

**Cross Party Group on Muscular Dystrophy and Neuromuscular Conditions AGM
Session, Wednesday 16th July 2014**

**Welsh Neuromuscular Network priorities for development of neuromuscular services
in Wales**

1. Jonathan Kingsley, Muscular Dystrophy Campaign, gives an **introduction to the session** and extends the Cross Party Group's thanks to Dr Andrew Goodall, who has been appointed Chief Executive of NHS Wales, for his hard work as Chair of the Welsh Neuromuscular Network (WNMN). Our priorities remain to push for the recommended £650,000 investment and ensure that a new Chief Executive Chair of the WNMN is appointed as soon as possible. The Petitions Committee in the Welsh Assembly has written to the Health Minister to press for this post to be filled.
2. Jonathan went on to give a **Secretariat Update** on behalf of the Muscular Dystrophy Campaign, updating the group on the charity's work to secure faster access to potential emerging treatments for muscle-wasting conditions in Wales. He also briefed the group on the All Party Parliamentary Group for Muscular Dystrophy's report on 'newborn screening for Duchenne muscular dystrophy'.
3. The group then discussed **equipment funding** which has been secured for neuromuscular patients in Wales. Ray Thomas raised concerns that Care Advisors were finding it difficult to procure this equipment and that ABMU Health Board had not agreed to absorb maintenance costs for equipment. Ray is meeting the Vice- Chair of ABMU to discuss this issue and it is hoped that, as North Wales and Cardiff and Vale have agreed to absorb the costs, ABMU will do likewise. There were also concerns raised by Rachel Salmon that identifying people who would benefit from equipment funding takes some time and that, as the funding was for one financial year, it may be lost from April 2015. The group agreed it would be a priority for any incoming WNMN Chair to ensure unspent funds remained ring fenced into the next financial year
4. Dr Jenni Thomas informed that group that the temporary **consultant post**, currently held by Dr Ellie Marsh, has been extended until the end of the year and it is hoped that funding can be secured on a permanent basis.
5. Dr Mark Rogers went on to raise concern about **consultant time**. Since Dr Fenton-May retired, demand has been increasing and patients who should be seen every year are now waiting a year and a half, with risk that waits could increase further still. The group agreed lack of consultant capacity needs to be addressed urgently.
6. **Lack of capacity elsewhere in the service** was highlighted. Rachel Salmon raised the point that both hers and Sarah Harris' caseloads were extremely high with the additional problem that, because they are employed by different Health Boards, neither can provide cover for one another. Sarah Clements is likewise very overstretched with a lack of capacity in the service to deal with demand.
7. The group agreed to compile patient case studies to support the need to build capacity in the service. Health professionals will also document their caseload, perhaps through an audit as appropriate.

8. Concerns were expressed by Ray Thomas and Margaret Ware about waiting times in **wheelchair services**. Dr Jenni Thomas explained the pressures the service is under and the complex needs of patients requiring chairs. However, she acknowledged that waiting times were too long and that improvements could still be made, although work is being done to streamline the process and ensure patients receive a suitable chair as quickly as possible. Jonathan Kingsley reported that some people with neuromuscular conditions continue to be offered unsuitable chairs and that professionals' knowledge of the conditions needs to be secure.
9. Gareth Llewellyn updated the group on the **WNMN**. He highlighted the network would continue as planned but that it is currently weakened without a Chief Executive Chair. The Network structure is currently being reviewed and Gareth will update the group as this review develops. However, it is very much hoped that the review would not pose a threat to the WNMN.
10. All those in attendance agreed that the AGM should be submitted, along with the annual report.
11. Bethan Jenkins AM closed the meeting at 7.30 with thanks to all those who attended.