

Cross Party Group on Muscular Dystrophy AGM – 24th June 2014

Present:

Jackie Baillie, MSP
Nanette Milne MSP
Jim Eadie MSP
Sheonad Macfarlane, Chair of Muscular Dystrophy Campaign's Scottish Council
Gary Kernahan, Muscular Dystrophy Campaign
Mariana Pierotti, Muscular Dystrophy Campaign
Dean Widd, Muscular Dystrophy Campaign
Mark Chapman, Chair of Muscular Dystrophy Campaign's Scottish Muscle Group and Trustee of DMD Pathfinders
Rachael Andrews, Anderson Strathern
Libby Milton, Prince and Princess of Wales Hospice & Adult Hospice, Glasgow
Jo Yates, Leuchie House
Babs Henderson, Children's Hospice Association Scotland
Karen Swan, Genzyme
Paul Lenihan, Action Duchenne
John Miller, Action Duchenne
Sally Egan, NHS Lothian
Paul Currie, DG Health and Social Care
Liz McDermott
Frances O'Hagan
Jim O'Hagan

1. Jackie Baillie MSP gave an **introduction to the session** and welcomed guests and MSP colleagues
2. **Sheonad Macfarlane, Chair of the Muscular Dystrophy Campaign's Scottish Council, presented the charity's report on hospice and respite care for young disabled adults in Scotland, *Give us a break*.** She praised Robert Watson, who initiated the campaign, and presented the report's recommendations, central to which is a thorough and wide ranging Government review of hospice and respite facilities for young adults, with a view to costed proposals in six months.
3. **Discussion and next steps**
 - A copy of the report has been sent to the Cabinet Secretary and Jackie Baillie will write to Alex Neil urging him to identify a lead and to bring forward a review as a matter of urgency
 - Jackie Baillie updated the group on plans for a debate, which her and MSP colleagues hope to be able to secure for around September
 - The group agreed that the report gives a useful snapshot of lack of provision, but it will still be helpful to collect supporting data to evidence need, both for a debate in the Scottish Parliament and to take the campaign forward. Jackie Baillie encourages group members to submit supporting data to the Muscular Dystrophy Campaign
 - Libby Milton spoke of the importance of securing a Government review, as the issue is a national one, requiring national leadership and brokerage, bringing together key stakeholders to move forward with a solution
4. **AGM** - moved by Nanette Milne and seconded by Jim Eadie and John Miller
5. **Paul Currie gave an overview of the Scottish Government's Implementation Plan for the UK Strategy for Rare Diseases.** He explained the draft plan – It's Not

Rare to Have a Rare Disease – is currently with the Cabinet Secretary for approval and is likely to be released by the end of the month. He highlighted that Managed Clinical Networks operate locally and nationally and do a good job in supporting particular conditions. He emphasised the need to work with others to push the plan forward, to cooperate to better deliver services for rare diseases and develop patient registers to allow for better planning of services. He also highlighted the need to develop undergraduate disease training and work to allow GPs to recognise conditions early on.

6. Questions and discussion

- John Miller asked what plans there were to sustain ring fenced funding for drugs for rare diseases. Paul Currie explained funding is in place to sustain this until 2015/16 although was not able to comment on plans beyond this as it was not an area he is personally involved with working on
- Liz McDermott highlighted Scotland is a small country and asked if the Government was looking at best practice in other small countries, such as Denmark. Paul Currie informed the group that it would be for the implementation group to look to the experience in other European countries
- Sheonad Macfarlane thanked Paul Currie for his presentation and echoed the need for improved undergraduate disease training
- Jackie Baillie highlighted the case of one family who contacted her. The family has one son who is receiving Duchenne muscular dystrophy drug Translarna as part of a clinical trial, but another who cannot access the drug as he is no longer ambulant. Translarna can only currently be made available to boys with a nonsense mutation, who are over five and can still walk. The group felt the limited availability of the drug highlighted the need for improved clinical trials infrastructure for rare diseases such as Duchenne, so that drugs can be trialled more widely. Jackie Baillie agreed to write to the Cabinet Secretary on this point.

7. Jackie Baillie agreed to Mark Chapman's request that DMD Pathfinders be added to the Cross Party Group membership list. She closed the meeting with thanks