



Muscular Dystrophy Campaign comment for the Petitions Committee on 25th November

The Muscular Dystrophy Campaign acknowledges the correspondence from the Minister for Health and Social Services to the Petitions Committee outlining the Neurological Conditions Delivery Plan and welcomes his statement that the issues identified by the Muscular Dystrophy Campaign will be considered as part of the implementation plan.

It is essential that the complex nature of muscular dystrophy and related neuromuscular conditions is recognised and not just generically grouped with neurological conditions or long-term conditions. Other specialisms are also needed for these rare and very rare conditions, such as genetic, respiratory, rehabilitation and cardiac support.

We understand that after five months there is still no appointment of a Chair of the Welsh Neuromuscular Network, which is a matter needing to be resolved as a matter of urgency to build on the progress made by Dr Andrew Goodall made when he was Chair of the Network.

The Muscular Dystrophy Campaign reiterates the call for Health Boards to act now to ensure that the Welsh Neuromuscular Network's investment priorities identified a year ago are implemented so that all people living with muscle-wasting conditions have comparable access to specialist services to other parts of the UK. The priorities for investment are as follows:

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

If the Health Boards in Wales agree to the recommended investment, emergency hospital care could be dramatically reduced.

The Muscular Dystrophy Campaign hopes that the urgent need for neuromuscular service development can be scheduled for a debate in the Assembly at the earliest available opportunity.