



Muscular Dystrophy Campaign comment for the Petitions Committee – 9th July 2014

The Muscular Dystrophy Campaign welcomes the responses from the Minister for Health and Social Services and Health Boards so far.

We would particularly like to place on record our thanks to Dr Andrew Goodall in his role as Chair of the Welsh Neuromuscular Network – steering the Network through its Vision Document, identifying priorities for investment in the Network’s business case presented at the National Assembly for Wales in November 2013, and the progress made with allocation of £358,000 to be used for the procurement of equipment for patients with neuromuscular conditions.

With Dr Goodall taking up the position of Chief Executive of NHS Wales, it is now vitally important that a new Chair is identified and appointed as quickly as possible so that the progress already achieved does not stall, but instead is maintained and built upon so that the remaining priorities for investment are supported and implemented by each of the Health Boards in Wales as a matter of urgency:

- **increased neuromuscular care advisor support**
- **specialist adult neuromuscular physiotherapy**
- **long-term dedicated neuromuscular consultant time**
- **specialist neuromuscular psychology support**

The Welsh Neuromuscular Network has recognised that unplanned emergency admissions to hospital for people with muscular dystrophy and neuromuscular conditions cost nearly £4million per year in Wales and that “access to high quality, specialist multi-disciplinary care would **significantly reduce** the considerable cost of these **unplanned emergency admissions.**” The Network is recommending £650,000 for service improvements and

therefore presents a compelling case for investment in specialist neuromuscular care in Wales to save NHS Wales money.

The Muscular Dystrophy Campaign hopes that the urgent need for neuromuscular service development can be scheduled for a debate in the Assembly at the earliest available opportunity.

The Muscular Dystrophy Campaign strongly urges each of the Health Boards to commit to the investment recommended by the Welsh Neuromuscular Network in its business case for improving neuromuscular services in Wales.