

ABPI CODE OF PRACTICE 2024

Disclosure for Patient Organisations and the Public including Patients and Journalists - 2025 Data Year

	Patient Organisation Name	Country	Types of the Support or Services Provided						Optional Indication of Patient Organisation's Total Income and/or the Company's Support as a Percentage	Description of Services	
			Financial Support			Non-financial Support	Contracted Services (fees and expenses should be disclosed separately)				Non-monetary Benefit for PO ¹
			Grants add a line for each Grant	Sponsorship of Meetings add a line for each sponsorship	Other Sponsorships add a line for each sponsorship	Donations add a line for each donation	Fees	Out of pocket/ expenses			
Patient Organisation	Aldiston Syndrome UK	United Kingdom					1,126.62			Participation in Aleveon UK Rare Disease Patient Council	
	Aldiston Syndrome UK	United Kingdom					1,340.40			Speaker and facilitator at Rare Disease Innovation Exchange event	
	Anthony Nolan	United Kingdom					900.00	151.2		Participation in Aleveon UK Rare Disease Patient Council	
	Anthony Nolan	United Kingdom						40.4		Participation in workshop on multi-indication medicines	
	Cambridge Rare Disease Network	United Kingdom		15,000.00						CamRAE Summit 2025 sponsorship	
	Cambridge Rare Disease Network	United Kingdom					1,090.66			Participation in Aleveon UK Rare Disease Patient Council	
	Cardiomyopathy UK	United Kingdom					2,859.00			Review of clinical trial patient materials	
	Childhood Tumour Trust	United Kingdom					465.00			Patient insights on challenges in NF1 Care Pathway	
	Childhood Tumour Trust	United Kingdom					1,079.00			Participation in Aleveon UK Rare Disease Patient Council	
	Children's Cancer and Leukaemia Group	United Kingdom		3,000.00						Sponsorship of the CCLG Annual Conference	
	Children's Cancer and Leukaemia Group	United Kingdom		3,500.00						Sponsorship of CCLG Paediatric Oncology Trainee Group meeting	
	Gene People	United Kingdom			3,000.00					Support for Gene People Patient Organisation Explainer Module	
	Genetic Alliance UK	United Kingdom			15,000.00					Rare Disease UK membership 2025-2026	
	Global LSD Collaborative	United Kingdom			15,000.00					Development of the Global LSD Patient Collaborative	
	Inflammatory Neuropathies UK	United Kingdom						226.90		Participation in Aleveon UK Rare Disease Patient Council	
	Kidney Care UK	United Kingdom						288.00		Input and review of homecare patient survey	
	Kidney Research UK	United Kingdom						1,094.70		Participation in Aleveon UK Rare Disease Patient Council	
	Lupus UK	United Kingdom						1,094.70		Participation in Aleveon UK Rare Disease Patient Council	
	Metabolic Support UK	United Kingdom		15,000.00						Sponsorship of Metabolic Support UK annual community conference 2025	
	Metabolic Support UK	United Kingdom						818.11		Participation in All-in Rethinking HPP PAG & Aleveon Workshop	
	Metabolic Support UK	United Kingdom						355.39		Participation in workshop on multi-indication medicines	
	Metabolic Support UK	United Kingdom						1,395.48		Participation in Aleveon UK Rare Disease Patient Council	
	Muscular Dystrophy UK	United Kingdom						1,023.00		Participation in Aleveon UK Rare Disease Patient Council	
	Myaware	United Kingdom						1,559.90	52.76	Participation in Aleveon UK Rare Disease Patient Council	
	Nerve Tumours UK	United Kingdom						1,031.65		Participation in Aleveon UK Rare Disease Patient Council	
	Parathyroid UK	United Kingdom						2,397.00		Participation in hypoparathyroidism UK advisory board	
	Parathyroid UK	United Kingdom						2,607.00		Participation in hypoparathyroidism UK advisory board	
	PW1 Support	United Kingdom						599.17		Input and review of homecare patient survey	
	Rareminds	United Kingdom		1,436.00						Sponsorship of an NRCTC health psychology training session	
	Scleroderma & Raynaud's UK	United Kingdom						1,023.00		Participation in Aleveon UK Rare Disease Patient Council	
	Soft Bones UK Foundation	United Kingdom						3,426.44	110	Participation in All-in Rethinking HPP PAG & Aleveon Workshop	
	Specialised Healthcare Alliance	United Kingdom			14,500.00					Support for Specialised Healthcare Alliance's 2025 work programme	
	The Aplastic Anaemia Trust	United Kingdom						288.00		Input and review of homecare patient survey	
	The Aplastic Anaemia Trust	United Kingdom						1,023.00		Participation in Aleveon UK Rare Disease Patient Council	
	The International XLH Alliance	United Kingdom						1,834.00		Participation in All-in Rethinking HPP PAG & Aleveon Workshop	
Members of the Public							N/A	N/A	N/A		
							N/A	N/A	N/A		
	Aggregate amount attributable to transfers of value to such Recipients						2,125.00	-	N/A	Interviews for Vox Pop on rare disease	
Patients	Number of Recipients in aggregate disclosure						17	-	N/A		
							N/A	N/A	N/A		
							N/A	N/A	N/A		
Journalists	Aggregate amount attributable to transfers of value to such Recipients						1,552.50	61.07	N/A	Fees for services and consultancy, including participation in rare disease events, consulting and advising via expert input forums, and a social media campaign	
	Number of Recipients in aggregate disclosure						5	2	N/A		
							N/A	N/A	N/A		
Journalists	Aggregate amount attributable to transfers of value to such Recipients						8,750.00	-	N/A	Filming the interview and presentation: Vox Pop on rare disease	
	Number of Recipients in aggregate disclosure						1	-	N/A		
							N/A	N/A	N/A		