

### 2019 UK Patient Group Support

Organization	Amount	Description
International Gaucher Alliance	£ 385.00	Support to implement 2019 strategic imperatives. i.e Improve patient access to diagnosis, treatment and care. Influence the Gaucher research agenda, support member organisations, provide a strong voice for Gaucher patients worldwide.
FIN	£ 7,000.00	Contribution towards FIN Members meeting
AGSD	£ 31,962.00	Reporting only, processed in the US. Contribution to support the organisations various core activities including the annual conference, Pompe support team meetings and training, GSD family days etc
CDKL5 UK	£ 5,143.00	Reporting only. Processed in the US. Contribution to 5th Intl Research and Family Conference in Edinburgh.
Birmingham IMD	£ 6,075.00	Educational video for their Fabry patients transitioning from paediatric to adult services.
MPS	£ 2,000.00	The Charitable Contribution request will go towards supporting an Expert Meeting on Anaesthetic and Surgical Considerations in Adolescent and Adult Patients with MPS, Fabry, Mucopolidoses and related conditions
NHS Greater Glasgow	£ 35,658.40	Project Funding for 12 months for a data manager/analyst and software licence to enable development of the West of Scotland Inherited Cardiac conditions service.
MPS Conference	£ 10,000.00	Part funding to support for MPS's first Fabry focussed conference.
Metabolic support UK	£ 10,000.00	Contribution towards a Patient Access Programme aims to improve patient access by reporting data, patient evidence and experience and by engaging fully as a stakeholder in the processes
MPS Fabry Advocacy	£ 45,000.00	Contribution towards to the core activities of the society's Fabry advocacy support service across English, Scotland, Wales in 2019
Medics for Rare Diseases	£ 5,000.00	Help organisation achieve their 2020 goals and objectives. i.e development of Rare Disease 101 Project in which they will provide materials for students & doctors to produce their own RD training day, develop M4RD ambassador scheme and run for 2nd year etc
Cambridge Rare Summit	£ 3,000.00	Bronze Sponsorship for RareSummit event Sept 19 focusing on patient centricity in rare diseases
Debra 2020	£ 2,500.00	Bronze Sponsorship of EB World Congress 2020.
Metabolic support UK	£ 5,000.00	Metabolic Support UK-conference 12th Oct : Bronze sponsorship.