

## 8 July 2015 meeting summary

Attendees:

*Bethan Jenkins AM, Aled Roberts AM, Julie Morgan AM, Mark Isherwood AM  
40-50 people affected by muscle-wasting conditions and health professionals  
Muscular Dystrophy UK  
Dr Tracey Cooper, Chair of Welsh Neuromuscular Network*

Bethan Jenkins AM opens the meeting.

Dr Grant Duncan, Deputy Director of Healthcare Policy at the Welsh Government, announced new money for neuromuscular care advisor support amounting to £60,000 as part of ongoing activity to improve access to specialist neuromuscular care in Wales.

Dr Tracey Cooper, Chief Executive of Public Health Wales and Chair of the Welsh Neuromuscular Network, spoke about the £358,000 funding for specialist equipment which has helped 100 individuals and families with muscle-wasting conditions and emphasised that it is important for the Network to be closer to where the decisions are happening. The Network can be an advisory resource for Health Boards for implementing the Network's recommendations for improving services in Wales.

There was an open discussion around accessing some of the £1.2million from the Neurological Conditions Implementation Group funding stream.

Psychological support highlighted as a major gap in services – many health professionals don't have an understanding of muscle-wasting conditions.

There was general recognition of the importance of patient case studies.

Brief update on access to Translarna in Wales.

Meeting closes.