

All Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions



EXPENDITURE STATEMENT

1. Period covered: from 4/11/2023 to 30/5/2024
2. Secretariat and employment cost (includes salary, pension contributions and National Insurance):
£4,630
3. Costs of contractors and freelance staff: £0
4. Visits and events (UK):
Genetic Alliance UK staff travel to Westminster to support APPG meetings: £253.80
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.

Genetic Alliance UK

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www.geneticalliance.org.uk

Registered charity numbers: 1114195 and SC039299

Registered company number: 05772999

ANNUAL REPORT

Group office holders

Liz Twist MP (Chair)
Baroness Neville-Jones (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 three meetings in the reporting period:

Research landscape for rare conditions, 11 December 2023

The meeting was organised amidst a series of announcements in the rare disease research field including the publication of the [Rare Diseases Research Landscape Project Report](#). Dr Sagair Hussein from DEBRA UK gave a presentation about the research landscape for epidermolysis bullosa. Attendees in the room spoke about their principal concerns and challenges for research in their field. Actions from the meeting included following up with the Minister about funding for patient registries for rare conditions.

Alert cards for rare conditions, 31 January 2024

The meeting was an opportunity for attendees to introduce the progress they had made on delivering alert cards for their community, the value they brought and the challenges they identified when implementing them in healthcare settings. Actions from the meetings included the Chair of the group, Liz Twist and the Secretariat, Genetic Alliance UK, following up on a letter written to the Minister for Health and Secondary Care, Andrew Stephenson, to share concerns arising in the meetings including the funding of patient registries and provision of alert cards for rare conditions. The APPG has also brought together a group of support organisations who have developed their own alert cards for their rare conditions which can be used as best practice examples. The group hopes to work together to push this issue forward. It was also agreed that the Royal College for Emergency should be invited to participate in this discussion.

Annual General Meeting, 17 April 2024

The group conducted the AGM at this meeting, agreeing the purpose of the group and looking at upcoming meetings for the APPG. Plans include a meeting with NICE to discuss access to rare disease medicines and a meeting with Genomics England to discuss the Generation Study, Newborn Genome Programme.

In the meeting, attendees also discussed the potential impact of amendment N41 submitted to the Criminal Justice Bill on the rare and genetic community. The amendment would limit the right to abortion for women carrying a fetus which has Down's syndrome. The adoption of this amendment will restrict the rights of pregnant women and make an exception under law for one particular genetic condition above all others. Genetic Alliance UK agreed to share a briefing with attendees.

The future of the APPG

Following the dissolution of Parliament on 30 May 2024, the APPG ceased to exist. We hope to re-establish the APPG when the new parliamentary session begins.