

ABPI Disclosure for Patient Organisations and the Public including Patients and Journalists - Activities Paid in 2024 - Chiesi Limited

	Patient Organisation Name	Country	Types of the Support or Services Provided					Description of Services	
			Financial Support			Non-financial Support	Contracted Services (Fees and expenses should be disclosed separately)		
			Grants/Donations	Sponsorship of Meetings	Other Sponsorships		Fees		Out of pocket/ expenses
Patient Organisation	Action for Pulmonary Fibrosis	UK	35,000.00	0.00	0.00		0.00	0.00	Funding to towards OneVoiceLD - to achieve earlier routes to diagnosis across the UK and patients better informed
	Adult Premie Advocacy Network	UK	0.00	0.00	100.00		0.00	0.00	Creation of video on patients perspective on asthma and COPD
	Adult Premie Advocacy Network	UK	0.00	720.00	0.00		0.00	0.00	World Prematurity Day Head Office Event - Participation, presentation and Q&A
	Adult Premie Advocacy Network CIC	UK	480.00	0.00	0.00		0.00	0.00	Providing Testimonial through an onsite video interview
	Cure EB	UK	1,300.00	0.00	0.00		0.00	0.00	Events for Epidermolysis Bullosa patients, updates on research, family day, webinars.
	Cystic Fibrosis Trust	UK	0.00	1,440.00	0.00		0.00	1,123.79	Workshop - Consultancy services
	Cystinosis network Europe	UK	0.00	303.58	0.00		0.00	1,190.74	World Orphan Drug Congress 2024 - Chiesi preparatory workshop
	Cystinosis Network Europe - CNE	UK	0.00	8,465.97	0.00		0.00	0.00	Community Advisory Board
	Cystinosis Network Europe - CNE	UK	0.00	42,329.83	0.00		0.00	0.00	CNE International Cystinosis Conference
	DEBRA Ireland	UK	4,012.87	0.00	0.00		0.00	0.00	Running a multi-channel awareness campaign, during Rare Disease Month. Awareness and understanding of a life impacted by Epidermolysis Bullosa.
	DEBRA Ireland	UK	5,083.81	0.00	0.00		0.00	0.00	Support the development of an implementation roadmap Epidermolysis Bullosa Butterfly Review. This project is focused on improving care services for individuals with EB in Ireland.
	DEBRA Ireland	UK	11,005.76	0.00	0.00		0.00	0.00	Creation and delivery of an educational information magazine delivered to people with Epidermolysis Bullosa across Ireland.
	Debra Ireland	UK	6,772.77	0.00	0.00		0.00	0.00	Donation
	DEBRA UK	UK	5,000.00	0.00	0.00		0.00	0.00	Members weekend for people living with EB, families and carers across the UK. Patients are able to connect, focus on mental health and receive updates on research.
	DEBRA UK	UK	0.00	960.00	0.00		0.00	397.60	Rare Disease Day 2024 Consultancy Contract DEBRA UK
	DEBRA UK	UK	5,000.00	0.00	0.00		0.00	0.00	HCP awareness campaign to enable many UK GPs with information on EB
	Genetic Alliance UK	UK	0.00	0.00	0.00		7,200.00	0.00	Consultancy - Plain language review of Patient facing documents for the FLY study
	Genetic Alliance UK	UK	0.00	0.00	6,000.00		0.00	0.00	EU Lipodystrophy Registry (MEASURE) Research Ethic Committee Document review
	Genetic Alliance UK	UK	5,000.00	0.00	0.00		0.00	0.00	EU Lipodystrophy Registry (MEASURE) Research Ethic Committee Document review
	Genetic Alliance UK	UK	5,000.00	0.00	0.00		0.00	0.00	How Decisions Are Made in Scotland project, a patient and public engagement project. Improve awareness and understanding the role of key decision making bodies in Scotland
	Genetic Alliance UK	UK	15,000.00	0.00	0.00		0.00	0.00	Rare Disease UK industry membership (November 2024 – November 2025)
	Gift of Living Donation (GOLD)	UK	0.00	360.00	0.00		0.00	0.00	Follow up Q&A Recording to the ENGAGE webinar
	Irish Neonatal Health Alliance	UK	0.00	714.53	0.00		0.00	29.99	World Prematurity Day Head Office Event
	Irish Neonatal Health Alliance	UK	0.00	477.17	0.00		0.00	0.00	Neonatology ENGAGE webinar
	Lipodystrophy UK	UK	18,720.00	0.00	0.00		0.00	0.00	Provide patients with all forms of Lipodystrophy, and their families, in the UK and Ireland, an opportunity to come together to receive support and education on Lipodystrophy.
	Lipodystrophy UK	UK	0.00	0.00	1,440.00		0.00	0.00	Patient Journeys to Diagnosis and Expert Care
	Lipodystrophy UK	UK	0.00	0.00	0.00		0.00	5,203.12	Patient roundtable discussion on Lipodystrophy
	Metabolic Support UK	UK	0.00	0.00	5,060.00		0.00	0.00	Condition Specific Images Insights Project
	Metabolic Support UK	UK	11,005.00	0.00	0.00		0.00	0.00	Questionnaire development translation, review and implementation relating to living with Cystinosis
	MPS Society	UK	0.00	0.00	2,140.00		0.00	0.00	Evaluation of two documents to be patient friendly based on the audience of each consent/assent form. Ensuring plain language is used to make these documents more patient centric.
	MPS Society	UK	0.00	720.00	0.00		0.00	0.00	Attendance and participation of Alpha Mannosidosis Global Cost-Effectiveness Model & Expert Elicitation Advisory Board
	MPS Society	UK	0.00	0.00	0.00		0.00	2,014.74	MPS to apply specialist knowledge and arrange for transportation of patient speaker to participate at SSEIM Chiesi symposium.
	MPS Society	UK	0.00	38,000.00	0.00		0.00	0.00	Sponsorship of Fabry Matters Conference - UK Fabry community and identify unmet requirements.
	MPS Society	UK	0.00	0.00	0.00		480.00	227.55	Consultancy for Patient Organisation Speakers for session at Internal Rare Disease Day meeting
	MPS Society	UK	0.00	1,440.00	0.00		0.00	0.00	Consultancy for patient expert to attend WORLD Symposium 2024 - Fabry disease and Alpha-mannosidosis
	MPS Society	UK	10,000.00	0.00	0.00		0.00	0.00	Funding towards patient support services to enable patients and families to receive support and information regarding life with an MPS or related Lysosomal storage disease
	MPS Society	UK	0.00	400.00	0.00		0.00	0.00	ENGAGE webinar - educational event held for HCPs on topics for respiratory.
	National Kidney Federation	UK	4,000.00	0.00	0.00		0.00	0.00	Production of patient cards for dialysis and transplant.
	Rareminds	UK	3,900.00	0.00	0.00		0.00	0.00	Development of an online mental wellbeing resource hub for everyone impacted by rare diseases.
	Sinus UK	UK	0.00	0.00	0.00		800.00	1,029.23	Consultancy Clearing the Air - Exploring the interplay between environmental policies and respiratory patients' behaviours
Members of the Public	Travel & Accomodation including contract expenses						N/A	N/A	
	Contracted Service Fees								
	Aggregate amount attributable to transfers of value to such Recipients						14,400.00	4,361.47	
Patients	Number of Recipients in aggregate disclosure = 34						19	19	
	Travel & Accomodation including contract expenses						N/A	N/A	
	Contracted Service Fees						N/A	N/A	
Journalists	Aggregate amount attributable to transfers of value to such Recipients						17,285.60	606.30	
	Number of Recipients in aggregate disclosure = 20						19	9	
	Travel & Accomodation						N/A	N/A	
Journalists	Aggregate amount attributable to transfers of value to such Recipients						0.00	529.13	
	Number of Recipients in aggregate disclosure = 1						0	1	

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