

CROSS-PARTY GROUP ANNUAL RETURN

NAME OF CROSS-PARTY GROUP

Cross-Party Group on Rare, Genetic and Undiagnosed Conditions

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.)

28th March 2017

DATE OF MOST RECENT AGM

17th April 2018

DATE ANNUAL RETURN SUBMITTED

24th April 2018

DATE OF PRECEDING AGM [this date is required to aid clerks in verifying that the most recent AGM has taken place within 11-13 months of the previous AGM]

28th March 2017 (initial meeting)

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.

The Cross Party Group on Rare, Genetic and Undiagnosed Conditions provides a forum to raise awareness of rare, genetic and undiagnosed conditions and explore relevant policy areas.

The Cross Party Group on Rare Genetic and Undiagnosed Conditions have held the

following meetings this year:

28th March 2017 - The initial meeting of the CPG to identify the purpose of the CPG, membership of the group and the workplan priorities. (MSP attendees - 3 Non MSP attendees - approx. 12)

27th June 2017 - Discussion of priority topics and potential co-working with other CPGs on issues such as disability, education and support for families with Autism. Discussion of the implementation of the Montgomery Review recommendations. (MSP - 2 , Non MSP - 20)

5th September 2017 - Continued and brief discussion on Montgomery Review recommendations. Key theme was care coordination and specialist nursing for rare, genetic and undiagnosed conditions and the variation in provision across specific conditions. (MSP - 2 , Non- MSP - 19)

5th December 2017 (Inquorate)- Specialist Nursing Meeting with Chief Nursing Officer Fiona McQueen to discuss the current issues around variation in specialist nursing provision for rare, genetic and undiagnosed conditions, the Specialist Nursing Fund and a proposal for a specialist nursing service for rare, genetic and undiagnosed conditions.

20th March 2018 - Scottish Plan for Rare Diseases - Victoria Milne (National Planning Team Leader, Scottish Government) and Angela Simpson (Senior Policy Manager for Rare Diseases, Scottish Government) attended the meeting to provide an overview of the Scottish Plan for Rare Disease, the policy context in which it exists and a summary of the Scottish Government's biennial report. There was also a short discussion on access to new medicines and the response received by the CPG from the Cabinet Secretary. (MSP - 2, Non- MSP 12)

17th April 2018 - AGM Meeting - AGM business and discussion of 2018/19 workplan (MSP - 2, Non-MSP - 13)

MSP MEMBERS OF THE GROUP

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

Bob Doris MSP (Scottish National Party)

John Scott MSP (Scottish Conservative Party)

Miles Briggs MSP (Scottish Conservative Party)

Anas Sarwar MSP (Scottish Labour Party)

Alex Cole- Hamilton MSP (Scottish Liberal Democrats)

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

Genetic Alliance UK
Cystic Fibrosis Trust
Tuberous Sclerosis Association
Turner Syndrome Society
PNH Scotland
British Liver Trust
UKPIPs
Action Duchenne
Funny Lumps
Fragile X Society
The Aarskog Foundation
CSF Leak Association
Behcet's Syndrome Society
EDS UK
Office for Rare Conditions (Glasgow)
Family Fund

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	Bob Doris MSP
Deputy Convener	John Scott MSP
Secretary	Natalie Frankish (Genetic Alliance UK)
Treasurer	Natalie Frankish (Genetic Alliance UK)

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).

Secretarial support is provided by Genetic Alliance UK. Genetic Alliance UK also provide funds for catering and refreshments at the CPG meetings.

In the year 2017/18, catering costs have totalled: £484.68

(Material Support) - Secretariat support will be provided by Natalie Frankish, Genetic Alliance UK's Policy and Engagement Manager for Scotland. Approximately 0.5 days per week is spent on work relating to the Cross Party Group on Rare Disease at an approx. value of (£3,050 salary costs and £1,016 overhead costs)

No other monies have been received, or spent, by the CPG.

SUBSCRIPTION CHARGED BY THE GROUP

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

No subscription charge is charged by the group.

CONVENER CONTACT DETAILS

Name	Bob Doris
Parliamentary address	M5.09 The Scottish Parliament Edinburgh EH99 1SP
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