

2018 UK Patient Group Support		
Organization Name	Amount	Description
CDKLS UK	£ 1,272.48	Support to upgrade their website and provide educational resources to support families and professionals.
MPS Society UK	£ 45,000.00	Support of MPS Fabry Advocacy Support initiatives across England, Scotland and Wales
RDUK (Genetic Alliance)	£ 12,500.00	Membership renewal to RDUK
MPS International	£ 3,000.00	Support for The 15th International Symposium on MPS and related diseases taking place from 2nd to 4th August 2018 in San Diego, California
Find a cure	£ 3,000.00	Support the updating and development of new content for their existing e-learning portal which was launched in 2016. The e-learning portal provides an essential hub of information and training for rare disease advocates.
Debra UK	£ 5,000.00	DEBRA UK has a series of family events planned for 2018. The Charitable contribution will also go towards supporting the DEBRA UK InTouch Magazine.
Debra Intl	£ 22,443.75	2 year Support EB without borders programme, clinical practise guideline coordiantor and small grants scheme
MPS Society UK	£ 10,000.00	Contribution towards the Christine Lavery Memorial Fund The aim of the Fund is to ensure the sustainability of the advocacy service. This Fund will help the MPS Society maintain and develop their unique services to meet the growing support needs of those affected by MPS and related diseases throughout the UK, in special recognition of Christine's great desire to support and to advocate for the best interests of these patients and their families.
MPS Society UK	£ 1,060.08	MPS Sponsorship attendance for Karen Tylee and Kathryn Brammeier to attend 15 th International Symposium on MPS and related diseases in San Diego.
Cure EB	£ 1,000.00	Advertising space in the brochure for the Cure EB Research Update May 2018.
Kidneys for Life	£ 60,630.00	Support the annual Fabry disease update meeting. Amicus to be a major sponsor of this event, and will have 3 reserved official registration slots with full participation at all of the meeting sessions.
European Gaucher Alliance	£ 1,082.04	European Gaucher Alliance Work Program 2018, the vision of the program is to improve quality of lives of patients and families; General Patient Family Education
CDKLS UK	£ 1,347.84	Website Resource Development Project
Association for Glycogen Storage Disease UK	£ 29,048.11	<ul style="list-style-type: none"> • Expert Training Days – an opportunity for patients to learn from experts promoting health and wellbeing • The Glycogen Storage Family day provides a fun networking and sharing forum for the patient community • A dedicated Specialist Care Advisor to support the patient community
Association for Glycogen Storage Disease UK	£ 111.33	Coverage of Currency Conversion Fee
Danish Fabry Organisation	£ 8,780.00	To support to send patients to the Fabry International Network expert meeting June 2018. The contribution was also used to support the annual meeting of the organisation on 28-29 September 2018 (10,000 Euros)