

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

### **Summary of meeting on Wednesday 7<sup>th</sup> March**

#### *AM attendees*

Bethan Jenkins AM

Dr Dai Lloyd AM

#### *Muscular Dystrophy UK update*

- Jonathan Kingsley provides an update on developments on spinal muscular atrophy treatment, Spinraza, and information about an AM Fast Track to treatments drop-in event in July.

#### *Welsh Neuromuscular Network discussion*

- Cardiff and Vale looking at job descriptions for the assistant care advisor posts – questions around recurrent funding
- Looking at increasing north Wales physio provision following appointments in south east and south west Wales
- Future of Neuromuscular Network – would it lose impact and voice within a Neurosciences network? Work towards a Managed Clinical Network
- Potential FOI enquiry to Health Boards about Thomas Report recommendations assessment
- Following Dr Hartley leaving her consultant paediatric neurologist post in Cardiff, patients going back into general paediatrics – need to create job plan
- Neurology training has changed in terms of sub-specialties
- Dr White in Swansea is semi-retired – doing 3 days per week for 2 years but a gap after that
- Role of NCIG in flagging this up?
- Increasing clinical trial capacity beyond London and Newcastle

#### *Discussion on GP knowledge*

- Writing to GPs to ask them to complete Muscular Dystrophy UK's GP online training module
- Some GPs do know about the conditions
- With GPs retiring you end up educating one at a time
- Designating GPs as having a special interest
- Target GP clusters of about 8-10 practices – what is the best practice model

#### *Mental health discussion*

- Initiatives such as Time to Change, Mental Health Matters
- Transition from paediatric to adult often challenging
- Need sustainable and long-term support
- Support at different stages of progression of the condition
- Share testimonies with AMs, who can ask health questions