

Summary of 29 March 2017 Cross Party Group on Muscular Dystrophy and Neuromuscular Conditions meeting

AMs in attendance

Bethan Jenkins AM, Chair of Cross Party Group on Muscular Dystrophy and Neuromuscular Conditions

Mike Hedges AM

David Rees AM

Update from Muscular Dystrophy UK, Secretariat for the Cross Party Group

- Emerging treatments: Exondys 51 for Duchenne muscular dystrophy and nusinersen for spinal muscular atrophy
- Recognition of clinical trial capacity gaps at UK muscle centres and working with NIHR to address this shortfall
- Update on improving admissions on hospital – positivity around role of alert cards and care plans due to rapid turnover of staff
- Physio recommendation – not just looking for fractures
- Flagging muscular dystrophy to enable to better response in an emergency
- Feedback example – not seen in A&E when showing a condition information card – need to educate casualty departments
- Influence through patient's forum – encouraging GP participation in the GP online module
- Route to GPs through the GP One website

MyCare update – Dr Mark Rogers

- Emergency care plan – currently in paper form, but now being trialled electronically in a cloud version
- Drop down menus to display information
- Easily updated as it's electronic
- Helpful to see what information needs to be gathered

Update from Dr Tracey Cooper, Chair of the Welsh Neuromuscular Network

- Working closely with health professionals and Muscular Dystrophy UK on developing the Welsh Neuromuscular Network
- Process of peer review with other Networks
- Recruitment for specialist physiotherapy support in south Wales – hoping a new postholder in place in May/June
- Care advisor interviews set to take place in a few weeks time – 3 posts, 20 hours per week in each of the 3 regions of Wales
- Network representatives making video messages to emphasise attraction of the posts as part of the overall Network
- Additional admin support has been helpful for care advisors
- Small amount of extra wheelchair funding has become available due to slippage in funding
- Continuing to engage with Health Boards and Welsh Health Specialised Services Committee
- Discussions with NHS partners are continuing
- Network benchmarking day with Scottish Muscle Network and South West on Thursday 19th May – presentations and workshops with commissioners, health professionals and patient representatives

- Need a stronger evidence base and benchmarking will help this process
- Patient representatives can contact Rebecca to attend
- Awareness of neuromuscular care amongst Health Board Chief Executives
- Structured and frequent multi-disciplinary gatherings for team support taking place

Discussion points

- No point of contact for physio and difficult to get ongoing support – referred back to GP and on long waiting lists
- Need access to continued community physio
- Change mindset of health professionals labelling a condition as just being seen by experts all the time
- Important to highlight that you can save money by investment
- Prudent healthcare initiatives – looking at early intervention
- Presenting a powerful business in both political and healthcare settings
- Emphasise the relative lack of therapies and therefore highlight importance of physiotherapy for quality of life and independent living.