

Cross Party Group on Muscular Dystrophy meeting minutes

19th February 2013, 6pm to 7.30pm, Room TG20-TG21

1. Jackie Baillie MSP, Chair of the Group, introduces the session and welcomes MSP colleagues and guests
2. Jonathan Kingsley, Muscular Dystrophy Campaign, Secretariat for the Cross Party Group, updates the group on recent campaigning activity in Scotland
3. Discussion on integration of health and social care

Key points and questions raised:

- Patients have been fit for discharge from hospital but sometimes have had to wait for months while care packages are negotiated or re-negotiated. What discussions are held between Health Boards and local authorities to make sure that there is structured, co-ordinated and joined-up health and social care provision?
 - Action needing to be taken to improve the set-up of care packages for people with muscle-wasting conditions
 - What are the differences between integration of health and social care in paediatric and adult services?
 - Impact Community Health and Social Care Partnerships having on service delivery
 - Role can neuromuscular care advisors play in bringing together provision of health and social care services?
4. Closing remarks – the group decides to include north of Scotland care advisor support and access to rare disease drugs in Scotland on the agenda for the next meeting.