

# Cross-Party Group Annual Report

## **Cross Party Group Details**

### **Cross Party Group Title:**

Muscular Dystrophy and Neuromuscular Conditions

## **Group membership and office holders**

### **Name of Group Chair:**

Huw Irranca-Davies

### **Names of other Members of the Senedd:**

Rhun ap Iorwerth

Mike Hedges

Mark Isherwood

### **Name of Secretary and Organisation:**

Rob Burley, Muscular Dystrophy UK (MDUK)

### **Names of other external members and organisations represented:**

N/A

## Other meetings of the Group since the last AGM

### Meeting 1

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#### Date of Meeting:

17th May 2023

#### Attendees:

Rhun Ap Iorwerth MS, Chair of the CPG on Muscular Dystrophy and Neuromuscular Conditions

Rhys Hughes, Office of Rhun Ap Iorwerth

Citta Widagdo, Health Policy Officer, Muscular Dystrophy UK

Rob Burley, Director of Care, Campaigns, and Support, Muscular Dystrophy UK

Lucia Gillespie, Advocacy & Information Officer – Wales, Muscular Dystrophy UK

David Heyburn, Chair of the Wales Neuromuscular Network

Veronica Roberts, Neuromuscular Care Advisor, North Wales Neuromuscular

Rhiannon Edwards, Neurological and Rare Diseases Implementation Groups Coordinator, NHS Executive

Heledd Tomos, Neuromuscular Specialist Physiotherapist, South Wales Adults Neuromuscular Service

Members of the public: PM, MR, JR, KL, LB, MD, WS, HL, RE.

#### Summary of the issues discussed:

Attendees discussed MDUK's response to the Wales Rare Disease Action Plan. MDUK then previewed the launch of the Westminster APPG on Muscular Dystrophy's inquiry report, 'Newborn Screening for Rare Diseases'. There was also an update by the Welsh Neuromuscular Network on business cases to support the improvement of neuromuscular care in Wales. Individuals with lived experience of muscle wasting and weakening conditions also shared their stories around inclusive exercise and access to specialist support.

## Meeting 2

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### Date of Meeting:

29th November 2023

### Attendees:

Members of the CPG:

Rhun ap Iorwerth MS (Now former chair of the CPG).

Huw Irranca-Davies MS (Now current chair of the CPG).

Rob Burley (Director of Campaigns, Care and Support at Muscular Dystrophy UK; CPG secretary).

Lucia Gillespie (Advocacy & Information Officer for Wales, at Muscular Dystrophy UK; CPG secretary).

Farhan Khan (Health Policy Manager at Muscular Dystrophy UK; CPG secretary).

Non-CPG members/invited observers/guest speakers included:

Rhys Hughes (office of Rhun ap Iorwerth MS).

Alice Fabre (Project Manager at UK SMA Newborn Screening Alliance).

David Heyburn (Head of Operations at Public Health Wales; Deputy Chair at Wales Neuromuscular Network).

Heledd Tomos (Physiotherapist at NHS Wales).

Joanne Oliver (Neurological Conditions Strategic Clinical Network manager at NHS Wales Executive).

Carolyn Middleton (person with lived experience).

Gareth Middleton (person with lived experience).

Sylvia Evans (person with lived experience).

Kenneth Lewis (person with lived experience).

Janet Neilson (person with lived experience).

Lucy Patten (person with lived experience).

Richard Haselgrove (person with lived experience).

Richard Enos (person with lived experience).

Paul Magness (person with lived experience).

William Silcox (person with lived experience).

Neil Thorneycroft (person with lived experience).

Welsh language interpreter from the Senedd.

**Summary of the issues discussed:**

The CPG held an Annual General Meeting (AGM). Attendees heard about the UK APPG on Muscular Dystrophy's inquiry report, 'Newborn Screening for Rare Diseases', Genomics England's new research study and the latest plans for Spinal Muscular Atrophy screening in the UK. Attendees also heard about the challenges facing neuromuscular services in Wales.

**Professional lobbyists, voluntary organisations and charities the Group have met during the previous year.**

[names of lobbyists/organisations/charities should be included as follows, e.g.]

**Name of Organisation:**

N/A

**Name of Group:**

N/A

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**Name of Organisation:**

N/A

**Name of Group:**

N/A

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## Annual Financial Statement

### Cross Party Group Title:

Muscular Dystrophy and Neuromuscular Conditions

### Date:

18/12/23

### Name of Chair:

Huw Irranca-Davies MS

### Name of Secretary and Organisation:

Rob Burley, Muscular Dystrophy UK (MDUK)

Title	Description	Amount
<b>Group's Expenses</b>	None	£0.00
<b>Costs of all goods</b>	No goods bought	£0.00
<b>Benefits received by the group or individuals members from external bodies</b>	No benefits received	£0.00
<b>Any financial support or other support.</b>	No financial support was received	£0.00
<b>Total</b>		<b>£0.00</b>

Services provided to the Group, such as hospitality.

All hospitality paid for [include the name of the group/organisation].

Date	Name and description of provider	Costs
N/A	N/A	N/A
N/A	N/A	N/A
<b>Total</b>		<b>£0.00</b>