

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 2019 – 31 December 2019 payments were made to Patient Organisations listed below.

Patient Organisation	Month	Purpose of Grant	Amount
UK Haemophilia Society	January	Consultancy agreement	£2,000
PID UK	April	Corporate Donation	£35,000
PID UK	June	Corporate Donation	£5,000
HAE UK	June	Corporate Donation	£35,000
UK Haemophilia Society	June	Corporate Donation	£35,000
IPOPI	October	Corporate Donation including IPIC sponsorship	£135,000
UK Haemophilia Society	November	Consultancy agreement	£2,100
UK Haemophilia Society	December	Consultancy agreement	£600

From 1 January 2020 – 31 December 2020 payments were made to Patient Organisations listed below.

Patient Organisation	Month	Purpose of Grant	Amount
IPOPI	January	Corporate Donation including IPIC sponsorship	£25,692
UK Haemophilia Society	January	Consultancy agreement	£1,000
UK Haemophilia Society	June	Corporate Donation	£35,000
PID UK	June	Corporate Donation	£35,000
Immune Deficiency Patient Group Wales	June	Corporate Donation	£500
HAE UK	June	Corporate Donation	£35,000
Irish Haemophilia Society	June	Corporate Donation	£7,500
Encephalitis society	June	Corporate Donation	£20,000

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

Last updated: 30 May 2024

GBR-CRP-0524