

Cross-Party Group Annual Report.

Wednesday 5th July

Cross Party Group on Muscular Dystrophy and Neuromuscular Conditions

1. Group membership and office holders.

Chair: Bethan Jenkins

Assembly Members: Bethan Jenkins, Dai Lloyd, Neil Hamilton, Mike Hedges, Huw Irranca-Davies, Mark Isherwood

Secretary: Jonathan Kingsley, Muscular Dystrophy UK

External members:

Jonathan Kingsley, Muscular Dystrophy UK

Dr Gareth Llewelyn FRCP, Welsh Neuromuscular Network

2. Previous Group Meetings since the last AGM.

Meeting 1.

Meeting date: 7th December 2016

Attendees: Dai Lloyd AM, Mark Isherwood AM
Muscular Dystrophy UK
David Heyburn, Deputy Chair, Welsh Neuromuscular Network
Caroline Lewis, Welsh Gov Major Health Conditions Policy Team
20 families affected by muscle-wasting conditions

Summary of issues discussed:

- Translarna access in Wales
- Additional care advisor support
- Standards of care
- Co-ordination of clinics
- Neurological Conditions Implementation Group

Meeting 2.

Meeting date: 29th March 2017

Attendees: Bethan Jenkins AM, Mike Hedges AM, David Rees AM
Muscular Dystrophy UK
Dr Tracey Cooper, Chair of the Welsh Neuromuscular Network
20 families affected by muscle-wasting conditions

Summary of issues discussed:

- Update on emerging treatments
- Improving admissions to hospital
- Emergency care plans
- Engagement with Health Boards
- Sharing best practice with other neuromuscular networks
- Access to community physiotherapy

Meeting 3.

Meeting date: 5th July 2017

Attendees: Bethan Jenkins AM, Dai Lloyd AM, Mark Isherwood AM
Muscular Dystrophy UK
Dr Tracey Cooper, Chair of the Welsh Neuromuscular Network
15 families affected by muscle-wasting conditions

Summary of issues discussed:

- Update on emerging treatments
- Physio appointments
- Care advisor roles
- Sharing best practice with other neuromuscular networks
- Access to community physiotherapy
- Topics for future CPG meetings

3. Professional lobbyists, voluntary organisations and charities with whom the Group has met during the preceding year.

[Include name of lobbyist/organisation/charities as follows. e.g.]

Voluntary and charities that have participated in meetings of the group are listed in the attendees section for each meeting.

Annual Financial Statement.

[5th July 2017]

Cross Party Group on Muscular Dystrophy and Neuromuscular Conditions

Chair: Bethan Jenkins

Secretary: Jonathan Kingsley, Muscular Dystrophy UK

Group's Expenses.	None.	£0.00
Costs of all goods.	No goods purchased.	£0.00
Benefits received by the group or individual Members from outside bodies.	No benefits received.	£0.00
Any secretariat or other support.	No financial support received.	£0.00
Services provided to the Group such as hospitality.		
All refreshments paid for by Muscular Dystrophy UK.		
Date	Description and name of provider	Cost
7 th December 2016	Charlton House Catering	£96.60
29 th March 2017	Charlton House Catering	£96.60
5 th July 2017	Charlton House Catering	£209.70
Total cost		£402.90