All Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions

EXPENDITURE STATEMENT

1. Period covered: from 4/11/2021 to 3/11/2022

2. Secretariat and employment cost (includes salary, pension contributions and National Insurance): £9,972

3. Costs of contractors and freelance staff: £0

4. Visits and events (UK):
   travel for speakers at meeting on 27.04.2022 : £50
   travel for staff support: £210

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 membership and office holders
Liz Twist MP (Chair)
Baroness Neville-Jones (Vice Chair)
Lord Turnberg (Vice Chair)
Lord Patel (Vice Chair)
Alex Sobel MP (Vice Chair)
Genetic Alliance UK (Secretariat)

Previous meetings
The APPG on Rare, Genetic and Undiagnosed Conditions held three meetings in the reporting period considering topics such as: progress towards the implementation of the UK Rare Diseases Framework ahead of the launch of the Rare Disease Action Plans; implementation of the Action Plans; and the experience of diagnosis.

The APPG hosted a drop-in session on research into mitochondrial disease in collaboration with the Wellcome Centre for Mitochondrial Research, also attended by the Lily Foundation.

The APPG worked with the APPG for Life Sciences, chaired by Daniel Zeichner MP, to host a meeting on the UK Rare Diseases Framework.

Plans for 2023
It is proposed that there will be four APPG meetings in 2023. In the upcoming year, the APPG plans to look into the coordination of care and access to medicines for rare conditions. The APPG also plans to continue the monitoring of 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 APPG are working with the Cell and Gene Catapult to organise a parliamentary drop-in on cell and gene therapies.

The group held their first hybrid meeting in 2022 to allow attendance from the wider community. This allowed a broad and rich input from a wide array of stakeholders in meetings. The group plans to 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