

Summary of Cross Party Group on Muscular Dystrophy on 9th November 2016

Attendees

Jackie Baillie MSP

Maree Todd MSP

Dr Anthony Bateman

Mark Chapman, DMD Pathfinders

Connor Colhoun

Sandra Colhoun

Clare Eadie

Gary Fegan

Yvonne Grant

Jonathan Kingsley, Muscular Dystrophy UK

Sheonad Macfarlane, Muscular Dystrophy UK

Edwina Manson

Mairi McCrae

Paul McGinley

John Miller, Action Duchenne

Oona Miller

Rhona Nimmo

Marie-Suzanne Stein

Robbie Warner, Muscular Dystrophy UK

Dean Widd, Muscular Dystrophy UK

Michelle Young

Meeting summary

Jackie Baillie MSP opens the meeting and introduces the discussion topics, followed by presentation to Yvonne Grant for Muscular Dystrophy UK Community Champion Award.

Adult social care funding discussion

- Integration of health and social care has been implemented with the introduction of Integration Joint Boards (IJBs) across Scotland.
- Money transferred from Health Boards to IJBs, but with cuts – for example £8m in Argyll and Bute.
- Robert Watson case has brought this into the spotlight. Robert has been in hospital for several months and is due for discharge, with Renfrewshire Council responsible for his care package.
- Jackie Baillie called a senior councillor at Renfrewshire Council who has said that if Robert and his family want him to be cared for at home, funding will be provided.
- Muscular Dystrophy UK's advocacy team is also supporting Robert and his family.
- Sheonad Macfarlane, Chair of Muscular Dystrophy UK's Scottish Council, wrote to the First Minister and Health Minister highlighting Robert's human rights.
- Care packages are not a new problem, with some taking up to a year to resolve while the patient is in hospital
- More and more adults needing 24/7 care, for example those with Duchenne.

- **Action – FOI request of who is in hospital with a neuromuscular condition; and discharge procedures**
- As well as the funding issues, there is also the need to address the attitude of those taking decisions on care packages.
- Question of whether local authorities are not familiar with legislation relating to Self Directed Support.
- Non Invasive Ventilation (NIV) – there can often be struggles to get overnight care with hours not being increased, and need to recognise the difficulties of moving NIV mask
- Need for national standards and awareness of fiscal responsibility of using carers/PAs.
- It is not known what legislation Renfrewshire Council are using in Robert Watson’s case.
- Emphasis on training for carers.

- Query on numbers with Duchenne in Scotland – including ages and mutation types for research purposes – so that needs are targeted at appropriate age.
- 91 in Glasgow and West of Scotland; 12 over 25s in west of Scotland
- **Action – consult with Scottish Muscle Network on numbers**
- Profile muscular dystrophy numbers in each Health Board

- Action – over next few months, gather evidence before next Cross Party Group meeting in the new year, to which we can invite Mike Holmes from Renfrewshire Council. Health Committee is looking at different models of IJBs. This is another angle to explore for the next Cross Party Group meeting.

Access to Translarna and latest developments of Exondys 51

- Update on access to Translarna – following Michael Young’s petition in June, letter from the First Minister that he will be able to access Translarna.
- Michael will receive 3 monthly prescriptions but still concern about repeat prescription in the long-term.
- Cormac Fegan has been on a 6 monthly review since November 2015 but also uncertainty about long-term access.
- Uncertainty about consistency between Health Boards of access to Translarna.
- Montgomery Review findings have been delayed.
- **Action – Jackie Baillie letter to First Minister about consistency between Health Boards on Translarna and long-term commitments on access in the light of 5 year Managed Access Agreement in England.**
- Exondys 51 – received accelerated approval from Food and Drug Administration in USA; subsequent application expected from Sarepta to European Medicines Agency (EMA) by end of calendar year. If approved by EMA, NICE and SMC assessments can take place.

Respiratory care

- Challenges to delivering the service for patients including geography, access to physio, respiratory support devices, care in hospital and setting up care packages for when patient is due to leave hospital.
- Need support in place from community professionals.
- Positive feedback on service provided by specialist nurses and ventilation unit team.

- Standards of Care – explore the development of a SIGN guideline along the model of the NICE guidance
- More information for patients and families would be helpful.
- Sometimes staff in hospital don't know who to contact and family who informs health professionals.
- British Thoracic Society guidance exists.
- Need continuity of providing care in the home with often complex needs.
- Explore situation regarding living wage for carers and their own personal development to try to retain continuity.
- Limits on number of cough assist machines available.
- **Actions – PQs on SIGN guidance and letter to Health Secretary.**

Hospice and respite facilities for young disabled adults in Scotland

- Uncertainty about continuation of the review which was set up after Muscular Dystrophy UK's *Give Us A Break* report in 2014.
- Suggestion from the Scottish Government that it is included in work around Strategic Framework for Action on Palliative and End of Life Care
- Need to look at respite break options.
- Hospices and centres highlighted include Prince and Princess of Wales Hospice, Butterfly Day Centre, Kilbride Hospice.
- Trying to capture the aspect of comradeship.
- **Action – explore further Government's plans for publishing report/findings from the review working group.**

Jackie Baillie closes the meeting – next meeting to focus on adult social care funding in the new year (date tbc)