

## **Cross Party Group on Muscular Dystrophy and Neuromuscular Conditions**

### **Summary of meeting on Wednesday 6<sup>th</sup> March – chaired by Bethan Sayed AM**

#### *Muscular Dystrophy UK update*

- Jonathan Kingsley provides an update on developments on spinal muscular atrophy treatment, Spinraza, Muscular Dystrophy UK disability benefits survey and Mental Health Matters campaign

#### *Personal Independence Payments*

- Several experiences of the Personal Independence Payments process were shared by attendees, including issues relating to the lack of knowledge of neuromuscular conditions by assessors
- Survey will help to inform overall picture and statistics, including specific issues in Wales

#### *Neuromuscular Network update*

- Continue to work with Welsh Government on the need for additional specialist posts
- Specialist physios in Cardiff and Swansea
- Further work on admin support – difficulty in recruiting additional care advisor posts
- Lack of long-term sustainability and succession planning with care advisor posts
- Neurological Conditions Implementation Group (NCIG) Lead is Michelle Price
- NCIG meeting in 2 weeks time
- Succession planning – NCIG bursary to encourage professional development

#### *Further discussion points*

- Bridgend – moving from one Health Board to another
- Lack of knowledge of neuromuscular conditions in hospital
- Overnight stay in hospital because of waiting for a taxi
- Mapping exercise to outline options of care
- Discussion on NCIG Delivery Plan on the agenda for the next meeting
- Assembly Question – Health Boards implementing NCIG Delivery Plan
- Specialists should be covering all of Wales – GP referral to a specialist
- Cross Party Group forum online – initially through MDUK Facebook group and will explore further options
- Genomics Roadshow with genetics team going round the hospitals
- Idea for something similar for neuromuscular to hospitals and A&E?
- Next meeting in July