

Cross Party Group on Muscular Dystrophy and Cross Party Group on Rare, Genetic and Undiagnosed Conditions meeting on Wednesday 11th September 2019

Convener: Jackie Baillie MSP

Deputy Convener: Annie Wells MSP

Guests

Bobby Ancil, Muscular Dystrophy UK

Mark Chapman (with PA)

Michelle Conway

Michelle How

Gerry Kelly

Jonathan Kingsley, Muscular Dystrophy UK

John Miller, Action Duchenne

Gill Mitchell

Jackie Munro, Muscular Dystrophy UK

Lynn Stewart

Fiona Wylie, Prince and Princess of Wales Hospice

Meeting summary

MSPs and guests introduce themselves.

AGM Business.

Muscular Dystrophy UK update

- Pleased to collaborate with Genetic Alliance UK on arranging this session and taking today's discussion forward
- Spinraza update – now prescribed for Types 2 and 3 under ultra-orphan pathway
- Brexit – messaging on concerns about no-deal Brexit and supply and access to medicines

Discussion on hospice provision and respite breaks

Prince and Princess of Wales Hospice (PPWH) comment and case study:

- Case study of a young man whose mother is in hospital and being cared for by siblings, with 2 hours provided by Carewatch, and difficulties in securing a care package
- Receiving emergency crisis calls because of a crisis within the home
- Public funds for a new hospice building
- 14 beds with funding from the Health and Social Care Partnership
- 2 beds for young adults are unfunded
- It would be unsustainable to be reliant on public and charitable funds
- Met with commissioners who have asked for strong evidence for value for money
- Many with complex need 1:1 care and sometimes 2:1 care
- Developing and piloting a model and had discussions with MDUK
- Need funding and resource, particularly nursing staff
- Also working with PAMIS (Promoting a more inclusive society)
- Glasgow City – can't find a care package to supply complex needs

Discussion points:

- How many young siblings aren't at school because they're carers?
- Who is the back-up? Concern for the future for families
- Origins of discussion – CHAS stopped services for young adults in 2013
- Scottish Parliament Petition from young disabled adults to
- CHAS funding framework – a model to follow?
- Question posed of whether specialist palliative care should provide respite
- Complex needs can't be met in the community
- MDUK working with palliative care team in Oswestry
- 17 young people receiving support from PPWH
- Working several organisations to generate pilot project
- Two families have contacted MSPs to get them involved
- Look at definition of respite and palliative
- Issue stretches beyond neuromuscular and rare conditions
- Centre for Rare Diseases has been talked about for a while

Actions:

- Renew connection with Cabinet Secretary for Health following request for meeting
- PPWH to gather case studies to present a comprehensive argument, even if anonymised
- Table PQs
- Request a members' debate