Cross Party Group on Rare, Genetic and Undiagnosed Conditions

Thursday 8 September 2022

AGM Formal Business

1. **Welcome**
   Bob Doris MSP opened the meeting and explained that this was a short AGM meeting to conduct the business which was unable to be completed at the June meeting. No other topics were to be discussed.

2. **Election of Convener**

   Bob Doris MSP is invited to continue in the post of Convener. MSPs in attendance will be invited to agree this.

3. **Election of Co-Convener**

   Paul McLennan MSP is invited to continue in the post of Co-Convener. Additional Co-Conveners are welcomed. MSPs in attendance will be invited to agree this.

4. **Election of Secretariat**
   Genetic Alliance UK request to continue providing secretariat support to the Cross Party Group on Rare, Genetic and Undiagnosed Conditions. MSPs in attendance will be invited to agree this.

5. **Treasurer Report**

   The CPG has not held an in person meeting during the 2021/2022 reporting period and therefore no costs for venues, catering, AV and printing have been incurred.

   Genetic Alliance UK continue to provide Secretariat and administrative resource to the CPG. This equates to approximately 2 hours per week of Genetic Alliance UK's Policy and Engagement Manager time.

6. **Work of CPG 2021/2022 and future plans**

   MSPs are invited to note that:
   - X of meetings have been held considering topics such as newborn screening, access to medicines, treatment and services for rare conditions, improving care coordination and the experience of diagnosis for people with rare, genetic and undiagnosed conditions, progress towards implementing the UK Rare Disease Framework in Scotland and how research is improving diagnosis for rare, genetic and undiagnosed conditions.

- It has been challenging to hold quorate meetings, however it is important to note that the CPG has also attracted non-member MSPs to attend some meetings. Genetic Alliance UK will conduct engagement work with MSPs throughout autumn/winter 2022 with a view to growing membership of the group.
- The CPG has attracted high numbers of external attendees – ranging between 20 and 45 individuals. This has included invited speakers from the Scottish Government, NHS Scotland, academia and individuals with lived experience. The CPG thanks all those who have contributed to meetings, particularly those who have shared their personal experiences.
- The CPG has had meaningful success in the last parliamentary year. This has included the CPG's report on improving the experience of care informing the development of Scotland's Action Plan for Rare Conditions and a campaign to encourage the development of a research programme for newborn screening for Spinal Muscular Atrophy.
- The CPG has worked closely with the CPG on Muscular Dystrophy, convened by Jackie Baillie MSP.
- It is proposed that there will be 4 CPG meetings in 2022/23, the first being a meeting to review progress of the implementation of the UK Rare Disease Framework in Scotland. This meeting will take place on 6 October 2023 and will include a review of progress against the Framework's four key priorities with invited speakers.
- The AGM is occurring later than expected this year. The AGM was due to take place in June 2022, however the meeting was not quorate. The meeting was rescheduled for as soon as possible following parliamentary recess and the Clerk to the Procedures and Standards Committee was informed of this. The CPG Secretariat will comply with any further requirements as requested by the Committee.

7. Purpose of CPG

MSPs in attendance are invited to agree that the purpose of the CPG will continue to be to:

a. Act as a channel of communication between the Scottish Parliament and families affected by rare, genetic and undiagnosed conditions.
b. 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.
c. Monitor and contribute to the implementation of the Scottish Plan for Rare Diseases in Scotland.
d. Identify areas where inequalities exist in provision of care for rare, genetic and undiagnosed conditions and campaigning for improvement.
e. Examine areas of health and social care policy or service provision relating to rare, genetic and undiagnosed conditions.