

Contributions to UK & Irish Patient Organisations 2022

Patient Organisation Name	Country	Types of the Support or Services Provided		Monetary Value of Financial Support and of Invoiced Costs	Description of Support
Muscular Dystrophy UK	UK	Financial Support	Sponsorship of meeting	£5000	UCL-MDUK Neuromuscular Translational Research Conference 2022
Ireland: Irish Platform for patient organisations, science & industry (IPPOSI)	UK	Financial Support	Sponsorship of membership	€8,500(£7163.72)	IPPOSI membership
The Aplastic Anaemia Trust	UK	Financial Support	Sponsorship of project	£20,000	National Community Survey Project
Findacure Foundation (Beacon: for rare diseases)	UK	Financial Support	Sponsorship of meeting	£2000	Cambridge Rare Disease Showcase 2022
Kidney Care UK	UK	Financial Support	Sponsorship of project	£25,000	Rare kidney diseases campaign
Genetic Alliance	UK	Financial Support	Sponsorship of membership	£12,800	Rare Disease UK membership
Muscular Dystrophy UK	UK	Financial Support	Sponsorship of meeting	£7,500	Muscles Matter Seminar Series and Virtual Muscle Groups
Cambridge Rare Disease Network	UK	Financial Support	Sponsorship of meeting and membership (combined)	£10,000	RAREfest and Membership of Companies Forum
Genetic Alliance	UK	Financial Support	Sponsorship of project	£12,000	Public Awareness Raising Campaign for Rare Disease Day 2022
Muscular Dystrophy UK	UK	Financial Support	Sponsorship of meeting	£5500	UCL-MDUK Neuromuscular Translational Research Conference 2023
Nerve Tumour UK	UK	Financial Support	Sponsorship of project	£15000	Public Awareness Raising and Support Campaign 2023 for Neurofibromatosis

Society for Mucopolysaccharide	UK	Financial Support	Grant	£35800	Research and report on the overall patient & carer experience of living with LAL D.
Brittle Bone Society	UK	Financial Support	Grant	£2000	Educational Information and Communications Support
Metabolic Support UK	UK	Contracted Services (Fees and expenses should be disclosed separately)	Fees	Fees: £250; Out of pocket/ expenses: None	Consultancy: Input into patient insight sessions
			Out of pocket/ expenses		

Reporting of Transfers of Value Patient Organisations Methodological Note for Reporting of 2022 Data in 2023

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 2022 Patient Organisation Disclosure Report covers ToVs made between 1st January 2022 and 31st December 2022.

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.