

Cross Party Group in the Welsh Assembly on Muscular Dystrophy and Neuromuscular Conditions session:

Making the case for investing in specialist neuromuscular care in Wales

**Wednesday 10th December 2014, 12.30pm – 1.30pm, Conference Room 21,
Ty Hywel, National Assembly for Wales, Cardiff, CF99 1NA**

Meeting Notes

- Welcome and introduction by **Bethan Jenkins AM**, Chair of the Cross Party Group on Muscular Dystrophy

- Ray Thomas gives an update on **The Thomas Report** and a review of progress, drawing attention to Recommendations 1, 2, 3, 4, 6, 10, 12

- **Muscular Dystrophy Campaign briefing** – presenting the case for investing in specialist neuromuscular care in Wales
 - Executive Lead still vacant
 - Focus on standards of care
 - Write to Director of WHSSC on business case for investment
 - Psychology support needed

- **Simon Barry** presents on *Support for adults with muscle-wasting conditions in Wales – including respite care, education and access to employment opportunities*
 - Bringing together 3rd sector, NHS, Local Authorities
 - Sub group of Welsh Neuromuscular Network?
 - Lack of hospice and respite