

2022 Patient Organization Support

Organization	Description	Amount
Kidney for Life	Funding to support 2022 7th Update on Fabry Nephropathy	£ 30,456.00
Genetic Alliance UK	Funding to support 2022 Rare Disease Campaign and company membership costs	£ 19,800.00
Genetic Alliance UK	Payment for expert speaker to participate in medical symposium	£ 284.00
Medics4Rare Disease	Funding to support general activities for 2022, e.g., meetings and educational resources to raise awareness of rare diseases among medical practitioners	£ 5,000.00
Medics4Rare Disease	Expert input into medical education videos	£ 4,000.00
Pompe Support Network	Funding to support general activities for 2022, e.g. website updates and attendance at educational meetings and conferences	£ 10,000.00
Gene People	Funding to support general activities for 2022, e.g. a genetic counsellor helpline, website resources and capacity building for the partnership network	£ 3,500.00
AGSD UK	Funding to support general activities for 2022, e.g. delivery of community outreach programmes, website and publication updates and organising community events and meetings	£ 10,000.00
MPS Society UK	Funding to support general activities for 2022, e.g. support for advocacy teams and mental health and wellbeing services	£ 40,000.00
Batten Disease Family Association (BDFA)	Funding to support the Family Well Being Project and Pier Befriending Programme 'Batten Befrienders'	£ 5,000.00
Metabolic Support UK	Funding to support general activities for 2022, e.g., community advice lines, and resources and information for patients	£ 20,000.00
Metabolic Support UK	Funding to support patient insights research project to understand impact of rising living costs in the UK on the community	£ 3,000.00
MPS Society UK	Funding to support community outreach and member service activities	£ 2,000.00