

Wales Cross Party Group on Muscular Dystrophy on Muscular Dystrophy and Neuromuscular Conditions meeting on 11 November 2015 - Conference Room 24, Tŷ Hywel

Attendees: Bethan Jenkins AM, Muscular Dystrophy UK, Action Duchenne and 20 people with muscle-wasting conditions and health professionals.

Bethan Jenkins AM opens the meeting and welcomes attendees.

Jonathan Kingsley from Muscular Dystrophy UK, Secretariat for the Cross Party Group, provides an update on:

- Muscular Dystrophy UK's new Wales Advocacy and Information Officer role
- Access to Translarna developments
- Muscular Dystrophy UK's Clinical Trial Capacity Audit and work with other charities to address concerns around muscle centres having to turn down clinical trials

Dr Tracey Cooper, Chief Executive of Public Health Wales and Chair of the Welsh Neuromuscular Network, updated the Cross Party Group:

- Recruitment for south west Wales care advisor post on secondment has twice been unsuccessful
- £52,000 additional funding for care advisor support to be split between two part time posts to make things more manageable
- Psychology and adult physiotherapy – mobilising support in the system
- Care Advisors don't have time for learning and development, or sharing case experiences
- Tracey meeting with Dr Andrew Goodall, Chief Executive of NHS Wales with the aim of releasing additional resources to address care advisor provision shortfall
- 2015-2016 – looking at good practice model in the South West
- Also exploring ways of utilising real-time face to face technology
- Meeting with Health Board Chief Executives which has resulted in a designated lead for neuromuscular conditions within 6 out of the 7 Health Boards
- For sustainable care advisor support, need to be innovative and to create a stable model

Q&A discussion:

- Potential for paediatric and adult support to be separated out due to capacity
- Explore different grades of care advisor service
- Need to develop relationship with local authorities – tap in via Public Health Wales
- Even with Cardiff and Vale Health Board hosting, the roles would extend beyond into other Health Board areas
- Line management needs to be developed with admin support for care advisors