**ABPI Code of Practice 2024**

# Transfers of Value 2025 Data: Patient Organisations and Members of the Public including Patients and Journalists

| | | Financial Support | | | Non-financial Support | Contracted Services | | |
|---|---|---|---|---|---|---|---|---|
| **Organisation Name** | **Country** | **Grants/ Donations** | **Sponsorship of Meetings** | **Other Sponsorships** | **Donations** | **Fees** | **Out of Pocket Expenses** | **Description of Services** |
| Adult Preemie Advocacy Network | UK | | | | | | £44.80 | Deliver presentation and participate in a question-and-answer panel discussion November 2024 at Chiesi UK head office event. Adjustment fee in 2025. |
| Beacon for Rare Diseases | UK | £3,000.00 | | | | | | Support towards a pioneering research study and publication of Rare Reality report. |
| BLISS - The National Charity for the Newborn | UK | £10,000.00 | | | | | | Support to print "Going Home from the Neonatal Unit" resource. Providing parents with accurate information, with Q&A. |
| Changing Faces | UK | | | | | £120.83 | | Consultancy for TFOR event. |
| Cure EB | UK | £800.00 | | | | | | Supports towards EB educational scientific Research Update Meeting - dissemination of scientific information to all stakeholders within EB care and EB medical research. |
| Cystinosis Support Network (CNE) | UK | £23,340.00 | | | | | | Support general activities in 2025. |
| DEBRA Ireland | IE | £5,835.00 | | | | | | Campaign raising awareness about epidermolysis bullosa (EB), affecting individuals and families across Ireland. |

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| DEBRA UK | UK | £3,300.00 | | | | | | Annual Members weekend event bringing those with EB together. |
| DEBRA UK | UK | £66,600.00 | | | | | | Support to develop two global, evidence-based guidelines (CAIMs and wound care) for epidermolysis bullosa to standardise best practices and improve coordinated care and patient quality of life. |
| DEBRA UK | UK | £8,525.70 | | | | | | Support delivery of a dedicated Epidermolysis Bullosa (EB) session at the ESDR Annual Meeting. |
| Ectodermal Dysplasia Society | UK | £1,000.00 | | | | | | 3-day ICED25 conference, supporting education, research and individuals with Ectodermal Dysplasia. |
| Genetic Alliance UK | UK | £5,000.00 | | | | | | Support towards Rare disease day 2025. |
| Genetic Alliance UK | UK | £15,000.00 | | | | | | Rare Disease UK membership |
| Genetic Alliance UK | UK | £5,000.00 | | | | | | Support towards Rare disease day 2026. |
| Irish Neonatal Health Alliance | IE | £864.35 | | | | | | In honour of World Prematurity Day 2024. For every kilometre cycled, by Chiesi employees, Chiesi Ltd pledged to donate £1. |

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| Leber's Hereditary Optic Neuropathy Society | UK | | | | | £700.00 | £93.35 | LHON Advisory Board meeting, Istanbul |
| Lipodystrophy UK | UK | | | | | £1,920.00 | | It's Rare for Me campaign - photoshoot, pre-event planning, patient communication, coordination and on-site logistical support. |
| Lipodystrophy UK | UK | | | | | £1,440.00 | | Lipodystrophy Diagnosis and Expert Care survey. |
| Lipodystrophy UK | UK | £22,387.60 | | | | | | Lipodystrophy UK Patient Day 2026. |
| LT 1992 Ltd | UK | | | | | £2,500.00 | | Ambassador Beyond the Bias campaign - 3 Media Interviews, Q&A Personal Image. |
| LT 1992 Ltd | UK | | | | | | £25.65 | Beyond the Bias campaign - Travel expenses. |
| LT 1992 Ltd | UK | | | | | £5,000.00 | | Discussion panel and speaker at Chiesi Conference. |
| Metabolic Support UK | UK | | £5,000.00 | | | | | Sponsorship, venue hire and AV hire - Living Well Symposium. |
| Metabolic Support UK | UK | | £5,000.00 | | | | | Bronze sponsorship of our annual community conference event. |
| Metabolic Support UK | UK | | | | | £358.00 | | Connecting the clinical and patient perspective in nephropathic cystinosis. |

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| Metabolic Support UK | UK | | | | | | £63.85 | ERA Travel expenses. |
| Metabolic Support UK | UK | | | | | £260.00 | | Consultancy - TFOR event. |
| Metabolic Support UK | UK | | | | | £10,450.00 | | Consultancy - True Faces of Rare report. |
| Metabolic Support UK | UK | | | | | £550.00 | | ERA Congress 2025 – speaker. |
| MPS Society | UK | £25,000.00 | | | | | | Patient/family advocacy services. Practical, financial, and mental wellbeing. |
| MPS Society | UK | | | | | £420.00 | £63.60 | Roundtable discussion - True Impact of Fabry Disease. |
| MPS Society | UK | | | | | £1,576.00 | | World Orphan Drugs Congress 2024 - preparatory workshops. |
| National Kidney Federation | UK | | | | | £2,200.00 | | Ambassador for the Look Beyond the Bias brand campaign. |
| Rareminds CIO | UK | £3,660.00 | | | | | | Continued development and expansion of an online mental wellbeing resource hub for individuals affected by rare diseases. |
| Same but Different CIC | UK | | | | | £120.83 | | True Faces of Rare Event – Speaker. |
| Society for Mucopolysaccharide Disease (MPS) | UK | | £2,120.00 | | | | | Virtual Meeting: Alpha Mannosidosis Community Connection. |

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| Society for Mucopolysaccharide Disease (MPS) | UK | | £3,981.5 | | | | | Sponsorship - Utilities in Alpha Mannosidosis" project. |
| The Ella Roberta Family Foundation | UK | £7,500.00 | | | | | | Initiatives addressing health inequalities in respiratory disease. |
| The Ella Roberta Family Foundation | UK | | | | | £250.00 | | Webinar: Health inequity's impact on respiratory disease. |
| The Lily Foundation | UK | £7,500.00 | | | | | | Support a qualitative research project exploring patient experiences of receiving a genetic diagnosis of mitochondrial disease. |
| UK Thalassaemia Society (UKTS) | UK | | | | | £400.00 | | Speaker in a panel discussion at Chiesi's 25 years of supporting the Thalassaemia community. |
| Unique | UK | £5,000.00 | | | | | | Support development of a new patient registry -individuals affected by rare chromosome and gene disorders. |

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| | | Contracted Services | |
|---|---|---|---|
| | | **Fees** | **Out of Pocket Expenses** |
| UK Members of the Public | Aggregate amount attributable to transfers of value to such Recipients | £20,524.81 | £2,961.89 |
| | Number of Recipients in aggregate disclosure | 18 | 14 |
| | | | |
| UK Patients | Aggregate amount attributable to transfers of value to such Recipients | £3,510.00 | £1,202.19 |
| | Number of Recipients in aggregate disclosure | 11 | 5 |
| | | | |
| UK Journalists | Aggregate amount attributable to transfers of value to such Recipients | £58,350.00 | 0 |
| | Number of Recipients in aggregate disclosure | 1 | 0 |

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