

## CROSS-PARTY GROUP ANNUAL RETURN

### NAME OF CROSS-PARTY GROUP

Cross-Party Group on Rare Diseases

**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.)

**June 25<sup>th</sup> 2013**

### DATE OF MOST RECENT AGM

**June 17<sup>th</sup> 2014**

**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]**

**N/A**

### DATE ANNUAL RETURN SUBMITTED

**17<sup>TH</sup> July 2014**

### 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.

- **June 25<sup>th</sup> 2013** – Initial meeting of the Cross Party Group on Rare Diseases – purpose of the group decided, office bearers elected and membership of the meeting discussed.
- 5 MSPs in attendance ( Jackie Baillie, Ken MacIntosh, Malcolm Chisholm, Bob Doris & Aileen McLeod)
- 10 non-MSPs in attendance

- **October 1<sup>st</sup> 2013** – ‘A strategy for Rare Diseases’ – at this meeting the UK Strategy for Rare Diseases was discussed. Speakers included Alastair Kent from Genetic Alliance UK who discussed the work ongoing in the UK to produce a UK Strategy for rare diseases, Liz Porterfield from the Scottish Government who discussed the Scottish Government’s input into the UK Strategy and plans for the development of a Scottish Implementation Plan for Rare Diseases.
  - 3 MSPs in attendance (Nanette Milne, Malcolm Chisholm & Aileen McLeod)
  - 19 non-MSPs in attendance
  
- **December 3<sup>rd</sup> 2013** – ‘Access to medicines for rare diseases’ – at this meeting the developments in accessing medicines for rare diseases were discussed. Speakers included Angela Timoney (Chair of Scottish Medicines Consortium) and Joan Fletcher (AGSD UK). Liz Porterfield from the Scottish Government provided an update on the UK Strategy for Rare Diseases.
  - 1 MSP was in attendance – Bob Doris
  - 11 non-MSPs in attendance
  
- **April 29<sup>th</sup> 2014** – ‘Research and Rare Diseases’ – at this meeting, there was a focus on how research for rare diseases is funded and conducted in Scotland. Speakers included Alan McNair (Chief Scientist Office), Gill Borthwick (NIHR) and Patricia Osborne (Brittle Bone Society). Liz Porterfield from the Scottish Government also attended to provide further update on the development of a Scottish implementation plan for rare diseases.
  - 1 MSP in attendance – Malcolm Chisholm
  - 18 non-MSPs in attendance
  
- **June 17<sup>th</sup> 2014** – AGM / ‘Coordination of Care – Scotland’s Managed Clinical Networks’ – at this meeting Deirdre Evans (Director of NSD) provided an overview of the services NSD provide for rare disease patients in Scotland and explained the important role of the managed clinical networks. Marina Di Marco (Lead for the Scottish Muscle Network) and Vicki Price (S.P.A.I.I.N Network) gave an overview of the work that their networks carry out and how this benefits patients with rare diseases. Lauren Roberts, Coordinator for SWAN UK, gave an overview of her work supporting families affected by a ‘syndrome without a name’. The AGM for the Cross Party Group was also held during this meeting and office bearers returned.
  - 3 MSPs in attendance – Bob Doris, Malcolm Chisholm and Aileen McLeod
  - 23 non-MSPs in attendance

## **MSP MEMBERS OF THE GROUP**

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

Malcolm Chisholm (Lab) – Co-Convener

Bob Doris (SNP) – CO-Convener

Nanette Milne (Con)

Jackie Baillie (Lab)  
 Aileen McLeod (SNP)  
 Ken Macintosh (Lab)  
 Richard Lyle (SNP)

**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	<p>Genetic Alliance UK          Turner Syndrome Support Society          PNH Scotland          Laurence Moon Bardet Beidl Syndrome Society          Brittle Bone Society          Carers Trust          Cystic Fibrosis Trust          TSA Association          Fragile X Society          PID UK          Haemophilia Scotland</p>

**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-Convener	Malcolm Chisholm
Co-Convener	Bob Doris
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).

Genetic Alliance UK supplies funds to provide catering at each quarterly meeting of the Cross Party Group on Rare Diseases. This breaks down as follows:

October meeting – £21.12

December meeting – 43.50

April meeting – £45

June meeting - £45

**Catering total = £154.62**

The Secretariat for the Cross Party Group on Rare Diseases is provided by the Development Officer for Scotland employed by Genetic Alliance UK. Approximately two days per calendar month are allocated to tasks relating to the support of the Cross Party Group including research, producing materials, liaising with members, general admin and arranging meetings. The estimated value of the support over a one year period is as follows:

Salary: £4429.50 per year

Overheads/Material costs: £1,368 per year

**SUBSCRIPTION CHARGED BY THE GROUP**

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

N/A

**CONVENER CONTACT DETAILS**

Name

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