lib Dem) – nominated by Baroness Howells

- Vice Chair: positions vacant – it was agreed to elect further Vice Chairs at a subsequent meeting.
- Joint Secretaries: Madeleine Moon MP (Lab); Paul Burstow MP (Lib Dem) – nominated by Russell Brown MP
- Treasurer: Jeremy Browne MP (Lib Dem) – nominated by Russell Brown MP

5. Appointment of Secretariat

Baroness Gale said that the Parkinson's Disease Society had agreed to provide the Secretariat to the prospective Group.

6. Parliamentary launch of the Parkinson's Disease Society Members' Survey

Baroness Gale introduced Steve Ford, Chief Executive of the Parkinson's Disease Society. Steve thanked Baroness Gale for hosting the meeting and thanked parliamentarians for their ongoing support for the issues affected by people with Parkinson's disease.

Steve talked about the new PDS Members' Survey, the findings of which highlight the problems of inequity of access to appropriate health and social services by people with Parkinson's disease and their carers.

Baroness Gale introduced Marion Wale who talked about her father's experience of Parkinson's disease. Marion recounted the problems her father encountered in residential care; the fact that he had been denied hospice care; the difficulties encountered in hospital in terms of timing of medication and the overall effect that these issues had on her mother who was the prime carer. Marion went on to describe how the National Service Framework for Long Term Conditions had since been introduced in her local area and how this was beneficial to people currently living with Parkinson's disease.

Baroness Gale thanked Marion for sharing her experiences and introduced Karen Rose who spoke about living with Parkinson's disease and the impact it has had on her life. She mentioned the support received from a number of sources including her local Parkinson's disease nurse specialist, her physiotherapist and her well informed GP.

Baroness Gale thanked Karen on behalf of the new Group and commented on the optimism, enthusiasm and confidence highlighted by Karen's story.

7. Questions and answers

- Baroness Shephard commented on the figure of 120,000 people living with Parkinson's disease in the UK. She asked whether this could be an underestimate.
- Steve Ford said that the figure was based on Parkinson's affecting one in 500 of the population. He acknowledged that there is a potential for under-diagnosis.
- Baroness Finlay thanked both speakers for their presentations and talked about the work of hospices and how many of them no longer have disease-boundaries. However, there remains a shortage of hospice beds. She agreed that the problem of managing medication timing remains an issue, especially in residential care. In this context, the question was asked about the PDS' local work aimed at educating professionals. Baroness Finlay also raised the point about access to specialist nurses and access being threatened when local budgets are cut.
- Steve Ford spoke about the work of the Parkinson's Disease Society's education team and plans to raise awareness of staff working in residential

care. The PDS is also funding research into the experiences of people with Parkinson's living in residential care and the outcomes of this will go towards shaping future education work.

- Lord Ashley said that he was very impressed with the two speakers. He emphasised how every individual has a different experience of Parkinson's disease. He emphasised the role that information has on supporting people living with the condition,
- Steve Ford agreed and said that the PDS' members' survey highlighted the need for information. The challenge is to ensure that information produced for people with the condition reaches everyone affected.
- Mark Hunter MP said that he is involved with his local Parkinson's Disease Society branch in Stockport. He also mentioned that his mother has Parkinson's disease. He referred to the PDS Members' Survey and how this highlighted the lack of understanding of staff working in residential care, especially in relation to the importance of the timing of medication. He posed the question, 'what can parliamentarians do to try and improve the care regime in care homes?'

8. Future agenda for the Group

Baroness Gale said that a number of ideas had been put forward for work to be carried out in the future. It was proposed that this be discussed amongst proposed Officers at a future meeting.

9. Any other business

There was no any other business.

10. Future meetings / dates

To be confirmed shortly.

Baroness Gale thanked parliamentarians for attending and closed the meeting.