

## **Cross Party Group on Muscular Dystrophy Minutes – 11/12/13**

### **Attending:**

**Jackie Baillie MSP, Chair of the Cross Party Group on Muscular Dystrophy**

**Nanette Milne MSP**

**Michael McMahon MSP**

1. Jackie Baillie MSP, Chair of the Group, gives an introduction to the session and welcomes guests and MSP colleagues. She also congratulates Robert Watson on the success of his recent petition on hospice and respite care for young disabled adults, which has led Parliamentary debate on the issue scheduled for this Spring.
2. Jonathan Kingsley, Muscular Dystrophy Campaign, Secretariat for the Cross Party Group, updates the group on recent campaigning activities in Scotland. He also adds his thanks to Robert Watson.
3. Discussion on hospice and respite care following Children's Hospice Association Scotland's decision to withdraw its services for young disabled adults.

### **Evidencing Need**

- Need to obtain data to determine the scale of the problem; improvements in care and life expectancy for young disabled people with life shortening conditions means numbers needing hospice and respite care is only likely to increase.
- Statistics from England extrapolated to Scotland would also suggest a high demand that is now going to go unmet.
- It would be particularly helpful to have access CHAS' own data would but we will also need to look at collecting information from other bodies, including Local Authorities, Healthcare Improvement Scotland and individual hospices
- Muscular Dystrophy Campaign's own research has provided useful data so far and steps will be taken to increase the number of people filling in the charity's online survey on hospice provision in Scotland

### **Finding Alternative Provision**

- CHAS' model is based on charitable funding. As such, the Government may be reluctant to provide funding itself, but it may be prepared to facilitate dialogue between interested parties
- Need to qualify terms within this discussion; hospice care is a broad area and care is provided within difference settings e.g. respite, palliative

- Health Boards may provide the best solution; if they could be persuaded to support this provision then greater long term stability could be ensured
- On an individual basis, smaller, independent hospices may also be able to provide facilities
- Need to enlist the support of other organisations supporting young disabled adults to help find new provision

### **Next steps**

- All efforts need to be put into the forthcoming Parliamentary debate, to ensure that a persuasive and comprehensive case on the value of hospice and respite care for young disabled adults is made
  - Muscular Dystrophy Campaign to lead on collating statistical evidence and case studies
  - Need to bring in other affected organisations/groups to brief the MSPs they are in contact with
4. Jackie Baillie thanks all those who attended and closes the meeting.