

**P-04-532 Improving Specialised Neuromuscular Services in Wales.doc –
Correspondence from the Petitioner to the Clerking team, 01.03.17**

Dear Kayleigh,

Thank you for the opportunity to comment. Please see below our comment submission:

We welcome the Minister's comments and we acknowledge the progress which has been made on increasing neuromuscular care advisor and physiotherapy support for people with muscular dystrophy and neuromuscular conditions.

However, this should not be viewed as the end of service developments which are required to build sustainable long-term provision. These include additional physiotherapy support, psychology support and dedicated neuromuscular consultant time.

We therefore urge Health Boards to adopt the service requirements for neuromuscular services which have been put forward into their Integrated Medium Term Plans and to take into account the savings of avoiding unplanned emergency admissions to hospital by investing in specialist multi-disciplinary care.

We also seek assurance that:

- a national decision-making forum with resources is sufficiently aware of service risks and thereby assign an informed priority to the situation;*
- neuromuscular services are included within the scope of the national review of neurosciences in Wales being led by WHSSC..*

Regards,

Jonathan