



FINANCIAL CONTRIBUTIONS TO UK AND IRISH PAOS FROM 2015 - 2020

PAO	Amount	Type of financial support	Year
International Gaucher Alliance	£1,200	Grant; Educating and empowering Gaucher patient advocates	2020
MPS Society	£5,000	Grant; Reaching Families in Need: MPS Society UK Telephone Helpline and Bereavement Outreach Support	2020
Metabolic Support UK	£15,000	Grant; Building communities and Improving patient involvement	2020
The Aplastic Anaemia Trust	£8,000	Grant; Emergency programme of focussed information and support	2020
Patients Association	£8,000	Grant; Shared Decision Making Resources	2020
Genetic Alliance	£8,500	Sponsorship; Public Awareness Raising Campaign for Rare Disease Day 2020	2020
Genetic Alliance	£15,000	Sponsorship; COVID- 19 weekly community check-ins	2020
Genetic Alliance	£50,325	Sponsorship; PATIENT EXPERIENCE SURVEY	2020
Findacure	£7,000	Sponsorship; Patient Group Mentoring Programme	2020
Genetic Alliance	£12,000	Sponsorship; Rare Disease UK membership	2020
Metabolic Support UK	£15,000	Sponsorship; Annual Conference	2020
Cambridge Rare Disease Network	£10,000	Sponsorship; RAREfest20 Conference	2020
Motor Neurone Disease Association	£2,500	Sponsorship; International Symposium on ALS/ MND	2020
Genetic Alliance	£2,400	Sponsorship; UK Report microsite	2020
Genetic Alliance	£9,000	Sponsorship; Public Awareness Raising Campaign for Rare Disease Day 2021	2020

Ireland: Irish Platform for Patient Organisations, Science & Industry (IPPOSI)	€7,000 Euros	Grant; Irish Citizen Jury on Patient Data	2020
Genetic Alliance UK	£8,000	Sponsorship; Rare Disease Day activities 2019	2019
Genetic Alliance UK	£11,000	Membership; Rare Disease UK 2019	2019
Metabolic Support UK	£7,500	Sponsorship; Annual Conference Metabolic Support UK	2019
UK MPS Society	£3,780	Sponsorship; UK National Conference on MPS and related disorders	2019
Findacure	£1,000	Sponsorship; Annual Drug Repurposing for Rare Diseases Conference	2019
Brittle Bones Society	£10,000	Sponsorship; Brittle Bones Society Annual Conference 2019	2019
Cambridge Rare Disease Network	£6,000	Sponsorship; RARE Summit 2019 Patients as Partners	2019
Metabolic Support UK	£10,000	Grant; Building communities to drive change for rare diseases	2019
IPPOSI IE	EUR 2,500	Grant; supporting IPPOSI Research and Advocacy activities	2019
Genetic Alliance UK	£14,990	Sponsorship; Resetting the Model project	2018
Genetic Alliance UK	£8,000	Grant; Rare disease day 2018 activities	2018
Genetic Disorders UK	£19,980	Sponsorship; 2018 Genetic Disorders Leadership Symposium	2018
BrittleBones UK	£15,000	Grant; BrittleBones 2018 Conference	2018
NMO Spectrum UK	£4,000	Grant; NMO Spectrum annual meeting	2018
IPPOSI IE	EUR 7,500	Membership	2018
Rare Disease UK	£12,500	Membership	2018
FindaCure	£5,000	Sponsorship; 2018 Drug Repurposing Conference	2018
PNH Support	EUR 700	Participation in two advisory board Meetings	2018
PNH Support	EUR 500	Speaking engagement in Zurich, Switzerland	2018
Brittle Bone Society	£ 10,000	Charitable Grant; Educational grant to help with costs associated with hosting BBS 2017 conference	2017
FindaCure	£13,025	Charitable Grant; Grants to support training and education activities for patient advocates	2017

NMO UK Rare Illness Research Foundation	£ 5,000	Charitable Grant; NMO Spectrum-UK Masquerade Ball, October 2016 in Oxfordshire	2016
Brittle Bone Society	£ 20,000	Charitable Grant; Educational grant to help with costs associated with hosting BBS events 2016/2017	2016
IPPOSI (Irish Platform for Patient Organisations) – Ireland	€ 7,500	Membership 2016	2016
Myaware	£ 15,000	Charitable Grant; Organization of 2 conferences in London and in the North of England 2016/2017 through the PAO's Young Generation Service	2016
GDUK (Genetic Disorders UK)	£ 15,000	Charitable Grant; UK Genetic Disorders Leadership Symposium March 2016	2016
Rare Disease UK (RDUK)	£ 10,000	Membership 2016	2016
GRDO (Genetic and Rare Disorders Organisation) - Ireland	€ 1,000	Sponsorship; Rare Disease Day Conference February 2016 in Dublin	2016
Findacure Foundation	£ 8,000	Charitable Grant; Developing a customized online platform for rare disease patient groups for interactive training modules, build, grow & connect patient group	2016
GRDO (Genetic and Rare Disorders Organisation) - Ireland	€ 1,000	Sponsorship; Rare Disease Day Conference February 2016 in Dublin	2016
Findacure Foundation	£ 8,000	Charitable Grant; Developing a customized online platform for rare disease patient groups for interactive training modules, build, grow & connect patient group	2016

NMO Research UK	£ 5,000	Charitable Grant; Funds to support the organization's annual meeting in August 2015 bringing together HPP patients and their families	2015
CLIMB (National Information Centre for Inherited Metabolic Diseases)	£ 10,000	Charitable Grant; Funds to provide an online support network for HPP patients in the UK	2015
aHUS UK/aHUS Alliance	£ 15,000	Charitable Grant; Funds for meeting to establish an international organization representing people with aHUS and their carers. Objective to bring representatives from different aHUS groups together to agree on format of the alliance and its goals & objectives	2015