



## **ALL-PARTY PARLIAMENTARY GROUP FOR PARKINSON'S (DISEASE)**

AGM and Inaugural meeting - 6 July 2010, 4.30pm, Committee Room 2,  
Palace of Westminster

### **MINUTES**

#### **APPG AGM Attendance**

Baroness Gale, Madeleine Moon MP, Lord Brooke of Sutton Mandeville, Mark Durkan MP, Lord Cobbold, Lord Walton, Tony Baldry MP, George Howarth MP, Steve Brine MP, Glyn Davies MP, Baroness Howells of St. Davids, Duncan Hames MP, Viscount Simon

Anjuli Veall, Social Policy and Campaigns Manager, Parkinson's UK; Debbie Moss, Parliamentary Officer, Parkinson's UK

#### **Apologies:**

Jim Cunningham MP, Baroness Finlay, Margot James MP, Phillip Lee MP, Baroness Thornton, Lord Dixon, Baroness McIntosh, David Amess MP, Mike Gapes MP, Andrea Leadsom MP, David Amess MP, Mark Hunter MP, Mike Weatherley MP, Lord Clement-Jones, Lord Bishop of Leicester, Bishop of Exeter, Bishop of Salisbury, Baroness Royall, James Brokenshire MP, Lord Myners, Baroness Wilkins, James Arbuthnot MP, David Blunkett MP, Caroline Dinenage MP, Lord Puttnam, John Penrose MP, Rebecca Harris MP, Keith Simpson MP, Bob Blackman MP, Lady Greenfield, Baroness Cumberlege, Lord Harrison, Anne Begg MP, Lord Jenkin, Bishop of Manchester, Baroness Garden, David Evennett MP

#### **Part 1 – AGM**

##### **1. Introductions and welcome**

Baroness Gale thanked everyone for coming and welcomed them to the AGM and first meeting of the new Parliament.

2. Approve minutes from the last meeting  
Minutes of the last AGM were approved

##### **3. Apologies and membership**

Baroness Gale drew our attention to the list of apologies and also to the healthy and growing membership list.

##### **4. AGM – election of officers**

The following officers were proposed and seconded:  
Chair: Baroness Gale (LAB)

Vice Chairs: Baroness Finlay (CROSSBENCHER) and Steve Brine MP (CON)  
Secretaries: Lord Brooke of Sutton Mandeville (CON), Madeleine Moon MP (LAB)  
Treasurer: Duncan Hames MP (LIB DEM)

**Further AGM business:** The Group approved the description of the Group – as on the Register, confirmed it was an APPG and that Parkinson’s UK would continue to provide the secretariat.

Baroness Gale thanked Emily Cogbill for her work on the group’s behalf and Madeleine Moon suggested the Group write to thank her and wish her well. Baroness Gale confirmed this would be done.

## **Part 2 – The APPG Meeting**

### **5. Baroness Gale – fuller introduction and annual report on activities following the APPG report**

Baroness Gale welcomed parliamentarians who had been gradually arriving and reported that a number of new MPs had joined the group. She added that she had received a letter from Paul Burstow MP, explaining that while neither he nor the Secretary of State could be present at the meeting, they “are looking forward to working with the sector, including the Parkinson’s APPG, to carry the agenda forward”.

Baroness Gale then spoke briefly about the APPG report into access to services for people with Parkinson’s, saying that it had concluded that there was a postcode lottery. The Group should now take forward a programme of work to influence the Government and the devolved administrations to implement our recommendations.

### **6. Brian Lymbery - expert service user with Parkinson’s**

- Brian Lymbery talked about being diagnosed in his mid 40s and said he was likely to spend as much of his life with Parkinson’s as without it.
- He welcomed the APPG report as a major achievement and talked about the need to address its findings urgently. This should include bringing about the training of medical professionals about the condition, addressing medicines management in hospitals and ensuring that people fully understood the meaning of a fluctuating condition.
- He also said the report’s recommendations would save money, eg. in the prevention of falls. He stressed the importance of implementing the Mid Point Review of the National Service Framework on long-term neurological conditions.
- Brian then talked about the symptoms of Parkinson’s, including how he had managed to serve as Chair of Lewisham PCT for five years whilst he had the condition.
- He noted that the report had found that many people from Black, Asian and Minority Ethnic (BAME) communities were undiagnosed and that this presented a significant challenge.

- He congratulated the APPG for its achievements in the last Parliament and hoped there would be many more in the new Parliament.

## **7. Discussion about next steps for taking forward the APPG report in the new Parliament**

Baroness Gale thanked Brian for helping those present to have a better understanding of Parkinson's and noted that her father had been affected by it.

Lord Walton said that as a retired neurologist he was impressed by what Brian had said. He noted that many people did not know that the kind of movements associated with Parkinson's (which can be confused with drunkenness) were not in fact a result of the condition, but of the treatment. He said that he and others in Parliament would do the best they could to support people with Parkinson's.

Brian commented that it will be interesting to see what effect the Government's proposed changes to the welfare system will have on people with Parkinson's. In particular, the assessment of benefits claimants may prove problematic for people with fluctuating conditions, as they could seem completely well at the time of the assessment and therefore fail to qualify for the assistance they need.

Baroness Gale said that Parkinson's UK were working on this policy issue, and Debbie Moss confirmed that Parkinson's UK could provide further briefing on this and other issues and invited parliamentarians to approach the secretariat at their convenience.

## **8. APPG Parkinson's / Parkinson's UK reception on 17 November 2010, 4-6pm, Terrace Pavilion, House of Commons**

### **9. Meeting for officers – to discuss priorities for the APPG in the new Parliament**

Baroness Gale proposed that this should take place in October.

CLOSE OF MEETING