

Chiesi Ltd Transfer of Value Declarations 2024

(Activities paid in 2023)

Funding to Patient Organisations		
Patient Organisation	Activity description	Amount £ (Excl. VAT)
Beacon for Rare Diseases	Provision of a grant for Beacon's Empowerment Programme designed to help rare disease patient groups form, grow, and professionalise.	15,000.00
Bliss	Service Agreement for World Prematurity Day Webinar	600.00
Cystinosis Foundation UK	Provision of a grant to support an initiative to host four separate 'Family Days', bringing together patients, families and clinicians of the Cystinosis community across four hub locations in the UK	10,600.00
Genetic Alliance UK	Provision of a grant towards the total cost of Rare Disease UK's planned activities for 2023-24: Administrative, advisory, communications and executive Rare Disease Day Parliamentary events Patient Empowerment Group and wider internal committee activity Website maintenance and software licences Meeting rooms, London office, administration and Overheads	12,800.00
Genetic Alliance UK	Provision of a grant for planned activities for Rare Disease Day 2024 campaign to create and raise awareness of a central source of data about rare diseases in the UK.	5,000.00
Genetic Alliance UK	Provision of a grant towards the Signposting to Support project.	5,000.00
Genetic Alliance UK	Provision of a grant for Rare Disease Day 2023 Campaign. Focus on key challenge identified by individuals affected by rare conditions and the organisations that support within the UK Rare Diseases Framework	5,000.00
Genetic Alliance UK	Rare Disease UK support renewal April 2022 – March 2023, support towards enabling to deliver key activities to work with Rare Disease patients.	12,800.00
Metabolic Support UK	Provision of a grant of Metabolic Support UK's annual community conference, with the to engage the metabolic community.	10,000.00
Metabolic Support UK	Provision of a grant for Metabolic Support Patient Insight Series: Support towards programme on providing tools and resources through co-produced insight, to support the IMD communities.	19,000.00

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MPS Society	Service Agreement for Launch Meeting entitled 'Stepping into the future with new options.'	480.00
Society for Mucopolysaccharide Diseases	Provision of a grant towards activities in 2023 – To Enable patients and families to access a range of mental health & wellbeing services to improve mental health and wellbeing, increase resilience and reduce feelings of isolation. Enable patients and families to access relevant financial support.	20,000.00
Society for Mucopolysaccharide Diseases	Provision of a grant towards Support and Advocacy Service, enhancing patient, parents, carers and family support required. Provision of a grant towards Website upgrade and redevelopment project.	20,000.00
National Kidney Federation	Provision of a grant towards Kidney Transplant patient information cards.	5,000.00
The Lily Foundation	Provision of a grant towards Lily Precision Medicine Diagnostic Project – to improve diagnosis for UK patients	15,000.00
United Kingdom Thalassaemia Society	Provision of a grant for produce and publishing of 4 magazines a year. Informative magazines, shared with relevant members, NHS officials/staff, other bodies, consultants and used during awareness events.	12,000.00
United Kingdom Thalassaemia Society	Provision of a grant to assist with website maintenance and support for wellbeing programs in 2023.	10,000.00
Rare Disease Research Partners	The conduction of a feasibility study to identify possible data sources and study.	14,009.06
Rare Disease Research Partners	The Service to organise and host 2 Alpha- Mannosidosis Forum	24,100.00
Rare Disease Research Partners	The conduction of a study to investigate the natural history of patients with alpha mannosidosis by obtaining a caregiver-based dataset retrieving information on the natural history of treated and untreated patients over time.	27,456.16

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IBD Relief Limited	Service agreement - Session Making a difference: Why partnership between industry and patients matters of the Event	1,565.62
Rare Disease Research Partners	Service Agreement	1,200.00
Cystinosis Support Network Europe	Developing a resource pack for families to educate teaching and health care staff involved with their children to better understand cystinosis as a condition and strategies for living with it. Redesigning the CNE website	21,744.75