

Relationships with Patient Organisations

CSL Behring provides financial support to several Patient Organisations in UK and Ireland. These payments are made in accordance with the requirements of Clauses 23 - 27 of the ABPI Code of Practice for the Pharmaceutical Industry. The payments are disclosed annually according to clauses 29-31. From 2022 onwards details of contracted services with members of the UK public, including patients is also disclosed annually.

From 1 January 2021 – 31 December 2021 payments were made to Patient Organisations listed below.

Patient Organisation	Month	Purpose of Grant	Amount
The Haemophilia Society	June	Corporate Donation	£35,000
Irish Haemophilia Society	June	Corporate Donation	£6,445.50
HAE-UK	June	A&E project	£9,000
HAE-UK	June	Corporate Donation	£35,000
Encephalitis Society	June	Corporate Donation	£20,000
Haemophilia Scotland	June	Corporate Donation	£10,000
Immunodeficiency UK	June	Corporate Donation	£35,000

From 1 January 2022 – 31 December 2022 payments were made to Patient Organisations listed below.
Total amount paid/PAG/year

Patient Organisation	Purpose of Payment	Amount
Encephalitis Society	Grant for the purpose of member support and World Encephalitis Day	£20,000
Haemophilia Scotland	Grant for the purpose of face-to-face educational events for newly diagnosed patients. Donation of 2 virtual training sessions on the HTA system	£14,038
Haemophilia Scotland/ The Haemophilia Society	Grant to raise awareness of haemophilia and other bleeding disorders with the use of a survey of the patient community to identify myths and misconceptions and share patient stories (joint proposal by The Haemophilia Society and Haemophilia Scotland)	£40,000
The Haemophilia Society	Grant for the purpose of member support	£35,000
Haemophilia Wales	Contracted service regarding Haemophilia Digital Diary Study	£300
Irish Haemophilia Society	Grant for the purpose of member support	£12,565

Local Families With Bleeding Disorders	Grant for the purpose of delivering a self-advocacy awareness program for haemophilia community	£25,210
Genetic Alliance UK	Support for Rare Disease UK Campaign run by Genetic Alliance	£12,800
Immunodeficiency UK	Grant for the purpose of continuing the work to support both the primary and secondary immunodeficiency community and to address mental health needs. Donation of 1 x virtual training session on the HTA system in the UK	£44,072
HAE-UK	Grant for the purpose of developing website, 24/7 Emergency Advice Line and A&E Awareness Campaign. Contracted Service to support CSL Behring in the process of recruitment of HAE patients for filming and photoshoot	£36,500

From 1 January 2022 – 31 December 2022 payments were made to patients listed below (contracted services).

	Purpose of Payment	Amount
7 Patients for 9 contracted services	Attending Advisory Board, presenting on patient experience, photoshoot and filming day, feedback on disease awareness campaign, patient perspective at educational day	£8,681.80

From 1 January 2023 – 31 December 2023 payments were made to Patient Organisations listed below.
Total amount paid/PAG/year

Patient Organisation	Purpose of Payment	Amount
The Haemophilia Society	Sponsorship Agreement - 3 Peaks Challenge Disease Awareness Video	£3,000
The Haemophilia Society	Grant for the purpose of activities providing member support	£35,000
UKPIPS	Grant for the purpose of updating IT systems in order to improve communications to raise awareness to the public and provide support to their members	£1,224
Haemophilia Scotland	Grant to develop education and awareness campaign, improve educational tools and materials and develop member website	£12,000
Haemophilia Scotland	Grant to pilot weekly specialist physiotherapy online sessions for people living with bleeding disorders (following submission of a proposal under the CSL Behring EU LEAD grant programme)	£10,000

Immunodeficiency UK	Grant for the purpose of covering activities including but not limited to members helpline and newsletters, production of condition specific booklets, raising awareness, clinical psychology service support	£35,000
Irish Haemophilia Society	Grant for the purpose of covering activities including but not limited to delivering education to members on haemophilia therapies via specific publications, in person meetings and events, member support	£12,915
Encephalitis Society	Grant for the purpose of assisting with activities including but not limited to virtual community and meetings, 24/7 emergency member support service, downloadable information resources for website, World Encephalitis Day	£10,000
HAE-UK	Grant for the purpose of covering activities including but not limited to developing A&E awareness campaign, developing a self-advocacy campaign and disease awareness, 24/7 advice line, website update	£35,000

From 1 January 2023 – 31 December 2023 payments were made to patients/members of the public listed below (contracted services).

	Purpose of Payment	Amount
8 patients for 8 contracted services	Attending Advisory Board, presenting on patient experience, photoshoot and filming day	£6,673
3 Members of the Public for 3 contracted services	Photoshoot and filming day, sharing experience, attending award ceremony	£2,260

From 1 January 2024 – 31 December 2024 payments were made to Patient Organisations listed below.
Total amount paid/PAG/year

Patient Organisation	Purpose of Payment	Amount
Encephalitis Society	Grant for the purpose of assisting with activities including but not limited to Providing scientifically accurate, peer reviewed information resources with PIF tick, 24/7 emergency member support service, downloadable information resources for website, World Encephalitis Day	£5,000
Haemophilia Northern Ireland	Expert input from patient organisations for a gene therapy patient support program to obtain patient perspective on content, usability and accessibility for patient support materials intended for patients, employers and care givers	£1,000
Haemophilia Northern Ireland	Grant for the purpose of supporting the community education day 2024. Funds will go towards the room hire, sustenance and event materials	£1,187.75

Haemophilia Scotland	Expert input from patient organisations for a gene therapy patient support program to obtain patient perspective on content, usability and accessibility for patient support materials intended for patients, employers and care givers	£1,000
Haemophilia Scotland	Grant for the purpose of covering activities including but not limited to developing education and awareness campaign, improving educational tools and materials and developing member website	£15,000
Haemophilia Society Wales	Expert input from patient organisations for a gene therapy patient support program to obtain patient perspective on content, usability and accessibility for patient support materials intended for patients, employers and care givers	£1,000
HAE-UK	Grant for the purpose of covering activities including but not limited to developing A&E awareness campaign, 24/7 advice line and mental health support guides	£30,000
Immunodeficiency UK	Grant for the purpose of covering activities including but not limited to members helpline and newsletters, production of condition specific booklets, raising awareness, clinical psychology service support, creating new website	£35,000
Irish Haemophilia Society	Grant for the purpose of covering activities including but not limited to delivering education to members on haemophilia therapies via specific publications, in person meetings and events, member support	£12,565
Irish Haemophilia Society	Expert input from patient organisations for a gene therapy patient support program to obtain patient perspective on content, usability and accessibility for patient support materials intended for patients, employers and care givers	£1,000
The Haemophilia Society	Grant for the purpose of covering activities including but not limited to providing member support, website, youth ambassador training	£35,000
The Haemophilia Society	Sponsorship Agreement - Disease Awareness Video	£4,500
The Haemophilia Society	Expert input from patient organisations for a gene therapy patient support program to obtain patient perspective on content, usability and accessibility for patient support materials intended for patients, employers and care givers	£1,000
International Alliance of Patient Organisations	Donation made at 77th World Health Assembly	£4,263

From 1 January 2024 – 31 December 2024 payments were made to patients/members of the public listed below (contracted services).

	Purpose of Payment	Amount
17 patients for 19 contracted services	Attending Advisory Board, presenting on patient experience	£9,931.70

From 1 January 2025 – 31 December 2025 payments were made to patients/members of the public listed below (contracted services).

Patient Organisation	Purpose of Payment	Amount
Encephalitis International	Grant for the purpose of supporting a variety of patient focused activities including but not limited to development of resources for those affected by autoimmune encephalitis, this includes a podcast, factsheet and patient story	£5,000
Haemophilia Scotland	Grant for the purpose of covering activities including but not limited to delivering face to face event, improving educational tools and materials and developing member website	£15,000
HAE-UK	Talk on patient experiences of HAE at company meeting	£375
Immunodeficiency UK	Grant for the purpose of covering activities including but not limited to the helpline mental health support services, provision of hardship grants, distribution of education materials, support for needle phobia, maintaining the website and supporting access to improve care and medicines	£30,000
Irish Haemophilia Society	Hands off, educational and disease awareness grant to cover development, translation and dissemination of a series of four podcasts with written summary e-magazine articles	£19,000
The Haemophilia Society	Grant for the purpose of assisting with delivering a round table on haemophilia therapy in the UK	£35,400
The Haemophilia Society	Grant for the purpose of assisting the patient organisation in reaching out to centres, members, sports clubs and schools to hold their own Sports Day event. They are looking to build a network of places across the UK where people can meet up with others in the community to be more active and meet other families	£8,000
The Haemophilia Society	Grant for the purpose of covering activities including but not limited to staff support for answering phone calls and emails, website development, project and event planning	£35,000
British Liver Trust	Grant for the purpose of developing patient-facing educational resources about Hereditary Haemochromatosis	£10,000

From 1 January 2025 – 31 December 2025 payments were made to patients/members of the public listed below (contracted services).

	Purpose of Payment	Amount
10 patients for 13 contracted services	Presenting on patient experience at company symposia and internal company meetings, consultancy services and insights for the development and implementation of clinical trials	£9,713

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