

Wales Cross Party Group on Muscular Dystrophy and Neuromuscular Conditions meeting on 19 May 2015

Attendees:

Bethan Jenkins AM, Jenny Rathbone AM

30-40 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 and welcomes Dr Tracey Cooper, the new Chair of the Wales Neuromuscular Network.

Dr Tracey Cooper:

- Need to engage with the Wales Neurological Conditions Implementation Group and that more access to specialist adult physiotherapy and psychology support is a high priority
- The business case compiled by the Welsh Neuromuscular Network needs to be refreshed
- Emphasise the investing to save principle – saving money and helping people
- Working with North Wales Neurosciences Network – important to not lose neuromuscular focus
- Expectation that Neurological Conditions Implementation Group recommendations are embedded into Health Boards
- Hydrotherapy – you have six sessions and then finishes – which doesn't help people with muscle-wasting conditions
- Need more multidisciplinary clinics and better co-ordination of services
- Look at one-stop shop principle for clinic appointments

Muscular Dystrophy UK updates attendees on new project to develop peer to peer support for people with muscle-wasting conditions.