

## **Cross Party Group on Muscular Dystrophy AGM meeting minutes**

**29<sup>th</sup> May 2013, 1pm to 2.30pm, Committee Room 1**

1. Jackie Baillie MSP, Chair of the Group, introduces the session and welcomes MSP colleagues and guests
2. Jonathan Kingsley, Muscular Dystrophy Campaign, Secretariat for the Cross Party Group, updates the group on recent campaigning activity in Scotland
3. Discussion on adult respite care

The gap in this vital aspect of care for young adults affected by muscle-wasting conditions has been highlighted by the decision of the Children's Hospice Association Scotland (CHAS) to withdraw its services for young adults.

Jackie Baillie MSP, Chair of the Cross Party Group, invited representatives from CHAS to outline its transition programme to find alternative provision. Our supporters from across Scotland shared their concerns about the lack of potential alternatives available and the group intends to raise these comments with the Scottish Government to address the lack of services as soon as possible.

4. North of Scotland Care Advisor update – Jackie Baillie updates the group about her recent PQ and the Minister's answer on the remit and evaluation process
5. Discussion on access to rare disease drugs focusing on the appraisal process for treatments and inconsistencies uncovered across Scotland
6. Closing remarks and ideas discussed for next Cross Party Group session in the autumn