

Cross Party Group on Rare, Genetic and Undiagnosed Conditions

Tuesday 28th March 2017 – 1pm to 2pm

Scottish Parliament

Note of Meeting

1. Welcome and Introductions

1.1 Bob Doris MSP welcomed all in attendance and invited attendees to introduce themselves.

2. The CPG on Rare, Genetic and Undiagnosed Conditions - Purpose

2.1 It was agreed that the purpose of the Cross Party Group on Rare, Genetic and Undiagnosed Conditions would be 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 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

2.2 The Cross Party Group will meet a minimum of three times per year. Meetings will focus on key topics which will be identified at the first meeting following formal recognition of the Cross Party Group. It is likely that there will crossover of issues with other cross party groups – in which case the Secretariat of the CPG on Rare, Genetic and Undiagnosed Conditions will contact the Secretariat of the relevant CPG to discuss collaborative working possibilities. The group will look at the challenges that cross cut the large number of rare, genetic and undiagnosed conditions rather than focus on specific conditions.

3. Cross Party Group on Rare, Genetic and Undiagnosed Conditions – Membership

3.1 The CPG MSP membership includes Bob Doris MSP, Anas Sarwar MSP, Miles Briggs MSP, John Scott MSP and Alex Cole-Hamilton MSP.

3.2 The Non-MSP membership will include patient organisations supporting patients with rare, genetic and undiagnosed conditions. Group meetings will be open to all with an interest to attend.

3.3 It was agreed that Bob Doris MSP would be the Convener of the Group, with Anas Sarwar MSP and John Scott MSP sharing the Deputy Convener role.

3.4 Natalie Frankish, Genetic Alliance UK's Policy and Engagement Manager for Scotland, will provide Secretariat and Treasurer duties for the group.

4. Next Steps

4.1 It was noted that the next step was to submit the formal paperwork to the Standards and Procedures Committee of the Scottish Parliament for consideration. Once the Group is accorded formal recognition, details of the next meeting will be circulated.