

2023 Patient Organization Support

Organization	Request Description / NAF Summary	Amount Agreed Local Currency
Association Of Glycogen Storage Disease UK	Funding to support general activities for remainder of 2023 including patient outreach, peer support and training, updating information and continuing with advocacy and support.	£ 11,700.00
Beacon for Rare Diseases	Funding for general activities including the 2023 Empowerment Programme which provides rare disease patient groups with a broad	£ 5,000.00
Cambridge Rare Disease Network UK	Bronze level sponsorship for Cambridge Rare Disease Network's (CamRARE's) 6th RAREsummit in 2023	£ 3,500.00
Gene People UK	Sponsorship for travel and subsistence bursaries for patient organisations to attend the Gene People's Leadership Symposium in November 2023	£ 3,500.00
Genetic Alliance UK	Funding to support the new signposting hub which aims to turn Genetic Alliance UK's website into a leading information and signposting hub for the UK's rare disease community.	£ 4,000.00
Genetic Alliance UK	General funding for Rare Disease Day activities in 2024	£ 10,000.00
Genetic Alliance UK	Funding for general activities to help Genetic Alliance implement their 5 year strategy which is to work together to improve the lives of 3.5 million	£ 5,000.00
Genetic Alliance UK	General funding for Rare Disease Day activities in 2023	£ 7,000.00
Medics 4 Rare Disease	Funding for general 2023 activities including delivering education on rare diseases to doctors and medical students	£ 5,000.00
Metabolic Support UK	Funding for a project to provide patient education on the IMD therapy landscape.	£ 10,000.00
MPS Society UK	Funding for general activities to include patient and family advocacy support services, mental health and well being services and a patient and public facing website re-development.	£ 20,000.00
Pompe Support Network UK	Restricted funding for specific elements of 2023 activities including member communications, service provision, Pompe Island Disks disease awareness podcast, educational films and videos	£ 10,000.00
Pompe Support Network UK	The purpose of this funding is to support the attendance of Pompe	£ 3,500.00