CROSS-PARTY GROUP REGISTRATION FORM

NAME OF CROSS-PARTY GROUP

Cross-Party Group on Rare Diseases

PURPOSE OF THE GROUP AND PROPOSED DISCUSSION TOPICS

1. Please provide a brief explanation of the purpose of the Group and why the purpose is in the public interest.
2. Please also provide details of any overlaps with the purpose of existing Cross-Party Groups and an explanation of why, regardless of any such overlap, the Group should be established.
3. Please also provide an indication of the topics which the Group anticipates discussing in the forthcoming 12 months.

1. Purpose of the Cross Party Group on Rare Diseases
   - To act as a channel of communications between the Scottish Parliament and families affected by rare diseases in Scotland.
   - To act as a channel of communications between the Scottish Parliament and people and organisations working in rare disease research, treatment, care and prevention.
   - To monitor the development and implementation of a Strategy for Rare Diseases in Scotland.
   - To identify areas where inequalities exist in the provision of care and campaign for their improvement.
   - To examine areas of policy or service provision relating to rare diseases in Scotland.

   With 1 in 17 people being affected by a rare disease, and with currently no strategy for rare diseases in Scotland, a Cross Party Group on rare diseases is in the public interest.
2. The Cross Party Group on Rare Diseases will provide an opportunity to raise awareness of rare diseases in Scotland and the problems facing patients affected by them. This Group will explore broad topics relating to rare diseases in general – such as a National Strategy for Rare Diseases & access to medicines for rare diseases. Whilst there may be a very small degree of cross over (in terms of issues raised) with some of the other health related cross party groups (i.e CPG on muscular dystrophy or CPG on learning disability), the Cross Party Group will be the only Group to represent the over 6,000 rare diseases and the issues affecting the over 300,000 rare disease patients in Scotland.

3. Topics that the Group is likely to discuss over the 12 month period include:
   - Progress towards a national plan for rare diseases and it's

implementation in Scotland

- Access to new medicines for rare diseases in Scotland
- Coordination of Care for Rare Diseases

MSP MEMBERS OF THE GROUP

Please provide names of all MSP members of the Group. Note that only names need to be provided, no party designation or other information is required.

Malcolm Chisholm

Bob Doris

Ken Macintosh

Jackie Baillie

Aileen McLeod

Richard Lyle

Nanette Milne

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	Rare Disease UK Turner Syndrome Support Society Funny Lumps (supporting children with neurofibromatosis) PNH Scotland Laurence Moon Bardet Beidl Syndrome Society Brittle Bone Society Carers Trust Cystic Fibrosis Trust Genzyme Therapeutics Ltd

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	Malcolm Chisholm MSP (Co-Convener)
Deputy Convener	Bob Doris MSP (Co-Convener)
Secretary	Natalie Frankish (Rare Disease UK)
Treasurer	Natalie Frankish (Rare Disease UK)

FINANCIAL BENEFITS OR OTHER BENEFITS

Please provide details of any financial or material benefit(s) the Group anticipates receiving 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.

Rare Disease UK will supply funds to provide catering at each quarterly meeting of the Cross Party Group on Rare Diseases. This is anticipated to be no more that £75 per meeting or £300 in a calendar year.

Secretariat support will be provided by Rare Disease UK – this will be at no cost.

SUBSCRIPTION CHARGED BY THE GROUP

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

N/A

CONVENER CONTACT DETAILS

Name	Malcolm Chisholm
Parliamentary address	M1.16 The Scottish Parliament Edinburgh EH99 1SP
Telephone number	0131 348 5908

<table>
<tr><th colspan="2">STATEMENT ON COMPLIANCE WITH THE CODE OF CONDUCT</th></tr>
<tr><td colspan="2">I declare that the Cross-Party Group on Rare Diseases is constituted and will comply with the terms of Section 6 of the Code of Conduct for Members of the Scottish Parliament.</td></tr>
<tr><td>Signed</td><td></td></tr>
<tr><td>Date</td><td></td></tr>
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