

Summary of Cross Party Group on Muscular Dystrophy on Wednesday 1st March

Attendees:

Jackie Baillie MSP, Chair of Cross Party Group on Muscular Dystrophy
Maree Todd MSP
Mark Chapman (with PA), DMD Pathfinders
Aurora Constantin
Marina di Marco, Chair of Scottish Muscle Network
Jonathan Kingsley, Muscular Dystrophy UK
Sheonad Macfarlane, Chair of Muscular Dystrophy UK's Scottish Council
John Miller, Action Duchenne
Oona Miller
Gill Paton
Claire Turnbull, CHAS
Jeff Wight
Michelle Young

Meeting summary

Introduction

Jackie Baillie MSP opens the meeting and introduces the discussion topics.

Update from Jonathan Kingsley on emerging treatments under consideration by the European Medicines Agency, including Exondys 51 and Raxone for Duchenne muscular dystrophy, and nusinersen for spinal muscular atrophy.

Adult social care discussion

Jackie Baillie introduces the discussion, highlights the case of Robert Watson. Muscular Dystrophy UK's advocacy team have been supporting him and his parents to ensure that he returns home with the appropriate care package in place, rather than going to a care home, when he is discharged from hospital.

The discussion takes place in the context of experiences shared ahead of the meeting and in the light of concerns on provision following the establishment of the Integration Joint Boards in April 2016.

- There are positive examples of adult social care provision – for example Jeff Wight shared the good experience of his son Stephen who has excellent care staff and a well organised care set-up, enabling him to have independence.
- Depends on what happens in each area – potential inconsistencies and postcode lottery of provision
- Awareness of financial constraints that all social workers are operating in and those can be barriers for social workers
- Mapping numbers is important for planning and the following figures from the Scottish Muscle Network illustrate the Duchenne muscular dystrophy (DMD) number by age and location.

North of Scotland: 0-16 yrs of age = 19 DMD Patients

North of Scotland: 17-18 yrs of age = 2 DMD Patients

North of Scotland: 19 + yrs of age = 6 DMD patients

East of Scotland: 0-16 yrs of age = 17 DMD patients
East of Scotland: 17-18 yrs of age = 4 DMD patients
East of Scotland: 19 + yrs of age = 11 DMD patients

West of Scotland: 0-16 yrs of age = 46 DMD patients
West of Scotland: 17-18 yrs of age = 5 DMD patients
West of Scotland: 19 + yrs of age = 28 DMD Patients

- More focus on patient needs before, whereas now social workers are caught in between patient needs and budget constraints.
- COSLA working group was set up over 10 years ago
- Need for minimum standards and there's an opportunity to harmonise standards
- Small number of carers in rural areas such as Argyll
- Access to Work – linking up home support with assistance at work
- Focus on eligibility criteria, complex care funding and access in rural areas
- **Action: explore possible FOI questions to local authorities and Integration Joint Boards**
- **Action: write to Health Secretary on key issues raised in meeting and in the briefing**

- Hayleigh Barclay – wanting to know why she needs written permission every time she wants to change feed
- Should be her choice on how much
- Used to be the case that district nurses could make decisions
- Marina di Marco – a lot of time spent teaching carers as there are frequent carer changes
- Look at changing terminology and including 'as required'

- Shortage of PAs also an issue, alongside concerns for the future about impact of Brexit

Case studies of finding suitable hospice and respite facilities for young disabled adults – Claire Turnbull, CHAS Transition Team Manager

- Diverse approaches and range of options
- There is no single place to go
- High percentage of those supported have Duchenne
- Two young men pooled their budget and PA support for respite break to Amsterdam managed through Self Directed Support
- Young man supported to be back at home for part of a week as parents have a break
- Young man with complex needs in a residential unit with high specialist input
- Heathfield House in Ayr has care facilities for younger people
- Acknowledge that adult hospices are not set out for respite

- Sheonad Macfarlane - also need to explore provision of respite for young children

Meeting closed by Jackie Baillie MSP.