

Muscular Dystrophy UK comment for the Petitions Committee on Welsh Neuromuscular Services

Muscular Dystrophy UK acknowledges the correspondence from the Health Boards to the Petitions Committee.

However, Muscular Dystrophy UK retains concerns that focus on muscular dystrophy and related neuromuscular conditions, requiring input from a range of specialists including genetic, respiratory, rehabilitation and cardiac support, would be lost within a broader grouping of neurological conditions.

Muscular Dystrophy UK continues to repeat calls for neuromuscular service investment including:

- increased neuromuscular care advisor support
- specialist adult neuromuscular physiotherapy
- long-term dedicated neuromuscular consultant time
- specialist neuromuscular psychology support

While the Health Boards have recognised the need for improvements and highlighted the Neurological Conditions Delivery Plan, Muscular Dystrophy UK would encourage proactive engagement between Health Boards and the Welsh Neuromuscular Network to identify how Health Boards can meet the complex needs of neuromuscular patients.

For example, ABMU Health Board has recognised that additional neuromuscular consultant time would be beneficial. Muscular Dystrophy UK would like these comments to be pursued to establish how ABMU and other Health Boards across Wales can work collaboratively to meet this need which has been highlighted.

Muscular Dystrophy UK hopes that the urgent need for neuromuscular service development can be scheduled for a debate in the Assembly at the earliest available opportunity and can be considered by the Health and Social Care Committee.