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 2018 – 31 December 2018 payments were made to Patient Organisations listed below.

Patient Organisation	Month	Purpose of Grant	Amount
Haemophilia Scotland	April	Corporate Donation	£5,000
Irish Haemophilia Society	April	Corporate Donation	£8,773.00
HAE UK	June	Corporate Donation	£35,000
UKPIPS	June	Corporate Donation	£20,000
The Haemophilia Society	June	Corporate Donation	£35,000
The Haemophilia Society	September	Corporate Donation	£7,613.00
The Haemophilia Society	November	Corporate Donation	£2,000.00

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

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