

Cross-Party Group Annual Report.

Tuesday 5th February 2019

Cross Party Group on Muscular Dystrophy and Neuromuscular Conditions

1. Group membership and office holders.

Chair: Bethan Sayed

Assembly Members: Bethan Sayed, 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 Mark Rogers, Welsh Neuromuscular Network

2. Previous Group Meetings since the last AGM.

Meeting 1.

Meeting date: 14th November 2017

Attendees: Dai Lloyd AM, Mark Isherwood AM, Rhun ap Iorwerth AM
Muscular Dystrophy UK
Dr Tracey Cooper, Chair, Welsh Neuromuscular Network
15 families affected by muscle-wasting conditions

Summary of issues discussed:

- Neuromuscular network collaboration
- Additional care advisor support
- Cardiac care provision
- Psychological support

Meeting 2.

Meeting date: 7th March 2018

Attendees: Bethan Sayed AM, Dai Lloyd AM

Muscular Dystrophy UK
20 families affected by muscle-wasting conditions

Summary of issues discussed:

- Update on emerging treatments including Spinraza
- GP knowledge
- Mental health support
- Future of Neuromuscular Network

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 Sayed

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
14 th November 2017	Charlton House Catering	£209.70
7 th March 2018	Charlton House Catering	£177.48
Total cost		£387.18