

Wales Cross Party Group on Muscular Dystrophy and Neuromuscular Conditions meeting on 5 March 2014

Attendees:

Bethan Jenkins AM, Mark Isherwood AM

30-40 people affected by muscle-wasting conditions and health professionals

Muscular Dystrophy Campaign

Action Duchenne

Bethan Jenkins opens the meeting.

Dr Andrew Goodall highlights:

- Work on Emergency Care Plans
- Training and awareness of GPs and health professionals
- Need to increase care advisor hours
- New specialist equipment budget – at least £300,00 – for cough assist machines, wheelchairs, hoists
- Expanded consultant time – locum support in Cardiff

Q&A

- Welsh Government Rare Disease Strategy – opportunity to contribute to consultation
- Hydrotherapy remains variable – need to make arrangements more flexible
- Care advisor caseload too high
- Need to receive feedback from Health Boards