

## 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.)
28 March 2017
<b>DATE OF MOST RECENT AGM</b>
17 May 2019
<b>DATE ANNUAL RETURN SUBMITTED</b>
11 June 2019
<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]
17 April 2018
<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:

- Act as a channel of communication between the Scottish Parliament and families affected by rare, genetic and undiagnosed conditions.
- 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.

### **11 September 2018 – Access to medicines for rare conditions**

At this meeting MSPs and non-MSP members heard from the Scottish Government and the Scottish Medicines Consortium regarding the implementation of the Montgomery review recommendations. Nick Meade, Director of Policy for Genetic Alliance UK provided a presentation on Genetic Alliance UK's project 'Resetting the Model'. (2 MSPs, 17 Non-MSP members)

### **6 February 2019 – European Reference Networks**

At this meeting an expert panel of clinicians involved in European Reference Networks (ERNs) presented evidence of the value of European collaboration in the field of rare diseases and expressed their concerns about the effect of Brexit on ERNs. Discussion centred on how members could support the campaign to ensure continued involvement of Scottish clinicians and institutions in ERNs post-Brexit. Actions for this meeting included writing to the First Minister and Prime Minister to express concern and encourage a commitment to continued involvement. (3 MSPs, 21 Non-MSP)

### **23 April 2019 – The Future of Genomics in Scotland**

At this meeting the CPG heard from a panel of experts drawn from Scotland's genetics community and discussed the findings of the SSAC Report on the Future of Genomic Medicine in Scotland. (3 MSPs, 26 Non-MSP)

### **14 May 2019 – AGM**

A short meeting was held to confirm membership of the CPG and office bearers. (2 MSPs, 1 Non-MSP)

Two further meetings were held without a quorum of MSPs members.

### **19 June 2018 – Young People's Experiences of Rare Conditions**

At this meeting, we welcomed children and young people to share their experiences of living with rare, genetic and undiagnosed conditions. Rare Disease UK presented the findings of their report “Understanding children and young people’s experiences” report.

**6 December 2018 – Raising awareness of rare, genetic and undiagnosed conditions in the clinical community**

At this meeting we explored how to raise awareness of rare, genetic and undiagnosed conditions with health professionals. We heard from patient Keith Swankie about his experience and explored initiatives such as digital passports as a means to help raise awareness. We had a presentation from Information Services Division on the development of the congenital and rare disease registration service for Scotland.

**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	<ul style="list-style-type: none"> <li>Genetic Alliance UK</li> <li>Tuberous Sclerosis Association</li> <li>Turner Syndrome Society</li> <li>PNH Scotland</li> <li>British Liver Trust</li> <li>UKPIPs</li> <li>Action Duchenne</li> <li>Funny Lumps</li> <li>Fragile X Society</li> </ul>

	<p>The Aarskog Foundation</p> <p>CSF Leak Association</p> <p>Behcet's Syndrome Society</p> <p>EDS UK</p> <p>Office for Rare Conditions (Glasgow)</p> <p>Family Fund</p> <p>PCD Support Group for Scotland</p> <p>NLRP12</p> <p>Haemophilia Scotland</p>
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**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, Policy and Engagement Manager for Scotland, Genetic Alliance UK
Treasurer	Natalie Frankish, Policy and Engagement Manager for Scotland, 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: £1041.66

(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 is charged.

### **CONVENER CONTACT DETAILS**

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