

Patient Organisation Support						
Country	Year	Name of Organisation	Nature of Organisation	Reason for Support	Amount Paid	Currency
UK	2024	CARDIOMYOPATHY UK	A charity in the UK supporting children, young people and adults with the life-limiting heart condition cardiomyopathy. A community of people affected by cardiomyopathy, medical experts, and charity professionals working to provide support and information, campaigning for better access to quality treatment, saving lives through raising awareness and providing hope through shaping research.	Sponsorship to support online education resource for healthcare professionals	10,000.00	GBP
UK	2024	National Kidney Federation	The National Kidney Federation is a PO run by kidney patients and their carers, for kidney patients.	Sponsorship to develop and make available information on PH1 in Urdu and English.	5,000.00	GBP
UK	2024	The British Porphyria Association	Aims to support and educate patients, relatives and medical professionals about the porphyrias, so as to improve the lives of those living with its effects.	Support for the Annual BPA Reconnect Patient Meeting	5,000.00	GBP
UK	2024	The British Porphyria Association	Aims to support and educate patients, relatives and medical professionals about the porphyrias, so as to improve the lives of those living with its effects.	Travel grant to attend The International Congress of Porphyrins and Porphyrias	1,555.00	GBP
UK	2024	The British Porphyria Association	Aims to support and educate patients, relatives and medical professionals about the porphyrias, so as to improve the lives of those living with its effects.	Development and participation in content for social media awareness project	1,295.00	GBP
UK	2024	Global Porphyria Advocacy Coalition	The Global Porphyria Advocacy Coalition (GPAC) operates as an umbrella organisation for national porphyria patient advocacy organisations, representing all types of porphyria. This organisation will establish and maintain a global network that seeks to support all individuals impacted by porphyria and to safeguard their interests.	Travel grant to attend The International Congress of Porphyrins and Porphyrias	2,290.00	GBP
UK	2024	Global Porphyria Advocacy Coalition	The Global Porphyria Advocacy Coalition (GPAC) operates as an umbrella organisation for national porphyria patient advocacy organisations, representing all types of porphyria. This organisation will establish and maintain a global network that seeks to support all individuals impacted by porphyria and to safeguard their interests.	Donation of stand space at the ICPP Congress	4,265.00	GBP
UK	2024	Amyloidosis UK	Amyloidosis UK is dedicated to supporting individuals affected by amyloidosis and focused on a multi-faceted approach to improve the lives of patients with this rare and serious condition.	Grant to support rebranding, communications strategy and website upgrade to increase access to and educational content of the Amyloidosis UK resources for patients.	15,000.00	GBP

Members of Public, including patients and journalists						
Country	Year	Members of Public type	Support type	Reason for support	amount	currency
UK	2024	Patient	Fee for services	Patient expert speaker for internal rare disease day event	337.50	GBP
UK	2024	Patient	Fee for services	Patient expert speaker for internal rare disease day event	270.00	GBP
UK	2024	Patient	Fee for services	Patient expert speaker at Nurse Network webinar about ATTR amyloidosis	270.00	GBP