**Cross Party Group on Rare, Genetic and Undiagnosed Conditions**
**Tuesday 14 May 2019**

## AGM Business – Minutes

This was a short meeting of the CPG on Rare, Genetic and Undiagnosed Conditions.

Appropriate notice of the AGM had been provided to the Scottish Parliament Standards, Procedures and Public Appointments Committee, and advertised on the Scottish Parliament website, following the rescheduling of AGM business from the meeting on 23 April 2019.

No MSP members or non-MSP members had indicated that they wanted to be removed from the CPG.

**Confirmation of MSP members**
Bob Doris MSP
John Scott MSP
Anas Sarwar MSP
Miles Briggs MSP
Alex Cole-Hamilton MSP

**Confirmation of non- MSP members**
Genetic Alliance UK
Tuberous Sclerosis Association
Turner Syndrome Society
PNH Scotland
British Liver Trust
UKPIPs
Action Duchenne
Funny Lumps
Fragile X Society
The Aarskog Foundation
CSF Leak Association
Behcet's Syndrome Society
EDS UK
Office for Rare Conditions (Glasgow)
Family Fund
NLRP12
PCD Support Group for Scotland
Haemophilia Scotland

**Office bearers**
The following office bearers were confirmed:

- Chair – Bob Doris MSP was confirmed as Chair
- Deputy Chair – John Scott MSP had provided the deputy chair role, he will be asked to confirm if he wishes to remain in post.
- Secretary – Natalie Frankish, Genetic Alliance UK
- Treasurer – Natalie Frankish, Genetic Alliance UK

**Annual Report from Secretariat**

The CPG was established in 2017 and held its last AGM on 17 April 2018. The purpose of the CPG is to provide a channel of communication between Scottish Parliament and families in Scotland living with rare, genetic and undiagnosed conditions.

In the last year, the CPG has held five meetings:

- June 2018* – 'End of term party' marking the year of young people and hearing directly from young people living with rare, genetic and undiagnosed conditions.

- September 2018 – Access to medicines in Scotland with updates on the implementation of the Montgomery Review recommendations provided by SMC and Scottish Government. Genetic Alliance UK introduced their new 'resetting the model' project.
- November 2018* – Raising awareness of rare genetic and undiagnosed conditions with health professionals. We heard about the value of patient passports and alert cards and heard experiences from patients that demonstrate the need for greater awareness and training for health professionals on how to recognise rare conditions. We heard about the Congenital and Rare Disease Registration service for Scotland.
- February 2019 – European Reference Networks. We heard about the value of ERNs and the threat posed by Brexit. The CPG heard from Scotland's clinicians involved in ERNs and agreed to write to the relevant Ministers in Westminster to raise concern. The CPG has collaborated with the APG on this matter.
- April 2019 – The Future of Genomic Medicine in Scotland. The CPG heard from a panel of experts and discussed the recent recommendations of the SSAC report on genomics in Scotland and explored the opportunities and challenges presented by genomic medicine.

The findings of the Cross Party Group meetings have been shared with the Strategic Working Group tasked with delivering the plan for Rare Diseases in Scotland.

In the coming year it is proposed that the CPG will hold four meetings, continuing our work to explore the inequity of care coordination services for rare, genetic and undiagnosed conditions and our work on raising the profile of rare, genetic and undiagnosed conditions in the clinical community.

**Treasurer's Report**

The CPG does not charge a subscription fee to non-MSP members. This is to ensure all groups, regardless of their size, resource or capacity have the opportunity to participate. Genetic Alliance UK provides Secretariat support to the CPG, including funds for catering of meetings. In the last year, support provided by Genetic Alliance UK amounts to £1,041.66 for catering and approximately £4,100 on staff time for work associated with the CPG.