

## CROSS-PARTY GROUP REGISTRATION FORM

### NAME OF CROSS-PARTY GROUP

Cross-Party Group on Rare, Genetic and Undiagnosed Conditions

### PURPOSE OF THE GROUP AND PROPOSED DISCUSSION TOPICS

1. Please state the purpose of the Group.
2. Please also provide a brief explanation of the purpose of the Group and why the purpose is in the public interest.
3. 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.
4. Please also provide an indication of the topics which the Group anticipates discussing in the forthcoming 12 months.

Purpose of the Cross Party Group on Rare, Genetic and Undiagnosed Conditions:

- 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.

Approximately 300,000 people in Scotland will be affected by a rare condition at some point in their lives. 80% of rare diseases will have a genetic component and often conditions are chronic and life-threatening. The conditions are frequently life-long and serious and gaining access to accurate diagnosis and appropriate care and support can be a struggle for families. Despite the scale of the issue, a significant proportion of families affected by rare, genetic and undiagnosed conditions do not have access to the right care and treatment.

The diversity of rare, genetic and undiagnosed conditions, the specialist knowledge required to diagnose and treat the conditions and the geography of Scotland brings challenges for health and social care services and their partners in delivering services. A Cross Party Group for rare, genetic and undiagnosed conditions is necessary to bring together key stakeholders and ensure the needs of families and carers across Scotland are supported and addressed by health and

social care policy. The Cross Party Group has the potential to make a difference to the lives of families in Scotland.

The Cross Party Group on Rare, Genetic and Undiagnosed Conditions will provide an opportunity to raise awareness of rare, genetic and undiagnosed conditions in Scotland and the problems facing families affected by them. This Group will explore broad topics relating to rare diseases in general such as the implementation of the Scottish Plan for Rare Diseases, access to medicines in Scotland, genomic research and coordination of care. 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 – 8,000 rare, genetic diseases and the issues affecting the over 300,000 patients in Scotland.

Topics that the Group is likely to discuss over the 12 month period include:

- Progress towards the implementation of the Scottish Implementation Plan for Rare Diseases
- Research developments and opportunities for rare, genetic and undiagnosed conditions in Scotland
- Access to new medicines for orphan and ultra-orphan medicines in Scotland
- Specialist nursing and coordination of care for families affected by rare, genetic and undiagnosed conditions

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

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

Bob Doris MSP (Scottish National Party)

Miles Briggs MSP (Scottish Conservative Party)

Anas Sarwar MSP (Scottish Labour Party)

John Scott MSP (Scottish Conservative Party)

Alex Cole-Hamilton (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	
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Organisations	Brittle Bone Society Cystic Fibrosis Trust Tuberous Sclerosis Association Turner Syndrome Society PNH Scotland British Liver Trust UKPIPs Action Duchenne Funny Lumps Fragile X Society Genetic Alliance UK The Aarskog Foundation CSF Leak Association  (It is anticipated that further members will be added at the first meeting following registration)
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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	Anas Sarwar MSP, John Scott MSP
Secretary	Natalie Frankish (Genetic Alliance UK)
Treasurer	Natalie Frankish (Genetic Alliance 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.

Genetic Alliance 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 than £75 per meeting or £300 in a calendar year.

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

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

#### **STATEMENT ON COMPLIANCE WITH THE CODE OF CONDUCT**

I declare that the Cross-Party Group on Rare, Genetic and Undiagnosed Conditions is constituted and will comply with the terms of Section 6 of the Code of Conduct for Members of the Scottish Parliament.

Signed

Date