

Cross Party Group on Muscular Dystrophy Summary on 18 November 2015

Summary of meeting:

Jackie Baillie welcomes guests to the meeting, followed by introductions.

Hospice and Respite:

- Update on most recent meeting of Government's review group.
- Claire Turnball (CHAS Transition team) to release report in December on findings of appropriate hospice and respite facilities for young disabled adults and host feedback event Jan 2016. *Claire to be invited to CPG meeting in the new year to provide update.*
- Important to chase as short time frame – no extension to 2017 transition deadline
- Looking at other options for hospice and respite for those living independently – CHAS style hospice not an option on its own
- Julie Robb from the Scottish Government to chase health boards for information on services

Translarna:

- Update on recent Translarna news
- Scottish Medicines Consortium timeframe discussed. New Drugs Committee is meeting on 15th December with the guidance conveyed to PTC and submitted to the Scottish Medicines Consortium. Final decision meeting scheduled for 2nd February (dependent on yes/no decision and subsequent Patient and Clinician Engagement)
- NICE released 'minded not to approve' decision on 16th October – with more information about data and costing from PTC requested
- Latest NICE meeting on 17th November with next version of NICE guidance expected early December
- Gary Fegan discussed Cormac's Individual Patient Treatment Request (IPTR) process which included a personal statement – need to resubmit in 6 months
- Discussion on consultants promote trials and providing more information at point of diagnosis
- Even with the £80million New Medicines Fund, not necessarily the case that all Health Boards will approve an IPTR for Translarna but rationale from NHS Lothian submission is being shared
- *Next steps to include:*
 - Parents of boys who can benefit, wider Duchenne community and broad age range – MDUK as CPG secretariat to gather testimonies on impact of the condition
 - Explore submitting a petition to petitions committee
 - Press coverage in run-up to 15th December
 - Backbencher motion

Housing:

- Findings from Muscular Dystrophy UK report on accessible housing shared with case studies of long waiting times for accessible homes and difficulties in securing adaptations
- Press coverage of Muscular Dystrophy UK report on BBC Scotland and in Glasgow Evening Times
- Need to upskill OTs and specialist OT input to ensure at least some knowledge of needs of people with muscle-wasting conditions regarding adaptations
- Muscular Dystrophy UK's adaptations manual – currently in process of being updated
- Jackie Baillie to table PQs

Next Steps:

- Waiting for CHAS report in December – evaluate and coordinate next steps
- Next steps for Translarna
- Housing PQs to be tabled
- Potential CPG date for January specifically focused on Translarna depending on subsequent timeframe after 15th December
- Late February date for further CPG meeting