

Cross Party Group on Muscular Dystrophy meeting on Wednesday 9th May

Co-Conveners: Jackie Baillie MSP and Annie Wells MSP

Guests

Lindsey Armstrong
Sharon Ballingall, CHAS
Nic Bungay, Muscular Dystrophy UK
Mark Chapman (with PA), DMD Pathfinders
Kevin Freeman-Ferguson, Healthcare Improvement Scotland
Jonathan Kingsley, Muscular Dystrophy UK
Sheonad Macfarlane, Muscular Dystrophy UK
John Miller, Action Duchenne
Oona Miller
Jackie Munro, Muscular Dystrophy UK
Robbie Warner
Fiona Wylie, Prince and Princess of Wales Hospice
Justin Young
Michelle Young

Also in attendance: Aileen Campbell MSP, Minister for Public Health and Sport, with Prof Alison Strath, Principal Pharmaceutical Officer, Scottish Government

Meeting summary

MSPs and guests introduce themselves.

The Minister gives an overview of the SMC's Spinraza decision, further action to implement the recommendations from the Montgomery Review on access to new medicines, and outlines that a Neurological Conditions Action Plan will be drafted later this year.

Discussion on SMC's Spinraza decision:

- Clinical and cost effectiveness stronger for Type 1, which is why that restricted use was limited to Type 1.
- Spinraza has a definition of ultra-orphan on a revised list
- New decision making pathway – test for ultra-orphan medicine
- Update to be sent to Health and Sport Committee shortly
- Open to application for Type 2 and 3
- Querying whether cost effectiveness calculation was correct
- Biogen keen for Spinraza to be assessed under new pathway
- Faster track through new pathway
- PACs Tier 2 process being introduced in June aimed at improving access apart from SMC process
- Views of adults were adequately conveyed by patient groups and representatives during the SMC process
- Need a robust process and culture of appreciating expertise and knowledge of parents
- Negotiations on pricing with Biogen
- **Action: encourage people to attend MDUK Fast Track event on 30th May and contact MSPs**

Psychological support:

- Sheonad Macfarlane presentation on “‘The Forgotten Generation” – the need for psychological support.’
- Need a trained psychologist to advise on how to deal with difficult conversations between children and parents and other family members
- **Action: FOI on psychological support in Scotland**

Hospice and respite provision:

- Impossible to use SDS for care – not enough hours
- SDS only works well if perfectly co-ordinated
- Many requests to adult hospices to meet the care needs of Duchenne
- Minister – work to improve SDS, identifying care gaps
- Respite services closing puts pressure on other existing services
- Healthcare Improvement Scotland – regulatory aspect, working with CHAS on age limit transition and supporting development of new services
- **Action: FOI on care packages**
- **Action: Follow-up with Scottish Government on restoring hospice and respite working group**