

CROSS-PARTY GROUP ANNUAL RETURN

NAME OF CROSS-PARTY GROUP

Cross-Party Group on Muscular Dystrophy

DATE GROUP ESTABLISHED (the date of establishment is the date in this parliamentary session that the Group held its initial meeting, where the office bearers were elected and not the date that the Group was accorded recognition. All Groups should hold their AGMs on, or before, the anniversary of this date.)

8th June 2011

DATE OF MOST RECENT AGM

16th June 2015

DATE OF PRECEDING AGM [this date is required to aid clerks in verifying that the most recent AGM has taken place within 12 months of the previous AGM]

24th June 2014

DATE ANNUAL RETURN SUBMITTED

19th June 2015

GROUP MEETINGS AND ACTIVITIES

Please provide details of each meeting of the Group including the date of the meeting, a brief description of the main subjects discussed and the MSP and non-MSP attendance figures.

Details of any other activities, such as visits undertaken by the Group or papers/report published by the Group should also be provided.

25th November 2014 – (2 MSPs; 15 non-MSPs) – access to Duchenne muscular dystrophy treatment called Translarna. Families share their perspectives on the importance of fast access to the treatment and Kathryn Fergusson, Head of the Medicines Division at the Scottish Government, explains the process for a submission being made to the Scottish Medicines Consortium.

22nd April 2015 (3 MSPs; 10 non-MSPs) – discussion on the need for north of Scotland care advisor support with patient case studies shared on how specialist support would have been beneficial; Claire Turnball from the Children’s Hospice Association Scotland Transition Team, updated the group on supporting individuals to find appropriate hospice and respite facilities, and discussions followed on longer term solutions for suitable hospice and respite support for young disabled people.

16th June 2015 (5 MSPs; 15 non-MSPs) – update on latest progress on access to Translarna, with contributions from Jo-anna Allen from PTC Therapeutics and Kathryn Fergusson from the Scottish Government. Michelle Young, whose son Michael is on the Translarna trial, gave her perspective of the need for collaboration to ensure fast access to the treatment in Scotland.

MSP MEMBERS OF THE GROUP

Please provide names and party designation of all MSP members of the Group.

Jackie Baillie, Scottish Labour
Nanette Milne, Scottish Conservative and Unionist
Jim Eadie, Scottish National Party
Alison McInnes, Scottish Liberal Democrats
Hugh Henry, Scottish Labour
John Wilson, Scottish National Party
Malcolm Chisholm, Scottish Labour
Mary Scanlon, Scottish Conservative and Unionist
Rhoda Grant, Scottish Labour

NON-MSP MEMBERS OF THE GROUP

For organisational members please provide only the name of the organisation, it is not necessary to provide the name(s) of individuals who may represent the organisation at meetings of the Group.

Individuals	
Organisations	Muscular Dystrophy UK (Secretariat) DMD Pathfinders

GROUP OFFICE BEARERS

Please provide names for all office bearers. The minimum requirement is that two of the office bearers are MSPs and one of these is Convener – beyond this it is a matter for the Group to decide upon the office bearers it wishes to have. It is permissible to have more than one individual elected to each office, for example, co-conveners or multiple deputy conveners.

Convener	Jackie Baillie MSP
Deputy Convener	Nanette Milne MSP Jim Eadie MSP
Secretary	Muscular Dystrophy UK
Treasurer	

FINANCIAL BENEFITS OR OTHER BENEFITS RECEIVED BY THE GROUP

Please provide details of any financial or material benefit(s) received from a single source in a calendar year which has a value, either singly or cumulatively, of more than £500. This includes donations, gifts, hospitality or visits and material assistance such as secretariat support.

Details of material support should include the name of the individual providing support, the value of this support over the year, an estimate of the time spent providing this support and the name of the organisation that this individual is employed by / affiliated to in providing this support.

Groups should provide details of the date on which the benefit was received, the value of the benefit and a brief description of the benefit.

If the Group is not disclosing any financial information please tick the box to confirm that the Group has considered the support received, but concluded it totalled under the threshold for disclosure (£500).

SUBSCRIPTION CHARGED BY THE GROUP

Please provide details of the amount charged and the purpose for which the subscription is intended to be used.

Nil

CONVENER CONTACT DETAILS

Name	Jackie Baillie MSP
Parliamentary address	MG.16, Scottish Parliament, Edinburgh

Telephone number	0131 348 5905
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