

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.)
15 th June 2016
DATE OF MOST RECENT AGM
27 th June 2018
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]
28 th June 2017
DATE ANNUAL RETURN SUBMITTED
28 th June 2018
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.
28 th June 2017 (3 MSPs, 19 non-MSPs) – access to new medicines with SMC panel, hospice and respite update 21 st November 2017 (2 MSPs, 12 non-MSPs) – hospice and respite discussion, update on new treatments for Duchenne and SMA 9 th May 2018 (3 MSPs, 15 non-MSPs) – discussion with Minister for Public Health and Sport, SMC decision on SMA treatment Spinraza, psychological support, hospice and respite FOI

27th June 2018 (3 MSPs, 6 non-MSPs) – update on new pathway for ultra-orphan medicines and priorities for CPG

MSP MEMBERS OF THE GROUP

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

Jackie Baillie, Labour;
Rhoda Grant, Labour;
Iain Gray, Labour;
Anas Sarwar, Labour;
Annie Wells, Conservative

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
Action Duchenne
DMD Pathfinders
Mike Matters

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.

Co-Conveners

Jackie Baillie MSP, Annie Wells MSP

Deputy Convener

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.

CONVENER CONTACT DETAILS

Name	Jackie Baillie MSP
Parliamentary address	MG 16
Telephone number	01389 734214