

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

Muscular Dystrophy UK acknowledges the correspondence from the Minister for Health and Social Services to the Petitions Committee, confirming the appointment of Dr Tracey Cooper, Chief Executive of Public Health Wales, as the Chair of the Welsh Neuromuscular Network.

This position has been vacant for 9 months, and Muscular Dystrophy UK warmly welcomes this appointment. We look forward to working closely with Dr Cooper to build upon the progress made by Dr Andrew Goodall, during his time as Chair of the Network.

Muscular dystrophy and related neuromuscular conditions are a group of rare and very rare conditions, requiring input from a range of specialists, including genetic, respiratory, rehabilitation and cardiac support. As such, it is essential that these complex conditions are recognised as clinically distinct and not generically grouped with neurological conditions or other long term conditions.

Muscular Dystrophy UK repeats its call for Health Boards and the Welsh Health Specialised Services Committee to act now to ensure that the Welsh Neuromuscular Network's investment priorities, identified a year and a half 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.

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.