

Contributions to UK Patient Organisations 2023

Patient Organisation Name	Country	Types of the Support or Services Provided		Monetary Value of Financial Support and of Invoiced Costs	Description of Support
Cambridge RARE Disease Network	UK	Financial Support	Sponsorship of meeting	£10,000	Gold Sponsorship of RARE Summit 2023
Genetic Alliance UK	UK	Financial Support	Sponsorship of meeting	£12,800	Genetic Alliance Corporate Sponsorship 2023
The Aplastic Anaemia Trust (AAT)	UK	Financial Support	Sponsorship of meeting	£684	All UK internal meeting Patient focus session
Metabolic support UK	UK	Contracted Services (Fees & Expenses disclosed separately)	Fees	£412.50	UK PAG review of patient facing materials for ALXN1850-HPP studies
			Out of pocket/ expenses	£0	

Reporting of Transfers of Value Patient Organisations Methodological Note for Reporting of 2023 Data in 2024

Introduction

Alexion is a member company of the Association of British Pharmaceutical Industry (ABPI). In accordance with the ABPI, companies must make publicly available annually, a list of patient organisations to which it provides donations, grants, or sponsorship (including in relation to events/meetings) or with whom it has engaged to provide contracted services over the reporting period.

Alexion is committed to operating with integrity, accountability, and transparency, and to complying with all applicable laws and regulations. Alexion fully participates in the Association of British Pharmaceutical Industry's (ABPI) Disclosure UK initiative to increase transparency about our interactions with patient organisations.

This note discloses the methodologies used by Alexion in preparing disclosures in compliance with ABPI Code of Practice.

Definitions

Definition of a Patient Organisation

A 'Patient organisation' means an organisation mainly comprising of patients and/or caregivers or any user organisation such as a disability organisation, carer or relative organisation and consumer organisation that represents and/or supports the needs of patients and/or caregivers.

Definition of an Individual Representing Patient Organisations

'Individuals representing patient organisations' means a person who is mandated to represent and express the views of a patient organisation.

ABPI Code Requirements

In accordance with Clause 29 of the ABPI Code:

29.1: Companies must make publicly available annually, a list of patient organisations to which it provides donations, grants or sponsorship (including in relation to events/meetings) or with whom it has engaged to provide contracted services over the reporting period. This information must be disclosed on the company website either on a national or European level. Each reporting period shall cover a full calendar year. Each company must include a note of methodologies used by it in preparing the disclosures and identifying support and contracted services provided.

29.2: The disclosure for the provision of donations, grants or sponsorship (including in relation to events/meetings) to a patient organisation must include:

- the monetary value of each financial contribution (grant or sponsorship) to include a description that is sufficiently complete to enable the reader to understand the nature of that support or the arrangements in accordance with Clauses 23 and 10*
- the monetary value for each non-financial and/or indirect support (donation); the published information must also include a clear description of each donation that is sufficiently complete to enable the reader to understand the nature of the support or the arrangements. If the non-financial and/or indirect support (donation) cannot be assigned a meaningful monetary value, the published*

information must describe clearly the non-monetary value that the organisation receives that is sufficiently complete to enable the reader to understand the nature of the support or the arrangements in accordance with Clause 23

The disclosure for contracted services provided by each patient organisation, in accordance with Clause 24, must include:

- the total amount paid per patient organisation per calendar year including a description of the services provided that is sufficiently complete to enable the reader to understand the nature of the services provided without the necessity to divulge confidential information*
- fees and expenses should be disclosed separately*

Transfer of Values: Alexion

The disclosure of ToVs and non-financial support provided to Patient Organisations by Alexion Pharma include ToVs made by Alexion UK to individual patients (e.g., for speaker services) who are acting on behalf of a Patient Organisation as representatives of the Patient Organisation.

The disclosure template used by Alexion Pharma UK contains the following information:

- Name of Patient Organisation
- Country of Patient Organisation
- Type of services provided engagement
- Type of support (financial/non-financial)
- Monetary Value of Financial Support and of Invoiced Costs
- Description of the support

The Alexion Patient Organisation Disclosure Report will be disclosed on the UK Alexion company website.

The 2023 Patient Organisation Disclosure Report covers ToVs made between 1st January 2023 and 31st December 2023.

Alexion discloses the exact amount paid to the PAO. This may include VAT, if included on the invoice. Please note that the disclosed amounts relating to grants are not inclusive of VAT.