

Cross Party Group on Muscular Dystrophy meeting on Tuesday 21st November

Co-Conveners: Jackie Baillie MSP and Annie Wells MSP

Guests

Lindsey Armstrong

Mark Chapman (with PA), DMD Pathfinders

Marina di Marco, Chair of Scottish Muscle Network

Jonathan Kingsley, Muscular Dystrophy UK

Sheonad Macfarlane

John Miller, Action Duchenne

Oona Miller

Gill Mitchell

Jackie Munro, Muscular Dystrophy UK

Gillian Sherwood, Prince and Princess of Wales Hospice

Robbie Warner

Fiona Wylie, Prince and Princess of Wales Hospice

Summary of meeting

Muscular Dystrophy UK update

Jonathan Kingsley, Parliamentary and Policy Manager for Muscular Dystrophy UK, gives update on Fast Track campaign and Exondys 51 and Spinraza. Discussion on Raxone not being granted licence by EMA and timelines for Early Access to Medicines Scheme.

Jackie Munro, Advocacy and Information Officer for Muscular Dystrophy UK, outlines increased support in clinics and plans for meetings and events across Scotland in 2018.

Hospice and respite discussion

- Small increases in provision but need a variety of different options as individuals' needs differ
- Prince and Princess of Wales Hospice has extra 2 beds for young adults and new building expected to be ready in June 2018
- Prince and Princess of Wales Hospice has supported 8 young people – 6 from CHAS and 5 with Duchenne
- Not just a medical model of care required, but also need social model of care
- Need respite care with competent healthcare provided for complex conditions
- Gathering case studies, practical evidence and service mapping required
- Respiratory team at QE Hospital in Glasgow instrumental in supporting Prince and Princess of Wales Hospice, including workshops for hospice staff
- Problem of lack of respite care in the community
- Ensure that we capture what services are wanted from young adults.

Next steps:

- Letter to Health Secretary
- Update from CHAS on its final transition figures
- PQs on adult physio in East of Scotland
- Montgomery Review follow-up