

Cross-Party Group Registration Form

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| Name of Cross-Party Group |
| Cross-Party Group on Rare, Genetic and Undiagnosed Conditions |
| Purpose of The Group and Proposed Discussion Topics <ol style="list-style-type: none">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. |
| <p>1. PURPOSE</p> <ul style="list-style-type: none">• 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. <p>2. PUBLIC INTEREST</p> <p>Rare, genetic and undiagnosed conditions in Scotland will affect more than 400,000 people in Scotland at some point in their lives. There are more than 6,000 rare conditions (defined by the European Union as a</p> |

condition that affects fewer than 1 in 2,000 people within the general population). 8 out of 10 rare diseases have a genetic cause and 99% of genetic conditions are classed as rare. These conditions can affect adults and children, and can often be chronic and life-threatening.

People living with rare, genetic and undiagnosed conditions experience many challenges including; a long journey to diagnosis, difficulties obtaining reliable information and support, health and social care professionals who do not know about, or understand, their condition, difficulties accessing appropriate care and support, limited opportunities to participate in research, limited options for care and treatment and a significant impact on mental and emotional wellbeing.

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. The CPG will play an active role in the implementation of the new UK Rare Disease Framework (2021), the development of the Scottish Government Rare Disease Action Plan and will work to support the development and implementation of other relevant health and social care policies that will have an impact on the community.

3. OVERLAP WITH OTHER GROUPS

The CPG on Rare, Genetic and Undiagnosed Conditions will provide the only forum in the Scottish Parliament to represent and explore the issues relevant to the over 400,000 people living in Scotland with a rare, genetic or undiagnosed condition.

From time to time there may be a slight overlap with the work of other condition-specific CPGs. However, should this occur, the CPG on Rare Genetic and Undiagnosed Conditions intends to work collaboratively with other groups.

4. TOPICS TO BE CONSIDERED

The workplan will be driven by the priorities identified by the CPG members. Topics likely to be covered in the first year include; rehabilitation of NHS services for rare conditions following the Covid-19 pandemic, the implementation of the UK Framework for Rare Diseases in Scotland, newborn screening requirements, improving diagnosis, raising awareness with health professionals, improving experiences of care, care coordination and access to treatment, medicines and services.

MSP Members of the Group

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

Bob Doris MSP (SNP)

Paul McLennan MSP (SNP)

Neil Gray MSP (SNP)

Miles Briggs MSP (Scottish Conservative)

Carol Mochan MSP (Scottish Labour)

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 Alternating Hemiplegia of Childhood UK (AHC UK) Autoimflammatory UK Behcet's UK British Liver Trust CHAMP 1 Children's Health Scotland EDS UK Haemophillia Scotland HSP Support Group MyAware NLRP12 Office for Rare Conditions PNH Scotland |

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| | PSP Association Rare Disease Nurse Network The Aarskog Foundation The Smith-Magenis Syndrome (SMS) Foundation Turner Syndrome Support Society |
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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.

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| Convener | Bob Doris MSP |
| Deputy Convener | Paul McLennan 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 meeting. This is anticipated to be no more than £100 per meeting or £400 in a calendar year.

Secretariat support will be provided by 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 £4,500.

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.

No subscription shall be charged.

Convener Contact Details

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| Name | Bob Doris MSP |
| Parliamentary address | The Scottish Parliament Edinburgh EH99 1SP |
| Telephone number | 0141 946 7700 |

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

30/6/21