

Contributions to UK Patient Organisations 2024

Patient Organisation Name	Types of the Support or Services Provided		Monetary Value of Financial Support and of Invoiced Costs	Description of Support
The Neurofibromatosis Association	Financial Support	Sponsorship of meeting	£15,000	Disease awareness and support campaign
The Neurofibromatosis Association	Financial Support	Sponsorship of meeting	£15,000	Funding for NF1 Medical Information Days
Genetic Alliance UK	Financial Support	Sponsorship of membership	£15,000	Genetic Alliance Corporate membership sponsorship 2024-2025
Genetic Alliance UK	Financial Support	Sponsorship of meeting	£15,000	Rare Disease Day February 2024
Kidney Care UK	Financial Support	Sponsorship of project	£15,000	Rare Renal Policy Expert Working group.
The Neurological Alliance	Financial Support	Sponsorship of project	£2000	Corporate sponsor of The Neurological Alliance's 'My Neuro Survey' including a series of listening and engagement activities, roundtables with and one- to-one interviews with relevant system partners and leaders.
Muscular Dystrophy UK	Financial Support	Sponsorship of meeting	£3300	Muscular Dystrophy UK's Virtual Seminar Series
Scleroderma & Raynaud's UK	Financial Support	Sponsorship of project	£5600	Corporate Sponsor of SR UK in its work as the secretariat for the Independent Advisory Group of the Rare Disease Forum
Metabolic Support UK	Financial Support	Sponsorship of project/meeting	£15,000	Sponsorship for Metabolic Support UK HPP Survey & Roundtable
The Aplastic Anaemia Trust	Financial Support	Sponsorship of project	£15,000	The Aplastic Anaemia Trust Personalised Support Project 2024

The Aplastic Anaemia Trust	Financial Support	Sponsorship of project	£15,000	Sponsorship of AAT Winter Warmth webinars & magazine 2024
Cambridge Rare Disease Network	Financial Support	Sponsorship of meeting	£12,000	Sponsorship of CamRARE RAREfest2 meeting
The Neurological Alliance	Financial Support	Sponsorship of meeting	£2750	Neurological Alliance Parliamentary event 2024
Childhood Tumour Trust	Financial Support	Sponsorship of meeting	£7900	Childhood Tumour Trust Patient Workshops 2024
Childhood Tumour Trust	Financial Support	Grant	£12400	Grant for What's It Got to Do With Me - NF1 Awareness Campaign
Beacon for Rare Diseases	Financial Support	Sponsorship of project	£12000	Sponsorship of 8 podcasts, YouTube Vlogs & newsletter
The Aplastic Anaemia Trust	Financial Support	Sponsorship of Meeting	£5000	The Aplastic Anaemia Trust's AAT Conference on Clinical Research into Aplastic Anaemia and related conditions
Metabolic Support UK	Financial Support	Sponsorship of Meeting	£15000	MSUK 2024 Conference Sponsorship
Myeloma UK	Financial Support	Sponsorship of Meeting	£12,000	Myeloma UK, 2024 Infodays sponsorship
Genetic Alliance	Financial Support	Sponsorship of Meeting	£10,000	Rare Disease Day 2025
Kidney Care UK	Contracted Services (Fees & Expenses disclosed separately)	Fees	£495	Kidney Care UK discussion on aHUS patient materials
		Out of pocket/ expenses	£0	
Childhood Tumour Trust	Contracted Services (Fees & Expenses disclosed separately)	Fees	£342	Paediatric patient journey feedback
		Out of pocket/ expenses	£0	
Nerve Tumours UK	Contracted Services (Fees & Expenses disclosed separately)	Fees	£456	Advice on NF1 patient initiation pack
		Out of pocket/ expenses	£0	

Tumour Support Scotland	Contracted Services (Fees & Expenses disclosed separately)	Fees	£456	Advice on NF1 patient initiation pack
		Out of pocket/ expenses	£0	
Childhood Tumour Trust	Contracted Services (Fees & Expenses disclosed separately)	Fees	£456	Advice on NF1 patient initiation pack
		Out of pocket/ expenses	£0	
Metabolic Support UK	Contracted Services (Fees & Expenses disclosed separately)	Fees	£495	Review of phase 4 patient-facing trial material
		Out of pocket/ expenses	£0	
Kidney Care UK	Contracted Services (Fees & Expenses disclosed separately)	Fees	£742.50	Kidney Care UK review of aHUS patient materials
		Out of pocket/ expenses	£0	
Childhood Tumour Trust	Contracted Services (Fees & Expenses disclosed separately)	Fees	£228	NF1 patient journey insights
		Out of pocket/ expenses	£0	
Nerve Tumours UK	Contracted Services (Fees & Expenses disclosed separately)	Fees	£82.50	NF1 patient journey insights
		Out of pocket/ expenses	£0	
Nerve Tumours UK	Contracted Services (Fees & Expenses disclosed separately)	Fees	£228	NF1 patient journey insights
		Out of pocket/ expenses	£0	
Kidney Care UK	Contracted Services (Fees & Expenses disclosed separately)	Fees	£247.50	Speaker fee for internal Alexion meeting
		Out of pocket/ expenses	£0	
Metabolic Support UK	Contracted Services	Fees	£82.50	Review of patient facing clinical trials materials
		Out of pocket/ expenses	£0	

	(Fees & Expenses disclosed separately)			
PNH Global Alliance	Contracted Services (Fees & Expenses disclosed separately)	Fees	£228	Review of PNH registry plain language summary review
		Out of pocket/expenses	£0	
PNH Support	Contracted Services (Fees & Expenses disclosed separately)	Fees	£3420	PNH study patient materials review
		Out of pocket/expenses	£96.28	
PNH Support	Contracted Services (Fees & Expenses disclosed separately)	Fees	£1140	Review of patient materials
		Out of pocket/expenses	£0	
Childhood Tumour Trust	Contracted Services (Fees & Expenses disclosed separately)	Fees	£570	Review of NF1 Patient materials
		Out of pocket/expenses	£0	

Reporting of Transfers of Value Patient Organisations

Methodological Note for Reporting of 2024 Data in 2025

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 2025 Patient Organisation Disclosure Report covers ToVs made between 1st January 2024 and 31st December 2024.

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.