

Shire Patient Organization Funding
For the Period: January 1, 2018 through December 31, 2018

Country	Name of Organization	Description of the Activity/Purpose	Amount	Currency	Total per Country
Argentina	AAPIDP(Asociacion Civil Ayuda al paciente con Inmunodeficiencia primaria)	Healthcare Organization Donations	49,000	ARS	
Argentina	ACELNEA(Asociación Civil Enfermos Lisosomales del Noroeste Argentino)	Healthcare Organization Donations	60,000	ARS	
Argentina Total				ARS	109,000
Australia	ADHD Australia Limited	Funding to support ADHD Australia Limited's 2018 projects: The Voice, ADHD Newsletter; and Re-thinking ADHD, by busting the myths through evidence-based research.	30,000	AUD	
Australia	AusPIPS Inc.	Funding to support AusPIPS Inc.'s initiation of a Working Party for the development of the National Standard Care for people living with Primary Immune Deficiency (PID) in 2018 and 2018 travel costs for AusPIPS Inc. meetings.	20,000	AUD	
Australia	Crohn's and Colitis Australia	Funding to support Crohn's & Colitis Australia's IBD Awareness Month and World IBD Day. Funding will be used to print posters and fliers for distribution at hospitals and IBD Clinics, community centers and around light up sites for IBD Awareness Month and World IBD Day.	5,000	AUD	
Australia	Crohn's and Colitis Australia	Funding to support Crohn's & Colitis Australia's 2018 quarterly Inside Insight educational magazines for patients with Inflammatory Bowel Disease.	55,000	AUD	
Australia	Fabry Australia Incorporated	Funding to support Fabry Australia's annual patient group meetings in NSW and WA and educational material for use by patients and their families.	25,000	AUD	
Australia	Gaucher Association of Australia & New Zealand	Funding to support Gaucher Association of Australia & New Zealand's (GAANZ) website creation, advocacy activities, annual conference activities, creation of patient educational materials, attendance at educational meetings, facilitation of committee meetings and administrative supplies.	10,000	AUD	
Australia	HAE Australasia	Funding to support HAE Australasia's patient and carer support, advocacy and education and event sponsorship of the 2019 Patient and Carer conference.	25,000	AUD	
Australia	HAE Australasia	Funding to support HAE Australasia's targeted education and community awareness programs.	26,000	AUD	
Australia	Haemophilia Foundation Australia Incorporated	Funding to support Haemophilia Foundation Australia's 2018 Ageing Project.	51,000	AUD	
Australia	Haemophilia Foundation Australia Incorporated	Funding to support Haemophilia Foundation Australia's musculoskeletal (MSK) management Continuing Education Fund which will be used for the costs of local or overseas MSK, sports medicine or orthopaedic experts to deliver presentations at their annual meeting.	1,818	AUD	
Australia	Haemophilia Foundation Australia Incorporated	Funding for gold sponsorship of Haemophilia Foundation Australia's 19th Australian Conference on Haemophilia, VWD & Rare bleeding disorders.	33,000	AUD	
Australia	Immune Deficiencies Foundation Australia	Funding to support the Immune Deficiencies Foundation Australia's Patient and Healthcare Professional Resource Kits.	30,000	AUD	
Australia	Learning and Attentional Disorders Society of WA (Inc.) (LADS)	Funding to support Learning and Attentional Disorders Society of WA (Inc.) (LADS) 2018 seminar programme.	12,000	AUD	
Australia	Rare Voices Australia	Funding for the renewal of company membership to Rare Voices Australia and Pharmaceutical Industry Round Table.	15,000	AUD	
Australia	Rare Voices Australia	Funding to support Rare Voices Australia's bi-annual National Rare Disease Summit.	20,000	AUD	
Australia Total				AUD	358,818
Austria	Die Chronischen Experten	Healthcare Organization Donations	5,000	EUR	
Austria	Morbus Fabry Selbsthilfeverein	Healthcare Organization Donations	5,000	EUR	
Austria	Multiple Sklerose Gesellschaft in Salzburg e.V. (ÖMSG)	Scientific HCP Education or Medical Sponsorship of Event	1,000	EUR	
Austria	ÖSPID - Österreichische Selbsthilfegruppe Primärer Immundefekte	Promotional and Informational HCP Education or Commercial Sponsorship of Event	2,400	EUR	
Austria	Österreichische Kinder-Krebs-Hilfe (ÖKKH)	Educational Grants - HCP Educational Sponsorships	20,000	EUR	
Austria Total				EUR	33,400
Brazil	Anjos da Guarda Associação de Apoiadores aos Portadores de Mucopolissacaridoses e de Doenças Raras	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	96,000	BRL	
Brazil	Assoc. Baiana Familiares Amigos Portadores de Mucopolissacaridoses	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	50,000	BRL	
Brazil	Associação Alagoana dos Familiares e Amigos dos Portadores de Mucopolissacaridoses - AMPS	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	10,000	BRL	
Brazil	Associação Brasileira de Familiares, Amigos e Portadores de Transtornos Afetivos	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	30,000	BRL	
Brazil	Associação Brasileira de Portadores de Angiodema Hereditário	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	22,760	BRL	
Brazil	Associação Brasileira de Portadores de Angiodema Hereditário - ABRANGHE	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	7,100	BRL	
Brazil	Associação Brasileira do Deficit de Atenção	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	28,800	BRL	
Brazil	Associação Brasileira do Deficit de Atenção	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	96,000	BRL	
Brazil	Associação Brasileira dos Portadores de Fabry e Familiares	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	220,800	BRL	
Brazil	Associação Brasileira dos Portadores de Fabry e Familiares	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	220,800	BRL	
Brazil	Associação Brasileira dos Portadores de Fabry e Familiares - ABRAFF	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	21,120	BRL	
Brazil	Associação Capixaba de Apoio as Pessoas com Doenças Raras	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	30,000	BRL	

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Brazil	Associação Catarinense de Doenças Raras	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	110,000	BRL	
Brazil	Associação Cearense de profissionais Atuantes em Doenças Genéticas, pacientes, Familiares e Voluntários - ACDG	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	201,600	BRL	
Brazil	Associação Cearense de profissionais Atuantes em Doenças Genéticas, pacientes, Familiares e Voluntários - ACDG	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	28,800	BRL	
Brazil	Associação Cearense de profissionais Atuantes em Doenças Genéticas, pacientes, Familiares e Voluntários - ACDG	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	201,600	BRL	
Brazil	Associação de Hemofilicos e Pessoas com Doenças Hemorrágicas e Hereditária	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	25,600	BRL	
Brazil	Associação de Mucopolissacaridoses do rio Grande do Norte	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	10,000	BRL	
Brazil	Associação dos Voluntários, Pesquisadores e Portadores de Coagulopatias - AJUDE-C	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	30,000	BRL	
Brazil	Associação dos Voluntários, Pesquisadores e Portadores de Coagulopatias - AJUDE-C	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	20,000	BRL	
Brazil	Associação Gaúcha de Mucopolissacaridoses	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	20,000	BRL	
Brazil	Associação Gaúcha de Pacientes Portadores da Doença de Fabry e Familiares	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	40,000	BRL	
Brazil	Associação Gaúcha de Pacientes Portadores da Doença de Fabry e Familiares - AGF	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	27,200	BRL	
Brazil	Associação MariaVitoria de Doenças Raras e Crônicas	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	30,000	BRL	
Brazil	Associação Mineira de Mucopolissaridoses	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	76,800	BRL	
Brazil	Associação Paraense de Síndrome de Williams	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	20,000	BRL	
Brazil	Associação Pernambucana de Mucopolissacaridoses Breno Bloise de Freitas	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	120,000	BRL	
Brazil	Associação Piauiense de Fabry	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	330,000	BRL	
Brazil	Associação Sergipana de Pessoas Com Doenças Raras	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	20,000	BRL	
Brazil	Centro dos Hemofilicos do Estado de São Paulo	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	45,000	BRL	
Brazil	Federação das Associações de Doenças Raras Norte e Nordeste - FEDRANN	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	20,000	BRL	
Brazil	Federação Brasileira de Hemofilia	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	67,200	BRL	
Brazil	Federação Brasileira de Hemofilia	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	192,000	BRL	
Brazil	Federação Brasileira de Hemofilia	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	124,800	BRL	
Brazil	Fundação Pró-Instituto de Hematologia -RJ	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	30,000	BRL	
Brazil	Instituto Amor e Carinho IAC	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	96,000	BRL	
Brazil	Instituto de Doenças Raras, Graves, e Crônicas Patrick Dorneles	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	20,000	BRL	
Brazil	Instituto Vidas Raras	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	75,880	BRL	
Brazil	Instituto Vidas Raras	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	24,672	BRL	
Brazil	Instituto Vidas Raras	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	240,000	BRL	
Brazil	Instituto Vidas Raras	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	10,000	BRL	
Brazil	Instituto Vidas Raras	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	240,000	BRL	
Brazil	Instituto Vidas Raras - Projeto Imunodeficiencia	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	13,000	BRL	
Brazil Total				BRL	3,343,532
Canada	Angio-Oedeme Hereditaire du Quebec (AOHQ)	Healthcare Organization Donations	35,000	CAD	
Canada	Association des Patients Immunodeficients du Quebec (APIQ)	Healthcare Organization Donations	25,000	CAD	
Canada	National Gaucher Foundation of Canada	Healthcare Organization Donations	105,000	CAD	
Canada	Canadian MPS Society	Healthcare Organization Donations	10,000	CAD	
Canada	Canadian Hemophilia Society	Healthcare Organization Donations	55,000	CAD	
Canada	HAE Canada	Healthcare Organization Donations	25,000	CAD	
Canada	Network of Rare Blood Disorder Organization (NRBDO)	Healthcare Organization Donations	50,000	CAD	
Canada	GBS/CIDP Foundation of Canada	Healthcare Organization Donations	99,100	CAD	
Canada	Centre for ADHD Awareness Canada (CADDAC)	Healthcare Organization Donations	97,000	CAD	
Canada	Canadian Immunodeficiencies Patient Organization	Healthcare Organization Donations	5,000	CAD	
Canada	World Federation of Hemophilia	Healthcare Organization Donations	250,000	USD	
Canada	Ronald McDonald House Charities Atlantic	Healthcare Organization Donations	5,000	CAD	
Canada	Center for ADHD Awareness Canada	Healthcare Organization Donations	50,000	CAD	
Canada	Sheena's Place	Healthcare Organization Donations	10,000	CAD	
Canada	National Initiative for Eating Disorders (NIED)	Healthcare Organization Donations	50,000	CAD	

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Canada	Craig's Cause Pancreatic Cancer Society	Healthcare Organization Donations	7,500	CAD	
Canada	Gastrointestinal Society	Healthcare Organization Donations	5,000	CAD	
Canada	Canadian Immunodeficiencies Patient Organization	Healthcare Organization Donations	7,475	CAD	
Canada	Equal Access for Rare Disorders	Healthcare Organization Donations	10,000	CAD	
Canada	Immunodeficiency Canada	Healthcare Organization Donations	125,000	CAD	
Canada	ANEB - Anorexie et boulimie Quebec	Healthcare Organization Donations	25,000	CAD	
Canada	Canadian Hemophilia Society	Healthcare Organization Donations	110,000	CAD	
Canada	HAE Canada	Healthcare Organization Donations	50,000	CAD	
Canada	World Federation of Hemophilia	Healthcare Organization Donations	25,000	USD	
Canada	Crohn's & Colitis Canada	Healthcare Organization Donations	15,000	CAD	
Canada	Canadian Fabry Association	Healthcare Organization Donations	85,000	CAD	
Canada	Canadian Immunodeficiencies Patient Organization	Healthcare Organization Donations	125,000	CAD	
Canada	World Federation of Hemophilia	Healthcare Organization Donations	250,000	USD	
Canada Total				CAD	1,186,075
Canada Total				USD	525,000
Croatia	Hrvatsko savez za rijetke bolesti	Healthcare Organization Donations	74,378	HRK	
Croatia	Hrvatsko savez za rijetke bolesti	Healthcare Organization Donations	25,545	HRK	
Croatia Total				HRK	99,923
Czech Republic	Česká asociace vzácných onemocnění z.s.	Fee For Service Related Expenses	150,000	CZK	
Czech Republic	Cesky svaz hemofiliku	Infrastructure Donations	250,000	CZK	
Czech Republic	Hemojunior, z.s.	Educational Grants - Accredited and Non-accredited Educational Activities	250,000	CZK	
Czech Republic	Sdružení META - spolek pacientů se střádavými onemocněními, z.s.	Educational Grants - Accredited and Non-accredited Educational Activities	200,000	CZK	
Czech Republic	Společnost pro mukopolysacharidosu	Educational Grants - Accredited and Non-accredited Educational Activities	150,000	CZK	
Czech Republic Total				CZK	1,000,000
Denmark	ADHD-foreningen	Promotional and Informational HCP Education or Commercial Sponsorship of Event	47,800	DKK	
Denmark	Danmarks Bløderforening (Dk)	Fee For Service	12,000	DKK	
Denmark	HAE Scandinavia	Fee For Service	20,000	DKK	
Denmark	HAE Scandinavia	Educational Grants - Accredited and Non-accredited Educational Activities	75,000	DKK	
Denmark	HAE Scandinavia	Educational Grants - Accredited and Non-accredited Educational Activities	120,000	DKK	
Denmark Total				DKK	274,800
Estonia	Estonian Hemophilia Society	Healthcare Organization Donations	3,350	EUR	
Estonia	Estonian Hemophilia Society	Healthcare Organization Donations	3,200	EUR	
Estonia	Estonian Paediatric Neurology Society	Educational Grants - Accredited and Non-accredited Educational Activities	3,000	EUR	
Estonia Total				EUR	9,550
Finland	ADHD-liitto ry	Fee For Service	360	EUR	
Finland	SHY - Suomen Hemofiliayhdistys	Fee For Service	6,000	EUR	
Finland	SHY - Suomen Hemofiliayhdistys	Educational Grants - Accredited and Non-accredited Educational Activities	8,250	EUR	
Finland	Suomen Fabry Yhdistys	Fee For Service	500	EUR	
Finland	SUOMEN HAE-YHDISTRYS RY	Fee For Service	500	EUR	
Finland	Suomen Hematologiyhdistys - The Finnish Association of Hematology	Educational Grants - Funding of Healthcare Positions in Training and Fellowships	2,400	EUR	
Finland Total				EUR	18,010
France	Alliance Maladies Rares - AMR	Healthcare Organization Donations	7,000	EUR	
France	Alliance Maladies Rares - AMR	Healthcare Organization Donations	50,000	EUR	
France	Association Française des Hémophiles - AFH	Healthcare Organization Donations	15,000	EUR	
France	Association Française des Hémophiles - AFH	Healthcare Organization Donations	5,000	EUR	
France	Association Française des Hémophiles - AFH	Healthcare Organization Donations	11,808	EUR	
France	Association Française des Hémophiles - AFH	Healthcare Organization Donations	6,381	EUR	
France	Association Française des Hémophiles - AFH	Healthcare Organization Donations	15,000	EUR	
France	Association Française des Hémophiles - AFH	Healthcare Organization Donations	8,416	EUR	
France	Association Française des Hémophiles - AFH	Scientific HCP Education or Medical Sponsorship of Event	20,000	EUR	
France	Association Française des Hémophiles - AFH	Healthcare Organization Donations	5,000	EUR	
France	Association Française des Hémophiles - AFH	Healthcare Organization Donations	5,321	EUR	
France	Association Française des Hémophiles - AFH Auvergne	Healthcare Organization Donations	2,500	EUR	
France	Association Française des Hémophiles - AFH Basse Normandie	Healthcare Organization Donations	2,000	EUR	
France	Association Française des Hémophiles - AFH PACA Corse	Healthcare Organization Donations	9,000	EUR	
France	Association Française des Hémophiles - AFH PLPC	Healthcare Organization Donations	2,500	EUR	

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For the Period: January 1, 2018 through December 31, 2018

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France	Association Laurette Fugain	Healthcare Organization Donations	10,000	EUR	
France	Association pour la Maladie de Fabry - APMF	Healthcare Organization Donations	30,000	EUR	
France	Eurordis Rare Diseases Europe	Healthcare Organization Donations	7,000	EUR	
France	Eurordis Rare Diseases Europe	Healthcare Organization Donations	130,000	EUR	
France	IRIS	Healthcare Organization Donations	12,500	EUR	
France	IRIS	Healthcare Organization Donations	15,000	EUR	
France	IRIS	Healthcare Organization Donations	6,500	EUR	
France	IRIS	Healthcare Organization Donations	15,000	EUR	
France Total				EUR	390,926
Germany	Allianz Chronischer Seltener Erkrankungen (ACHSE) e.V.	Healthcare Organization Donations	5,000	EUR	
Germany	CED Nord e.V	Promotional and Informational HCP Education or Commercial Sponsorship of Event	1,500	EUR	
Germany	CED-Hilfe e.V.	Promotional and Informational HCP Education or Commercial Sponsorship of Event	600	EUR	
Germany	Deutsche Hämophiliegesellschaft (DHG) zur Bekämpfung von Blutungskrankheiten e.V.	Healthcare Organization Donations	87,000	EUR	
Germany	dsai - Deutsche Selbsthilfe Angeborene Immundefekte e.V.	Promotional and Informational HCP Education or Commercial Sponsorship of Event	30,800	EUR	
Germany	EFCNI (The European Foundation for the Care of Newborn Infants)	Healthcare Organization Donations	170,000	EUR	
Germany	Gesellschaft für Mukopolysaccharidosen e.V. (MPS)	Promotional and Informational HCP Education or Commercial Sponsorship of Event	12,100	EUR	
Germany	Gesellschaft für Mukopolysaccharidosen e.V. (MPS)	Healthcare Organization Donations	23,000	EUR	
Germany	Gesellschaft für Mukopolysaccharidosen e.V. (MPS)	Membership Fees	200	EUR	
Germany	Interessengemeinschaft Niere - Region Kiel e.V.	Promotional and Informational HCP Education or Commercial Sponsorship of Event	500	EUR	
Germany	MPS EUROPE GMBH	Healthcare Organization Donations	35,000	EUR	
Germany	Netzwerk Hypophysen- und Nebennierenerkrankungen e.V.	Promotional and Informational HCP Education or Commercial Sponsorship of Event	7,250	EUR	
Germany Total				EUR	372,950
Hungary	Hemofiliások Baráti Köre	Healthcare Organization Donations	5,000,000	HUF	
Hungary Total				HUF	5,000,000
Ireland	HADD Ireland	Educational Grants - Accredited and Non-accredited Educational Activities	6,000	EUR	
Ireland	Irish Platform for Patient Organisations, Science and Industry (IPPOSI)	Membership Fees	7,500	EUR	
Ireland	IPPOSI	Promotional and Informational HCP Education or Commercial Sponsorship of Event	2,500	EUR	
Ireland Total				EUR	16,000
Italy	A.I.A.F.	Educational Grants - Accredited and Non-accredited Educational Activities	6,233	EUR	
Italy	A.N.N.A.	Infrastructure Donations	25,000	EUR	
Italy	AIG	Educational Grants - Accredited and Non-accredited Educational Activities	15,000	EUR	
Italy	AIL	Fee For Service	10,000	EUR	
Italy	AIL CATANIA	Fee For Service	24,000	EUR	
Italy	AIMPS	Healthcare Organization Donations	15,000	EUR	
Italy	AIP	Healthcare Organization Donations	70,000	EUR	
Italy	APPI	Healthcare Organization Donations	15,000	EUR	
Italy	ASSOCIAZIONE ONLUS EMOFILICI E TALASSEMICI VINCENZO RUSSO SERDOZ	Healthcare Organization Donations	48,000	EUR	
Italy	FEDERAZIONE DELLE ASSOCIAZIONI EMOFILICI	Healthcare Organization Donations	51,000	EUR	
Italy	FEDRED	Healthcare Organization Donations	10,000	EUR	
Italy	FONDAZIONE PARACELSO	Healthcare Organization Donations	10,000	EUR	
Italy	UN FILO PER LA VITA	Fee For Service	25,000	EUR	
Italy Total				EUR	324,233
Japan	Advocacy Service for Rare and Intractable Disease Stakeholders in Japan (ASRID)	Healthcare Organization Donations	1,000,000	JPY	
Japan	Advocacy Service for Rare and Intractable Disease Stakeholders in Japan (ASRID)	Healthcare Organization Donations	150,000	JPY	
Japan	Advocacy Service for Rare and Intractable Disease Stakeholders in Japan (ASRID)	Healthcare Organization Donations	300,000	JPY	
Japan	Association of Gaucher Disease Patients in Japan	Healthcare Organization Donations	40,000	JPY	
Japan	Association of Gaucher Disease Patients in Japan	Healthcare Organization Donations	600,000	JPY	
Japan	Association of Metachromatic LeukoDistrophy (MLD) Patients and Families in Japan	Healthcare Organization Donations	200,000	JPY	
Japan	Center for Research, Education and Treatment of Angioedema (CREATE)	Healthcare Organization Donations	1,000,000	JPY	

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Japan	Fabry Next	Healthcare Organization Donations	150,000	JPY	
Japan	Fabry NEXT	Healthcare Organization Donations	150,000	JPY	
Japan	Fukuro no Kai (Japan Fabry Disease Association)	Healthcare Organization Donations	800,000	JPY	
Japan	HAE Japan	Healthcare Organization Donations	1,000,000	JPY	
Japan	Hemophilia Network Japan	Healthcare Organization Donations	1,000,000	JPY	
Japan	Hereditary AngioEdema (HAE) Patient Group in Japan	Educational Grants - HCP Educational Sponsorships	1,000,000	JPY	
Japan	Myeloproliferative Neoplasms (MPN) Japan	Healthcare Organization Donations	500,000	JPY	
Japan	PANCAN Japan	Healthcare Organization Donations	100,000	JPY	
Japan	PID Tsubasanokai	Healthcare Organization Donations	50,000	JPY	
Japan	Sakura Network Japan	Healthcare Organization Donations	316,000	JPY	
Japan	Sakura Network Japan	Healthcare Organization Donations	250,000	JPY	
Japan	Short Bowel Syndrome Association	Healthcare Organization Donations	500,000	JPY	
Japan Total				JPY	9,106,000
Latvia	Latvia Haemophilia society	Educational Grants - Accredited and Non-accredited Educational Activities	5,100	EUR	
Latvia Total				EUR	5,100
Lithuania	Association of Lithuanian People with Haemophilia	Educational Grants - Accredited and Non-accredited Educational Activities	4,800	EUR	
Lithuania	Association of Lithuanian People with Haemophilia	Educational Grants - Accredited and Non-accredited Educational Activities	600	EUR	
Lithuania	Lithuanian people with Hemophilia Association	Healthcare Organization Donations	8,640	EUR	
Lithuania Total				EUR	14,040
Mexico	Federación de Hemofilia de la Republica Mexicana A.C.	Healthcare Organization Donations	150,000	MXN	
Mexico	Federación de Hemofilia de la Republica Mexicana A.C.	Healthcare Organization Donations	225,000	MXN	
Mexico	Federación de Hemofilia de la Republica Mexicana A.C.	Healthcare Organization Donations	50,000	MXN	
Mexico	Fundación Mexicana para Niñas y Niños con Inmunodeficiencias Primarias	Healthcare Organization Donations	15,000	MXN	
Mexico	Fundación Mexicana para Niñas y Niños con Inmunodeficiencias Primarias	Healthcare Organization Donations	150,000	MXN	
Mexico	Grupo Fabry de Mexico I.A.P.	Healthcare Organization Donations	300,000	MXN	
Mexico	Grupo Fabry de Mexico I.A.P.	Healthcare Organization Donations	120,000	MXN	
Mexico	Patronato del Hospital Psiquiatrico Infantil Dr. Juan N. Navarro	Healthcare Organization Donations	15,000	MXN	
Mexico	Proyecto Pide un Deseo, A.C.	Healthcare Organization Donations	500,000	MXN	
Mexico	Tabasqueña de Hemofilia A.C.	Healthcare Organization Donations	75,000	MXN	
Mexico Total				MXN	1,600,000
Norway	Foreningen For Blødere I Norge	Educational Grants - Accredited and Non-accredited Educational Activities	15,000	NOK	
Norway Total				NOK	15,000
Poland	Fundacja razem zdążymy	Healthcare Organization Donations	2,000	PLN	
Poland	Krajowe Forum na Rzecz Terapii Chorób Rzadkich - ORPHAN	Healthcare Organization Donations	10,000	PLN	
Poland	Krajowe Forum na Rzecz Terapii Chorób Rzadkich - ORPHAN	Healthcare Organization Donations	10,000	PLN	
Poland	Polskie Stowarzyszenie Pomocy Chorym z obrzękiem Naczynioruchowym PIĘKNIE PUCHNĘ	Healthcare Organization Donations	5,443	PLN	
Poland	Polskie Stowarzyszenie Pomocy Chorym z obrzękiem Naczynioruchowym PIĘKNIE PUCHNĘ	Healthcare Organization Donations	71,738	PLN	
Poland	Stowarzyszenie Chorych na(MPS) Mukopolisacharydozę i Choroby Rzadkie	Healthcare Organization Donations	30,000	EUR	
Poland	Stowarzyszenie na rzecz osób z niedoborami odporności Immunoprotect	Healthcare Organization Donations	12,000	PLN	
Poland	Stowarzyszenie na rzecz osób z niedoborami odporności Immunoprotect	Fee For Service Related Expenses	946	PLN	
Poland	Stowarzyszenie na rzecz osób z niedoborami odporności Immunoprotect	Fee For Service	1,058	PLN	
Poland	Stowarzyszenie na rzecz osób z niedoborami odporności Immunoprotect	Fee For Service Related Expenses	984	PLN	
Poland	Stowarzyszenie Pomocy Chorym	Fee For Service	12,000	USD	
Poland Total				PLN	114,169
Poland Total				EUR	30,000
Poland Total				USD	12,000
Romania	Alianta Nationala pentru Boli Rare Romania	Healthcare Organization Donations	7,000	EUR	
Romania	Asociatia Nationala a Hemofilicilor din Romania	Healthcare Organization Donations	70,500	RON	

Shire Patient Organization Funding
For the Period: January 1, 2018 through December 31, 2018

Country	Name of Organization	Description of the Activity/Purpose	Amount	Currency	Total per Country
Romania	Asociatia Nationala a Hemofilicilor din Romania	Healthcare Organization Donations	14,100	RON	
Romania Total				EUR	7,000
Romania Total				RON	84,600
Russia	All-Russian public organization All-Russian society of rare (orphan) diseases (VOOZ)	Healthcare Organization Donations	889,000	RUB	
Russia	Autonomic Non-commercial organization - Patients Support Centre Genome	Healthcare Organization Donations	700,000	RUB	
Russia	Autonomic Non-commercial Organization Helping Patients with Short Bowel Syndrome and Metabolic Disorders Wind of Hope	Healthcare Organization Donations	700,000	RUB	
Russia	Autonomic Non-commercial Organization Helping Patients with Short Bowel Syndrome and Metabolic Disorders Wind of Hope	Healthcare Organization Donations	800,000	RUB	
Russia	Khabarovsk regional organization of the All-Russian Charitable Public Organization of Disabled People All-Russian Society of Hemophilia	Healthcare Organization Donations	200,000	RUB	
Russia	Komi regional non-commercial children charitable foundation Power of good (Sila dobra)	Healthcare Organization Donations	576,703	RUB	
Russia	Multi-Regional Charity Public Organization Hunter Syndrome	Healthcare Organization Donations	4,646,000	RUB	
Russia	Multi-Regional Charity Public Organization Hunter Syndrome	Healthcare Organization Donations	4,500,000	RUB	
Russia	Multi-Regional Public Organization for FD and other rare diseases patients Road to life	Healthcare Organization Donations	600,000	RUB	
Russia	Multi-Regional Public Organization for FD and other rare diseases patients Road to life	Healthcare Organization Donations	600,000	RUB	
Russia	Multi-Regional Public Organization for FD and other RD patients Road to life	Healthcare Organization Donations	100,000	RUB	
Russia	Multi-Regional Public Organization of disable people Union of Patients and Patients Organizations With Rare Diseases	Healthcare Organization Donations	4,500,000	RUB	
Russia	Multi-Regional Public Organization Patients community with Hereditary Angioedema	Healthcare Organization Donations	1,000,000	RUB	
Russia	Multi-Regional Public Organization Patients community with Hereditary Angioedema	Healthcare Organization Donations	710,000	RUB	
Russia	Multi-Regional Public Organization Patients community with Hereditary Angioedema	Healthcare Organization Donations	1,000,000	RUB	
Russia	Multi-Regional Public Organization Support for disabled patients since childhood, suffering from Gaucher disease, and their families	Healthcare Organization Donations	297,500	RUB	
Russia	Multi-Regional Public Organization Supporting Patients with Inflammatory Bowel Disease (IBD) and Short Bowel Syndrome (SBS) Trust	Healthcare Organization Donations	600,000	RUB	
Russia	Multi-Regional Public Organization Union of Patients and Patients Organizations With Rare Diseases	Healthcare Organization Donations	4,000,000	RUB	
Russia	Russian charitable public organization of persons with disabilities Russian Hemophilia Society – Federal Level PO	Healthcare Organization Donations	4,000,000	RUB	
Russia	Russian charitable public organization of persons with disabilities Russian Hemophilia Society – Federal Level PO	Healthcare Organization Donations	2,000,000	RUB	
Russia	Russian charitable public organization of persons with disabilities Russian Hemophilia Society – Federal Level PO	Healthcare Organization Donations	2,000,000	RUB	
Russia	The Resource Center for Support of Socially-Oriented Organizations, Projects and Programs Foundation	Healthcare Organization Donations	150,000	RUB	
Russia Total				RUB	34,569,203
Serbia	Citizens' Association for Combating Rare Diseases in Children Life	Organizational Support	236,695	RSD	
Serbia	MPS Serbia	Organizational Support	260,365	RSD	
Serbia	National Organization for Rare Diseases of Serbia	Fee For Service	553,157	RSD	
Serbia	National Organization for Rare Diseases of Serbia	Fee For Service	666,763	RSD	
Serbia Total				RSD	1,716,980
Slovakia	Združenie pacientov s primárnou imunodeficienciou	Healthcare Organization Donations	7,200	EUR	
Slovakia	Slovenské hemofilické združenie	Healthcare Organization Donations	18,500	EUR	
Slovakia Total				EUR	25,700
Spain	ABADIP	Contracted Services by Patient Organization	152	EUR	

Shire Patient Organization Funding
For the Period: January 1, 2018 through December 31, 2018

Country	Name of Organization	Description of the Activity/Purpose	Amount	Currency	Total per Country
Spain	ABADIP	People Disease Education	1,500	EUR	
Spain	AEDAF	People Disease Education	3,750	EUR	
Spain	AEDAF	People Disease Education	4,900	EUR	
Spain	AEDIP	People Disease Education	5,100	EUR	
Spain	AEDIP	Contracted Services by Patient Organization	395	EUR	
Spain	AEDIP	People Disease Education	1,500	EUR	
Spain	AEEFEG Asociación Española de Enfermos y Familiares de enfermedad de GAUCHER)	People Disease Education	10,000	EUR	
Spain	AGADHEMO (Asociación Gallega de Hemofilia)	People Disease Education	9,630	EUR	
Spain	ANADIP	Contracted Services by Patient Organization	293	EUR	
Spain	ASHEGUI	Scientific HCP Education or Medical Sponsorship of Event	5,744	EUR	
Spain	ASHEMADRID	Contracted Services by Patient Organization	300	EUR	
Spain	ASHEMADRID	Scientific HCP Education or Medical Sponsorship of Event	1,138	EUR	
Spain	ASHEMADRID	People Disease Education	3,000	EUR	
Spain	Asociacion Cancer de Pancreas	Scientific HCP Education or Medical Sponsorship of Event	13,000	EUR	
Spain	Asociacion Malagueña De Hemofilia	Scientific HCP Education or Medical Sponsorship of Event	2,500	EUR	
Spain	Asociacion Malagueña De Hemofilia	People Disease Education	4,000	EUR	
Spain	D'Genes Asociacion de Enfermedades Raras	Event support	3,000	EUR	
Spain	Federación Española de Enfermedades Raras (FEDER)	Scientific HCP Education or Medical Sponsorship of Event	20,000	EUR	
Spain	Federación Española de Enfermedades Raras (FEDER)	People Disease Education	7,000	EUR	
Spain	FEDHEMO (Federación Española de Hemofilia)	Educational Grants - Accredited and Non-accredited Educational Activities	16,553	EUR	
Spain	FEDHEMO (Federación Española de Hemofilia)	Educational Grants - Accredited and Non-accredited Educational Activities	14,084	EUR	
Spain	Fundación Mas que Ideas	Contracted Services by Patient Organization	319	EUR	
Spain	Fundación Mas que Ideas	Contracted Services by Patient Organization	300	EUR	
Spain	GEPAC (Grupo español de pacientes con cáncer)	People Disease Education	3,000	EUR	
Spain	MPS	People Disease Education	3,000	EUR	
Spain	MPS	People Disease Education	4,980	EUR	
Spain	MPS	Contracted Services by Patient Organization	330	EUR	
Spain	MPS	People Disease Education	14,250	EUR	
Spain	NUPA	Contracted Services by Patient Organization	990	EUR	
Spain	NUPA	People Disease Education	2,308	EUR	
Spain	NUPA	Contracted Services by Patient Organization	190	EUR	
Spain	NUPA	People Disease Education	7,600	EUR	
Spain	Short Bowel Syndrom (SBS)	Contracted Services by Patient Organization	383	EUR	
Spain Total				EUR	165,188
Sweden	Blodcancerförbundet	Educational Grants - Accredited and Non-accredited Educational Activities	21,230	SEK	
Sweden	Cancerföreningen Palema	Scientific HCP Education or Medical Sponsorship of Event	50,000	SEK	
Sweden	Fabryföreningen i Sverige - Fabry Society Board in Sweden	Educational Grants - Accredited and Non-accredited Educational Activities	20,333	SEK	
Sweden	FBIS - Förbundet Blödarsjuka i Sverige	Educational Grants - Accredited and Non-accredited Educational Activities	65,000	SEK	
Sweden	FBIS - Förbundet Blödarsjuka i Sverige	Educational Grants - Accredited and Non-accredited Educational Activities	10,000	SEK	
Sweden	FBIS - Förbundet Blödarsjuka i Sverige	Educational Grants - Accredited and Non-accredited Educational Activities	30,000	SEK	
Sweden	FBIS - Förbundet Blödarsjuka i Sverige	Educational Grants - Accredited and Non-accredited Educational Activities	48,000	SEK	
Sweden	FBIS - Förbundet Blödarsjuka i Sverige	Educational Grants - Accredited and Non-accredited Educational Activities	4,740	SEK	
Sweden	FBIS - Förbundet Blödarsjuka i Sverige	Educational Grants - Accredited and Non-accredited Educational Activities	84,713	SEK	
Sweden	ILCO Tarm- URO- OCH Stomiförbundet	Educational Grants - Accredited and Non-accredited Educational Activities	35,000	SEK	
Sweden	ILCO Tarm- URO- OCH Stomiförbundet	Educational Grants - Accredited and Non-accredited Educational Activities	25,000	SEK	
Sweden	Morbus Gaucher Föreningen	Educational Grants - Accredited and Non-accredited Educational Activities	25,000	SEK	
Sweden	Morbus Gaucher Föreningen	Fee For Service	5,000	SEK	
Sweden	Primär Immunbrist Organisation	Fee For Service	8,000	SEK	
Sweden	Primär Immunbrist Organisation	Educational Grants - Accredited and Non-accredited Educational Activities	20,000	SEK	
Sweden	Primär Immunbrist Organisation - PIO	Fee For Service	24,156	SEK	
Sweden	Primär Immunbrist Organisation - PIO	Membership Fees	600	SEK	
Sweden	Primär Immunbrist Organisation - PIO	Scientific HCP Education or Medical Sponsorship of Event	50,000	SEK	
Sweden	Primär Immunbrist Organisation - PIO	Educational Grants - Accredited and Non-accredited Educational Activities	12,000	SEK	
Sweden	Svensk förening för hypoparatyreoidism	Educational Grants - Accredited and Non-accredited Educational Activities	22,850	SEK	
Sweden	Svenska HPN föreningen	Fee For Service	440	EUR	
Sweden Total				SEK	561,622

Shire Patient Organization Funding
For the Period: January 1, 2018 through December 31, 2018

Country	Name of Organization	Description of the Activity/Purpose	Amount	Currency	Total per Country
Sweden Total				EUR	440
Switzerland	Acute Leukaemia Advocates Network ALAN	Healthcare Organization Donations	25,000	EUR	
Switzerland	AHA Allergiezentrum Immunschwäche Schweiz	Healthcare Organization Donations	15,100	CHF	
Switzerland	AHA Allergiezentrum Immunschwäche Schweiz	Promotional and Informational HCP Education or Commercial Sponsorship of Event	1,700	CHF	
Switzerland	ESMO to Rare Cancers Europe	Healthcare Organization Donations	25,000	EUR	
Switzerland	HAE Vereinigung Schweiz	Healthcare Organization Donations	20,000	CHF	
Switzerland	HAEi	Healthcare Organization Donations	250,000	EUR	
Switzerland	HAEi	Promotional and informational HCP Education or Commercial Sponsorship of Events	433,600	EUR	
Switzerland	Magendamliga Schweiz	Scientific HCP Education or Medical Sponsorship of Event	3,000	CHF	
Switzerland	Schweizer Selbsthilfeorganisation Pankreaserkrankungen SSP	Healthcare Organization Donations	2,500	CHF	
Switzerland	Schweizerische Hämophilie-Gesellschaft (SHG)	Healthcare Organization Donations	16,000	CHF	
Switzerland	SMCCV Schweizerische Morbus Crohn / Colitis ulcerosa Vereinigung	Healthcare Organization Donations	500	CHF	
Switzerland Total				EUR	733,600
Switzerland Total				CHF	58,800
Ukraine	Public Organization of disable persons Ukrainian Hemophilia Association	Event support	20,000	UAH	
Ukraine	Public Organization of disable persons Ukrainian Hemophilia Association	Healthcare Organization Donations	40,000	UAH	
Ukraine Total				UAH	60,000
Patient organisations: financial support, and significant nonfinancial support					
United Kingdom	Add Up	Infrastructure Donations	1,920	GBP	
United Kingdom	ADHD Action	Educational Grants - Accredited and Non-accredited Educational Activities	10,000	GBP	
United Kingdom	ADHD Foundation	Promotional and Informational HCP Education or Commercial Sponsorship of Event	10,000	GBP	
United Kingdom	Cancer 52	Educational Grants - Accredited and Non-accredited Educational Activities	6,000	GBP	
United Kingdom	Cancer Campaigning Group	Promotional and Informational HCP Education or Commercial Sponsorship of Event	6,000	GBP	
United Kingdom	Cardiomyopathy UK	Promotional and Informational HCP Education or Commercial Sponsorship of Event	1,461	GBP	
United Kingdom	Cardiomyopathy UK	Promotional and Informational HCP Education or Commercial Sponsorship of Event	2,500	GBP	
United Kingdom	Crohn's and Colitis UK	Educational Grants - Accredited and Non-accredited Educational Activities	15,000	GBP	
United Kingdom	Dundee and Angus ADHD Support Group	Promotional and Informational HCP Education or Commercial Sponsorship of Event	3,000	GBP	
United Kingdom	Dundee and Angus ADHD Support Group	Educational Grants - HCP Educational Sponsorships	5,000	GBP	
United Kingdom	European Gaucher Alliance	Promotional and Informational HCP Education or Commercial Sponsorship of Event	45,600	GBP	
United Kingdom	European Gaucher Disease Network	Educational Grants - Accredited and Non-accredited Educational Activities	50,000	EUR	
United Kingdom	Genetic Alliance	Educational Grants - Accredited and Non-accredited Educational Activities	10,000	GBP	
United Kingdom	Honeypot Children's Charity	Event support	1,000	GBP	
United Kingdom	Hypopara UK	Promotional and Informational HCP Education or Commercial Sponsorship of Event	26,002	GBP	
United Kingdom	Immune Deficiency Patient Group	Promotional and Informational HCP Education or Commercial Sponsorship of Event	897	GBP	
United Kingdom	IPOPI	Healthcare Organization Donations	213,500	EUR	
United Kingdom	NRG Collective	Philanthropic Donations: Community Related Donations made by Businesses to Non Healthcare Organizations	5,000	GBP	
United Kingdom	PID UK	Educational Grants - Accredited and Non-accredited Educational Activities	5,000	GBP	
United Kingdom	SBS & Friends	Promotional and Informational HCP Education or Commercial Sponsorship of Event	4,703	GBP	
United Kingdom	Scottish ADHD Coalition	Educational Grants - Accredited and Non-accredited Educational Activities	8,000	GBP	
United Kingdom	The Children's Sleep Charity	Promotional and Informational HCP Education or Commercial Sponsorship of Event	17	GBP	
United Kingdom	The Children's Sleep Charity	Promotional and Informational HCP Education or Commercial Sponsorship of Event	350	GBP	
United Kingdom	The Gauchers Association Ltd	Promotional and Informational HCP Education or Commercial Sponsorship of Event	31,700	GBP	
United Kingdom	The Haemophilia Society	Promotional and Informational HCP Education or Commercial Sponsorship of Event	30,000	GBP	
United Kingdom	The MPS Society	Educational Grants - Accredited and Non-accredited Educational Activities	4,500	GBP	
United Kingdom	The MPS Society	Promotional and Informational HCP Education or Commercial Sponsorship of Event	20,000	GBP	
United Kingdom	UK PIPS	Promotional and Informational HCP Education or Commercial Sponsorship of Event	5,700	GBP	
Subtotal Patient Organization financial support, and significant non-financial support:				GBP	259,350
				EUR	263,500
Patient Organisation Service Payments					
United Kingdom	ADHD Norfolk	Fee For Service Related Expenses	102	GBP	
Subtotal Patient Organization Services:				GBP	102
United Kingdom	ADHD Foundation	Fee For Service Related Expenses	350	GBP	
Subtotal Patient Organization Services:				GBP	350
United Kingdom	Adult ADHD Solutions	Fee For Service Related Expenses	30	GBP	
Subtotal Patient Organization Services:				GBP	30

Shire Patient Organization Funding
For the Period: January 1, 2018 through December 31, 2018

Country	Name of Organization	Description of the Activity/Purpose	Amount	Currency	Total per Country
United Kingdom	Adult ADHD NI	Fee For Service	600	GBP	
United Kingdom	Adult ADHD NI	Fee For Service Related Expenses	96	GBP	
United Kingdom	Adult ADHD NI	Fee For Service Related Expenses	466	GBP	
Subtotal Patient Organization Services:				GBP	1,162
United Kingdom	European Gauchers Alliance	Fee For Service	1,150	GBP	
United Kingdom	European Gauchers Alliance	Fee For Service Related Expenses	1,699	GBP	
Subtotal Patient Organization Services:				GBP	2,849
United Kingdom	Fabry International Network	Fee For Service	280	GBP	
Subtotal Patient Organization Services:				GBP	280
United Kingdom	Genetic Alliance	Fee For Service Related Expenses	173	GBP	
Subtotal Patient Organization Services:				GBP	173
United Kingdom	HAE UK	Fee For Service	380	GBP	
United Kingdom	HAE UK	Fee For Service Related Expenses	45	GBP	
United Kingdom	HAE UK	Fee For Service Related Expenses	78	GBP	
Subtotal Patient Organization Services:				GBP	503
United Kingdom	Haemophilia Scotland	Fee For Service Related Expenses	260	GBP	
Subtotal Patient Organization Services:				GBP	260
United Kingdom	Leukaemia Care	Fee For Service Related Expenses	94	GBP	
Subtotal Patient Organization Services:				GBP	94
United Kingdom	MPS Society	Fee For Service Related Expenses	32	GBP	
Subtotal Patient Organization Services:				GBP	32
United Kingdom	Pancreatic Cancer Action	Fee For Service Related Expenses	45	GBP	
United Kingdom	Pancreatic Cancer Action	Fee For Service	120	GBP	
Subtotal Patient Organization Services:				GBP	165
United Kingdom	Royal Free Charity	Fee For Service	10,000	GBP	
Subtotal Patient Organization Services:				GBP	10,000
United Kingdom	Short Bowel Survivor and Friends	Fee For Service Related Expenses	245	GBP	
Subtotal Patient Organization Services:				GBP	245
United Kingdom	The Children's Sleep Charity	Fee For Service Related Expenses	116	GBP	
United Kingdom	The Children's Sleep Charity	Fee For Service Related Expenses	450	GBP	
Subtotal Patient Organization Services:				GBP	566
United Kingdom	The Gauchers Association Ltd	Fee For Service Related Expenses	43	GBP	
United Kingdom	The Gauchers Association Ltd	Fee For Service	310	GBP	
United Kingdom	The Gauchers Association Ltd	Fee For Service Related Expenses	166	GBP	
Subtotal Patient Organization Services:				GBP	519
United Kingdom Total				GBP	276,679
				EUR	263,500