All Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions

EXPENDITURE STATEMENT

1. Period covered: from 4/11/2022 to 3/11/2023

2. Secretariat and employment cost (includes salary, pension contributions and National Insurance): £8,502

3. Costs of contractors and freelance staff:
   £480 (cost of photographer across four hours at the APPG meetings)

4. Visits and events (UK):
   travel for staff support: £207

5. Visits and events (abroad): £0

6. Cost of generating income: £0

7. Office and communications costs: included in secretariat and employment cost: £0

8. Other (please explain): £0

Genetic Alliance UK provides the secretariat to the All Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions. Genetic Alliance UK uses unrestricted income to support the All Party Parliamentary Group.
Genetic Alliance UK is a registered charity, our charity numbers are 1114195 and SC039299.

ANNUAL REPORT

Group office holders
Liz Twist MP (Chair)
Baroness Neville-Jones (Vice Chair)
Lord Patel (Vice Chair)
Marion Fellows MP (Vice Chair)
Catherine West MP (Vice Chair)
Genetic Alliance UK (Secretariat)

Previous meetings
The APPG on Rare, Genetic and Undiagnosed Conditions held two meetings in the reporting period considering topics such as: progress towards the implementation of the UK Rare Diseases Framework; care coordination for people with rare genetic and undiagnosed conditions; and the experience of diagnosis.

The APPG hosted two drop-in sessions. The first drop-in session was held in collaboration with the Wellcome Centre for Mitochondrial Research on research into mitochondrial disease and was also attended by the Lily Foundation. The second drop-in was held in collaboration with the Cell and gene Therapy Catapult on cell and gene therapies and was also attended by Alex TLC and the Haemophilia Society.

Following actions agreed at these meetings, APPG members have submitted parliamentary questions enquiring progress on work regarding issues such as cell and gene therapies, alert cards for rare conditions and the Major Conditions Strategy.

The Chair of the group, Liz Twist and the Secretariat, Genetic Alliance UK, also wrote a letter to the Minister, Andrew Stephenson, to share concerns arising in the meetings including the funding of patient registries and provision of alert cards for rare conditions.

Plans for 2024
It is proposed that there will be four APPG meetings in the reporting period 2023-2024.

The APPG held a meeting on 11 December 2023 to consider research into rare conditions.

In the upcoming year, the APPG is planning a meeting to discuss the Newborn Genomes Programme and its implications for newborn screening. The group is also planning a meeting with NICE to consider access to medicines for rare conditions. The APPG will continue to monitor the implementation of the Rare Disease Action Plans in each of the UK nations. The APPG ensures that the priorities for the APPG are influenced by the current issues for the rare condition community and what is most important to them.

The group continued to use a hybrid approach to meeting in 2023 to allow attendance from the wider community. This allowed a broad and rich input from a wide array of stakeholders in meetings. There have been challenges around technology to allow online attendees to contribute to discussion. The secretariat will work to improve these challenges and the group will continue to hold hybrid meetings, where possible.

Purpose of APPG

Members in attendance are invited to agree that the purpose of the APPG will be to:

- Act as a channel of communication between the Parliament and families affected by rare, genetic and undiagnosed conditions.
- Act as a channel of communication between the 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 Action Plans for Rare Diseases.
- 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