

## CROSS-PARTY GROUP ANNUAL RETURN

<b>NAME OF CROSS-PARTY GROUP</b>
Cross-Party Group on Rare, Genetic and Undiagnosed Conditions
<b>DATE GROUP ESTABLISHED</b> (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.)
<b>28 March 2017</b>
<b>DATE OF MOST RECENT AGM</b>
<b>26 May 2020</b>
<b>DATE ANNUAL RETURN SUBMITTED</b>
<b>09 June 2020</b>
<b>DATE OF PRECEDING AGM</b> [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]
<b>17 May 2019</b>
<b>GROUP MEETINGS AND ACTIVITIES</b>
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 purpose of the Cross Party Group is to: <ul style="list-style-type: none"><li>• Act as a channel of communication between the Scottish Parliament and families affected by rare, genetic and undiagnosed conditions.</li></ul>

- Act as a channel of communication between the Scottish Parliament and those working in the fields of research, treatment, care and prevention of rare, genetic and undiagnosed conditions.
- Monitor and contribute to the implementation of the Scottish Plan for Rare Diseases in Scotland.
- Identify areas where inequalities exist in provision of care for rare, genetic and undiagnosed conditions and campaigning for improvement. • Examine areas of health and social care policy or service provision relating to rare, genetic and undiagnosed conditions.

The Cross Party Group on Rare Genetic and Undiagnosed Conditions have held the following meetings this year.

23.9.2020 – Discussion on access to new medicines, Scottish Government update on implementation of Montgomery Review and update on Genetic Alliance UK's 'Resetting the Model' Project. (INQUORATE – 1 MSP, 12 NON-MSP)

3.12.2020 – Discussion on care coordination for rare conditions, evidence gathering session from patient organisations. (QUORATE – 2 MSP, 13 NON-MSP)

26.02.2020 – Discussion on proposed care coordination report, agreement on key recommendations. Screening of Rare Disease UK film festival movie (INQUORATE – 1 MSP, 12 NON-MSP)

26.05.2020 – Virtual CPG featuring a question and answer session with Professor Jason Leitch, National Clinical Director for Scottish Government. (QUORATE – 2 MSP – 42 NON-MSP)

26.05.2020 – AGM meeting (QUORATE – 2MSP – 38 NON-MSP)

### **MSP MEMBERS OF THE GROUP**

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

Bob Doris MSP (SNP)

Mark McDonald MSP (IND)

John Scott MSP (CON)

Anas Sarwar MSP (LAB)

Miles Briggs MSP (CON)

Alex Cole-Hamilton MSP (LIB DEM)

## 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  
MyAware  
Autoinflammatory Disease UK  
PCD Family Support Group Scotland  
Children's Health Scotland  
Hereditary Spastic Paraplegia (HSP) Support Group  
PSP Association  
Turner Syndrome Support Society  
Brittle Bone Society  
Sickle Cell and Thalassemia Support Group  
Haemophilia Scotland  
Behcet's UK  
Office for Rare Conditions (Scotland)  
Action Duchenne  
Primary Immunodeficiency UK (PID UK)  
Ehlers-Danlos Support UK  
NHS Scotland Laboratory Genetics Consortium  
Clinical Genetics (NHS Tayside)

## 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  
Mark McDonald 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).

Catering Costs – Provided by Genetic Alliance UK - TOTAL: £491.40

(Material Support) - Secretariat support will be provided by 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 is charged by the group

**CONVENER CONTACT DETAILS**

Name	Bob Doris MSP
Parliamentary address	M5.09 The Scottish Parliament Edinburgh EH99 1SP
Telephone number	0131 348 6547