



Shire Patient Organization Funding
For the Period: January 1, 2016 through December 31, 2016

| Country | Name of Organization | Description of the Activity/Purpose | Amount | Currency | Total per Country |
|-------------------------|--|---|------------|------------|-------------------|
| Argentina | ACELNEA (Asociación Civil Enfermos Lisosomales del Noroeste Argentino) | Provide support for activities related to LSDs patients in the Argentine northwest region. | 60,000.00 | ARS | |
| Argentina | FADEPOF (Federación Argentina de Enfermedades Poco Frecuentes) | Provide support for activities related to LSDs & HAE patients associations. | 100,000.00 | ARS | |
| Argentina Total: | | | | ARS | 160,000.00 |
| Australia | Crohn's & Colitis Australia | Funding to support Crohn's and Colitis Australia's 2016 quarterly "Inside Insights" educational magazines for patients with inflammatory bowel disease. | 50,000.00 | AUD | |
| Australia | Crohn's & Colitis Australia | Funding to support Crohn's & Colitis Australia's Awareness month posters distributed in hospitals and through Crohn's & Colitis Australia's networks. | 5,000.00 | AUD | |
| Australia | Crohn's Colitis Cure | Funding to support Crohn's & Colitis Cure Inflammatory Bowel Disease (IBD) research consortium meeting. | 2,875.67 | AUD | |
| Australia | Fabry Australia Inc. | Funding to support Fabry Australia's annual patient group meeting and educational materials for use by patients and their families. | 25,000.00 | AUD | |
| Australia | HAE Australasia | Funding to support independent HAE Australasia meetings looking at the identification and management of hereditary angioedema. | 5,000.00 | AUD | |
| Australia | HAE Australasia | Funding to support HAE Australasia in raising community awareness and supporting the organisation's strategy workshop. | 4,500.00 | AUD | |
| Australia | HAE Australasia | Funding to support HAE Australasia's workshops on 'How to cope and adapt to life with HAE'. | 5,000.00 | AUD | |
| Australia | Hemophilia Foundation of Australia (HFA) | 18th Australian & New Zealand Conference on Haemophilia and Rare Bleeding Disorders. | 30,000.00 | AUD | |



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| Australia | Immune Deficiencies Foundation Australia (IDFA) | Funding to support Immune Deficiencies Foundation Australia's Biennial National Conference "You, Me and PID" a 3 day national conference bringing together patients, carers and family members affected by primary immune deficiencies. | 20,000.00 | AUD | |
| Australia | Parenteral Nutrition Down Under Inc. | Support the costs of conducting the PACIFHAN Meeting. | 1,256.00 | GBP | |
| Australia | Parenteral Nutrition Down Under Inc. | Funding to support Parenteral Nutrition Down Under to conduct workshops and patient perspective representations at forums and conferences. | 5,000.00 | AUD | |
| Australia | Rare Voices Australia Ltd | Funding to support Rare Voices Australia's "Fair for Rare" Campaign aimed at raising community awareness of the impact of rare disease. | 13,636.36 | AUD | |
| Australia | Rare Voices Australia Ltd | Funding to support Rare Voices Australia to undertake disease awareness and patient education projects throughout 2016. | 27,272.73 | AUD | |
| Australia Total: | | | | AUD | 193,284.76 |
| | | | | GBP | 1,256.00 |
| Austria | European Crohn's and Colitis | ECCO Corporate Membership 2017. | 2,500.00 | EUR | |
| Austria | Gesellschaft für Mukopolysaccharidosen (MPS) und ähnliche Erkrankungen e.V. | Donation to contribute in the costs of the Patient Organisation | 10,000.00 | EUR | |
| Austria | OEHG- Austrian Hemophilia Society | Training Materials. | 12,000.00 | EUR | |
| Austria | ÖGG - Österreichische Gesellschaft für Gaucherekrankungen e. V. | Donation to contribute in the costs of the Patient Organisation | 3,000.00 | EUR | |



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| Austria | OHG (Austrian Hemophilia Patient Organization) | Video-Case Interviews. | 1,000.00 | EUR | |
| Austria | OHG (Austrian Hemophilia Patient Organization) | Summer Camp 2016. | 6,000.00 | EUR | |
| Austria | OHG (Austrian Hemophilia Patient Organization) | Sponsorship for 2 OHG members to attend World Hemophilia Congress (Orlando). | 1,000.00 | USD | |
| Austria | OSPID- PID Patient Organization | OSPID Annual Meeting 2016. | 1,200.00 | EUR | |
| Austria | Österreichische Selbsthilfegruppe für Hereditäres Angioödem (HAE-Austria) e. V. | Donation to support the statutory objectives of the organization. | 2,500.00 | EUR | |
| Austria | Pro Rare Austria - Allianz für seltene Erkrankungen | Donation "Patientenselbsthilfe". | 4,000.00 | EUR | |
| Austria | SHG - Selbsthilfegruppe Pankreaskarzinom | Awareness Campaign on World Pancreatic Cancer Day / Seminar for patients about Pancreatic Cancer. | 11,000.00 | EUR | |
| Austria Total: | | | | EUR | 53,200.00 |
| | | | | USD | 1,000.00 |
| Belgium | AHVH (association belge de l'hémophilie / vereniging voor hemofilie patiënten) | Support to AHVH for the organization of 2016 Educational Events for their patients (family meeting & senior meeting). | 20,000.00 | EUR | |
| Belgium | AIRG Belgique | Donation to contribute in the costs of the Patient Organisation | 3,000.00 | EUR | |
| Belgium | Angioedema Belgium ASBL | Donation to contribute in the costs of the Patient Organisation | 1,000.00 | EUR | |
| Belgium | Belgium Fabry Support Group | Donation to contribute in the costs of the Patient Organisation | 4,900.00 | EUR | |



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| Belgium | BOKS vzw-Belgian organization for children and adults with metabolic disease | Donation to contribute in the costs of the Patient Organisation | 3,000.00 | EUR | |
| Belgium | Centrum ZitStil | Financial support to contribute in the costs of project ZitStil2.0 | 12,500.00 | EUR | |
| Belgium | EFCCA-The European Federation of Crohn's & Ulcerative Colitis Associations | Annual Corporate Membership 2016 Disease awareness activities such as IBD World Day Summer and Youth camps Patient portal creation Toilet finder development. | 58,500.00 | EUR | |
| Belgium | EFCCA-The European Federation of Crohn's & Ulcerative Colitis Associations | ECCO-EFCCA Patient Guidelines translation into Community languages Launch of the training online platform: a new tool to empower and education patients. | 30,000.00 | EUR | |
| Belgium | European Hemophilia Consortium (EHC) | Annual Conference. | 30,000.00 | EUR | |
| Belgium | European Hemophilia Consortium (EHC) | EIN- Standards of Care Meeting. | 45,000.00 | EUR | |
| Belgium | Epilepsie Liga | Donation to contribute in the costs of the Patient Organisation | 500.00 | EUR | |
| Belgium | European Patient's Forum | EPH 2016 Portfolio of Activities. | 10,000.00 | EUR | |
| Belgium | EURORDIS- Rare Diseases Europe | Contribution to renew Baxalta's Emerald ERTC Membership (EURORDIS Round Table of Companies). | 10,000.00 | EUR | |
| Belgium | Pancreatic Cancer Europe | Support for 2016 Activities. | 57,000.00 | EUR | |
| Belgium Total: | | | | EUR | 285,400.00 |
| Brazil | AAMPS - Associação Alagoana de Familiares e Amigos dos Portadores de Mucopolissacaridoses | Support MPS families with supplementary medication, sponsorship of specific clinical exams unavailable in the Public Healthcare System (SUS) and purchase of equipment/material for infusion. | 10,000.00 | Brazilian Reais | |



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| Brazil | ABAMPS - Associação Baiana dos Familiares e Amigos dos Portadores de Mucopolissacaridoses | Donation to contribute in the costs of the Patient Organisation | 40,000.00 | Brazilian Reais | |
| Brazil | ABRAFF - Associação Brasileira dos Portadores de Fabry e Familiares | To support Fabry disease awareness actions and support related social services, education. | 701,400.00 | Brazilian Reais | |
| Brazil | ABRANGHE - Associação Brasileira de Angioedema Hereditário | Support Patient Education about HAE | 15,000.00 | Brazilian Reais | |
| Brazil | ACDG - Associação Cearense de Profissionais Atuantes em Doenças Genéticas, Pacientes, Familiares e Voluntários | Support for Disease Awareness, Healthcare policy and National/International Research | 67,600.00 | Brazilian Reais | |
| Brazil | ACDG - Associação Cearense de Profissionais Atuantes em Doenças Genéticas, Pacientes, Familiares e Voluntários | Support to patients regarding access to treatment | 208,333.00 | Brazilian Reais | |
| Brazil | ACDR/ACAMU - Associação Catarinense de Doenças Raras | Support to patients regarding access to treatment | 15,000.00 | Brazilian Reais | |
| Brazil | ACDR/ACAMU - Associação Catarinense de Doenças Raras | Support to patients regarding access to treatment | 146,458.00 | Brazilian Reais | |
| Brazil | AGF - Associação Gaúcha de Fabry | Support to patients and creating awareness on Fabry Disease. | 15,000.00 | Brazilian Reais | |



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| Brazil | AGMPS - Associação Gaúcha de Mucopolissaridoses | Call MPS Families and other rare diseases, contact infusion centers, institutions and health professionals for disease awareness and attend public hearings, meetings with government and authorities. | 9,000.00 | Brazilian Reais | |
| Brazil | AMMPS - Associação Mineira de Mucopolissaridoses | Support project "Quem não enfrenta desafios para viver" | 67,480.00 | Brazilian Reais | |
| Brazil | AMPS/PE - Associação Pernambucana de Mucopolissacaridoses Breno Bloise de Freitas | Provide a wide range of services to MPS patients such as: transportation (home - infusion center), disease promotion, purchase and glasses' repair for patients, aiming at improving quality of life. | 515,000.00 | Brazilian Reais | |
| Brazil | Anjos da Guarda - Associação de apoiadores aos portadores de mucopolissacaridose e de doenças raras | Support to MPS disease awareness for HCPs and public | 38,000.00 | Brazilian Reais | |
| Brazil | ANMPS - Associação Natalense de Mucopolissaridoses | Support to MPS disease awareness for HCPs and public | 6,000.00 | Brazilian Reais | |
| Brazil | ANPIC - Associação Nacional dos Portadores de Imunodeficiência Primária Congênita | Support for patient awareness and communication programs | 4,000.00 | Brazilian Reais | |
| Brazil | APMPS/DR - Associação Paulista de Mucopolissacaridoses e Doenças Raras | Disease Awareness events, IPOPI (International Patient Organization Primary Immunodeficiencies) attendance. | 59,424.00 | Brazilian Reais | |



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| Brazil | APMPS/DR - Associação Paulista de Mucopolissacaridoses e Doenças Raras | The main goal of APMPS is to ensure the effective treatment of patients with Hunter Syndrome and other genetic and rare conditions . Beyond that APMPS has an important influence on call the government to develop public policies through clinical protocols (main activity for 2017). | 624,000.00 | Brazilian Reais | |
| Brazil | ASMPS - Associação Sergipana de Mucopolissacaridoses | Implement disease awareness with MPS patients and support access to treatment to new ones. | 3,000.00 | Brazilian Reais | |
| Brazil | ASPIFF - Associação Piauiense de Familiares de Fabry | Support to Patients Organization initiatives | 329,680.00 | Brazilian Reais | |
| Brazil | AWSPA&DG - Associação Paraense da Síndrome de Willians e outras Doenças Genéticas | Support to Patients Organization initiatives | 10,500.00 | Brazilian Reais | |
| Brazil | BNAI - Associação Beneficente e Cultural Bnai Brith | Support "teatro Mergulho" project | 563,541.00 | Brazilian Reais | |
| Brazil | FBH - Federação Brasileira de Hemofilia | Disease Awareness, events for families, patients, HCPs. Support on WDH (World Day of Hemophilia) - disease activation, awareness, media. | 300,000.00 | Brazilian Reais | |
| Brazil | IGEIM - Instituto de Genetica e Erros Inatos do Metabolismo | Funding for reference center in genetics that is in charge of MPS diagnosis analyses for Elapraxe providing monthly reports on patient finding. | 341,667.00 | Brazilian Reais | |
| Brazil Total: | | | | Brazilian Reais | 4,090,083.00 |
| Bulgaria | National Alliance of People with Rare Diseases | Funding for HCP Education and Awareness | 11,734.98 | BGN | |



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| Bulgaria Total: | | | | BGN | 11,734.98 |
| Canada | ANEB- Anorexie et boulimie Québec | Donation - Support for the organization's mission Sponsorship - Annual meeting. | | | |
| Canada | APIQ-Association des Patients Immunodéficients du Québec | Donation - Support for the organization's mission. | | | |
| Canada | CADDAC-The Centre for ADHD Awareness Canada | Donation - Support for the organization's mission. | | | |
| Canada | CAAIF- Canadian Allergy, Asthma, and Immunology Foundation | Inaugural Gala & Auction: "Building Capacity: Excellence in Research and Education in Allergy, Asthma, and Immunology". | | | |
| Canada | Canadian Fabry Association | Sponsorship - Canadian National Fabry Conference Donation - Patient support grants. | | | |
| Canada | Canadian Hemophilia Society | Support Patient Organization Activities | | | |
| Canada | Canadian Hemophilia Society | Chapter support for Summer Camps and Educational Activities. | | | |
| Canada | Canadian Hemophilia Society | Support Patient Education Activities | | | |
| Canada | Canadian Hemophilia Society | 6th National Family Inhibitor Workshop. | | | |
| Canada | Canadian Hemophilia Society | Comprehensive Standards of Care Program/ Advocacy Workshops. | | | |
| Canada | Canadian National Institute of the Blind (CNIB) | Sponsorship - Vision Health Month Public Education Campaign. | | | |
| Canada | CanLearn | Donation - Support for the organization's mission. | | | |
| Canada | Canadian Immunodeficiencies Patient Organization | Patient Education Days, Support Group Days, World PI Week (WPIW). | | | |



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| Canada | Canadian Immunodeficiency Society | World Primary Immunodeficiency Week 2017. | | | |
| Canada | CORD- Canadian Organization for Rare Disorders | Corporate membership Sponsorship - Annual meeting | | | |
| Canada | Crohn's Colitis Canada (CCC) | Donation - Support for the organization's mission. | | | |
| Canada | GI Society | Donation - Support for the organization's mission. | | | |
| Canada | HAE Canada | Donation - Support for the organization's mission. | | | |
| Canada | iBelieve Foundation | Sponsorship - Rare Disease Evening events. | | | |
| Canada | Immunodeficiency Canada | Corporate Partnership - Builders Level. | | | |
| Canada | Isaac Foundation | Sponsorship - Annual event. | | | |
| Canada | MPS Society | Donation - Support for the organization's mission. | | | |
| Canada | National Gaucher Foundation | Donation - Regional patient meetings and patient support program. | | | |
| Canada | NEDIC-National Eating Disorder Information Centre | Sponsorship - A Taste for Life Donation - Support for the organization's mission | | | |
| Canada | NIED-National Initiative for Eating Disorders | Donation - Support for the organization's mission. | | | |
| Canada | Rare Disease Foundation | Sponsorship - Rare Disease Day. | | | |
| Canada | RQMO- Regroupement Quebecois Des Maladies Orphelines | Donation - Support for the organization's mission. | | | |
| Canada | Sheena's Place | Sponsorship - Annual event. | | | |
| Canada Total: | | | | CAD | 908,500.00 |
| Colombia | Asociación de Pacientes con Enfermedades de genéticas de baja ocurrencia. APEGO | Support people with genetic diseases. | 20,000,000.00 | COP | |



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| Colombia | BioVital Foundation of Hemophilia | Educational Journey for Patients About Joint Health | 1,500,000.00 | COP | |
| Colombia | BioVital Foundation of Hemophilia | Educational Journey for Patients about Joint Health. | 23,596,043.00 | COP | |
| Colombia | Colsubsidio | Patient Education Event. | 3,867,604.00 | COP | |
| Colombia | FAHES COLOMBIA FOUNDATION | Support Program: "SABER SANA". | 16,000,000.00 | COP | |
| Colombia | FIP Foundation (Fundación Diana García de Olarte para las Inmunodeficiencias Primarias) | Event: FIP Foundation- "10 Years Cultivating Love for Life". | 7,000,000.00 | COP | |
| Colombia | Fundación Amor Activo | Project focused on improving knowledge of rare diseases in children with emphasis on ICBF population - Colombia. | 45,000,000.00 | COP | |
| Colombia | Fundación Amor Activo | Humanitarian product donation, Cartgena | 94,203,800.00 | COP | |
| Colombia | Fundación Amor Activo | Humanitarian product donation, Bogota | 67,020,000.00 | COP | |
| Colombia | Fundacion Bio Vital | Patient Education on Oral Hygiene at Hospital Medellin. | 2,100,000.00 | COP | |
| Colombia | Fundación Social Cuidarte | The project focuses on the active strategy T, which consists of linking patients according to their unsatisfied needs to the state support networks. | 210,320,000.00 | COP | |
| Colombia | Hemophilia League of Antioquia | Multiple Hemophilia Events. | 58,500,000.00 | COP | |
| Colombia | Imbanaco | Support for Patient Education Day. | 1,000,000.00 | COP | |
| Colombia | Organizacion General del Norte | World Hemophilia Day Luncheon. | 2,100,000.00 | COP | |
| Colombia | SOUTHWEST COLOMBIAN HEMOPHILIA FOUNDATION | Multiple Hemophilia Events. | 45,000,000.00 | COP | |
| Colombia Total: | | | | COP | 597,207,447.00 |
| Croatia | Association of Dialysis CH Dubrava | Financial support for International Meeting of transplanted and dialyzed patients | 1,640.00 | HRK | |



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| Croatia | Croatian Alliance for Rare Diseases | Financial support for organizing "International Gaucher Day" at Hotel Terme Tuhelj, Croatia from 1st until 2nd of October 2016. | 22,518.68 | HRK | |
| Croatia | Croatian Alliance for Rare Diseases | Support for Rare Disease Day 2016 meeting | N/A | N/A | |
| Croatia | Croatian Alliance for Rare Diseases | Support for Patient program initiatives of the patient organization | 24,856.04 | HRK | |
| Croatia | Croatian Hemophilia Society | 10th Annual Summer Camp for persons with Hemophilia. | 12,000.00 | EUR | |
| Croatia Total: | | | | EUR | 12,000.00 |
| | | | | HRK | 49,014.72 |
| Czech Republic | Czech Association for Rare Diseases (ČAVO) | Support of the project "Raising awareness and knowledge about rare disease and improving care for RD patients in the Czech Republic in 2016". | 150,000.00 | CZK | |
| Czech Republic | Czech Hemophiliacs Association | 2016 Newsletter & Educational Brochure for Pediatricians. | 101,500.00 | CZK | |
| Czech Republic | Czech Hemophiliacs Association | Educational Meeting & Patient Programs. | 300,000.00 | CZK | |
| Czech Republic | Hemojunior | 2016 Educational Programming. | 27,300.00 | CZK | |
| Czech Republic | Hemojunior | Educational Meeting & Patient Programs. | 330,000.00 | CZK | |
| Czech Republic | Občanské sdružení imunodeficitních pacientů HAE/AAE | Support for Patient Organization Mission | 50,000.00 | CZK | |
| Czech Republic | Sdružení META - sdružení pacientů se střádavými onemocněními, o.s. | Support for Patient Education regarding Fabry Disease | 200,000.00 | CZK | |
| Czech Republic | Společnost pro mukopolysacharidosu | The financial support was used for payment of a part of the expenses necessary to cover the national meeting of families with children suffering with MPS (June 2016). | 150,000.00 | CZK | |
| Czech Republic | Život bez střev | Support the costs of conducting the PACIFHAN Meeting. | 1,256.00 | GBP | |



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| Czech Republic Total: | | | | CZK | 1,308,800.00 |
| | | | | GBP | 1,256.00 |
| Denmark | ADHD-foreningen | Expenses related to producing and printing the invitation, program and compendium for a conference with approx. 450 participants. | 186,756.75 | DKK | |
| Denmark | Danish Bleeding Association | Registration to WFH & Yearly Meeting of DBA. | 210,000.00 | DKK | |
| Denmark | Danish PID Patient Organization | Information Meeting for Adults with PID. | 5,600.00 | DKK | |
| Denmark | Fabry Patientforening Danmark | Support to contribute to the costs of activities of the patient organisation | 45,000.00 | DKK | |
| Denmark | Gaucher Foreningen i Danmark | Funding to support Patient Organization Meeting | 15,000.00 | DKK | |
| Denmark | Gaucher Foreningen i Danmark | Sponsorship of an event to create awareness of the Metabolic Disorders. | 20,000.00 | DKK | |
| Denmark | HAEI-International Patient Organization for C1 Inhibitor Deficiencies | HAEI Donation. | 600,000.00 | DKK | |
| Denmark | Landsforening for Brugere af hjemmeparenteral Ernæ | Support the costs of conducting the PACIFHAN Meeting. | 1,256.00 | GBP | |
| Denmark | Sjaeldne Diagnoser | Annual fee Kontaktudvalg 2016. | 12,500.00 | DKK | |
| Denmark Total: | | | | DKK | 1,094,856.75 |
| | | | | GBP | 1,256.00 |
| Estonia | Estonian Haemophilia Society (EHS) | Hemophilia Patient Summer Seminar. | 5,280.00 | EUR | |
| Estonia Total: | | | | EUR | 5,280.00 |
| Finland | ADHD-liitto ry | Funding to support Patient Organization Event | 350.00 | EUR | |
| Finland | Finnish Hemophilia Society | Hemophilia Day for Patients 2017. | 6,000.00 | EUR | |



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| Finland | SUOMEN HAE-YHDISTRYS RY | Sponsorship of an event to increase awareness of HAE disease. | 3,000.00 | EUR | |
| Finland Total: | | | | EUR | 9,350.00 |
| France | Association Française des Hémophiles (AFH) comité Auvergne | Support to contribute to the costs of activities of the patient organisation | 2,000.00 | EUR | |
| France | Association Française des Hémophiles (AFH) comité Basse Normandie | Support to contribute to the costs of activities of the patient organisation | 5,000.00 | EUR | |
| France | Association Française des Hémophiles (AFH) comité Midi-Pyrénées | Support to contribute to the costs of activities of the patient organisation | 4,000.00 | EUR | |
| France | Association Française des Hémophiles (AFH) comité Paca-Corse | Support to contribute to the costs of activities of the patient organisation | 8,000.00 | EUR | |
| France | Association Française des Hémophiles (AFH) comité Pays Loire Poitou-Charentes | Support to contribute to the costs of activities of the patient organisation | 2,500.00 | EUR | |
| France | Association Française des Hémophiles (AFH) Comité Rhone-Alpes | Support to contribute to the costs of activities of the patient organisation | 1,500.00 | EUR | |
| France | Association Française des Hémophiles (AFH)- Paris | 2016 World Hemophilia Day. | 10,000.00 | EUR | |
| France | Association Française des Hémophiles (AFH) sub-committee, Auvergne | Von Willebrands Workshop: 2016 World Hemophilia Day. | 2,500.00 | EUR | |
| France | Association Française des Hémophiles (AFH), Midi-Pyrenees | Support to contribute patient programs | 4,000.00 | EUR | |



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| France | Alliance Maladies Rare | Support to contribute to the costs of activities of the patient organisation | 50,000.00 | EUR | |
| France | APMF association patient Maladie de Fabry | Support to contribute to the costs of activities of the patient organisation | 30,000.00 | EUR | |
| France | Association de patients : Association pour l'Information et la recherche sur les maladies Rénales Génétiques (AIRG) | Support to contribute to the costs of activities of the patient organisation | 2,500.00 | EUR | |
| France | Eurordis-Rare Diseases Europe | Launch of Rare Disease International Leadership partnership for the EURORDIS Fundraising Awards Evening Ruby Membership in the EURORDIS Round Table of Companies (ERTC) Premium support of ECRD 2016 Edinburgh | 120,000.00 | EUR | |
| France | IRIS-Primitive Immunodeficiency, Research, Information, Support | National Patient survey - PID. | 43,525.00 | EUR | |
| France | IRIS-Primitive Immunodeficiency, Research, Information, Support | Support to contribute to the costs of activities of the patient organisation | 10,000.00 | EUR | |
| France | La Vie par un Fil | Support to contribute to the costs of activities of the patient organisation | 36,000.00 | EUR | |
| France | La Vie par un Fil | Support the costs of conducting the PACIFHAN Meeting. | 1,256.00 | GBP | |
| France | Laurette Fugain | Support to contribute to the costs of activities of the patient organisation | 10,000.00 | EUR | |
| France | Vaincre les Maladies Lysosomales | Support to contribute to the costs of activities of the patient organisation | 30,000.00 | EUR | |



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| France Total: | | | | EUR | 371,525.00 |
| | | | | GBP | 1,256.00 |
| Germany | Allianz Chronischer Seltener Erkrankungen (ACHSE) e.V. | Support to contribute to the costs of activities of the patient organisation | 5,000.00 | EUR | |
| Germany | Care-for-Rare Foundation Stiftung bürgerlichen Rechts | Donation to help become center of excellence at Care-for-Rare Center of Dr. von Hauner'sche Kinderspital. | 45,000.00 | EUR | |
| Germany | Deutsche Gesellschaft für Rehabilitationssport für chronisch Nierenkranke e.V. (ReNi) | Sponsoring the event "8. ReNi-Forum on 17-Apr-2016 in Berlin". | 500.00 | EUR | |
| Germany | Deutsche Hämophiliegesellschaft (DHG) e.V. | Support to contribute to the costs of activities of the patient organisation | 45,000.00 | EUR | |
| Germany | DSAI- German Patient Association (PI) | Corporate Sponsorship 2017. | 40,000.00 | EUR | |
| Germany | DSAI- German Patient Association (PI) | PID Brochure for Patients. | 1,500.00 | EUR | |
| Germany | DSAI- German Patient Association (PI) | Publication support. | 3,500.00 | EUR | |
| Germany | Gaucher Gesellschaft Deutschland e.V. (GGD) | Donation to support objectives of patient organization | 15,000.00 | EUR | |
| Germany | Gesellschaft für Mukopolysaccharidosen e.V. (MPS) | Donation to support objectives of patient organization | 23,300.00 | EUR | |
| Germany | HAE Vereinigung e.V. | Donation to support objectives of patient organization | 15,000.00 | EUR | |
| Germany | Interessengemeinschaft Hämophiler (IGH) | Corporate Sponsorship 2017. | 30,000.00 | EUR | |
| Germany | Interessengemeinschaft Niere - Region Kiel e.V. | Sponsoring the event "17. Kieler Nierenwoche 2016" on 14-17.09.2016 in Kiel. | 1,000.00 | EUR | |



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For the Period: January 1, 2016 through December 31, 2016

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|---------|--|---|------------|----------|-------------------|
| Germany | ITP-Patient Association Gießen | ITP Support Group- 2016 Annual Meeting. | 600.00 | EUR | |
| Germany | Leben mit Hämophilie e.V. | Sponsoring der Informationsveranstaltung der LMH am 08.11.2015 in Münster. | 2,500.00 | EUR | |
| Germany | MedConcept GmbH | Steglitzer Cancer Forum for Affected Persons. | 4,000.00 | EUR | |
| Germany | Morbus Fabry Selbsthilfegruppe e.V. (MFSH) | Donation to support objectives of patient organization | 10,000.00 | EUR | |
| Germany | Morbus Fabry Selbsthilfegruppe e.V. (MFSH) | Basisfinanzierung 2015 (Core Funding for 2015). | 10,000.00 | EUR | |
| Germany | Netzwerk Hypophysen- und Nebennierenerkrankungen e.V. | Sponsoring the event "20. Überregionale Hypophysen- und Nebennierentag in Würzburg, plus 5 bis 6 regionale im ganzen Bundesgebiet". | 5,000.00 | EUR | |
| Germany | Netzwerk Hypophysen- und Nebennierenerkrankungen e.V. | Donation to support objectives of patient organization | 8,000.00 | EUR | |
| Germany | PONTIXX e.V. | Sponsoring the scientific event "ADHS und komorbide Störungen" on 13.03.2016 in Oldenburg. | 2,500.00 | EUR | |
| Germany | Sucht und Prävention e.V. | Sponsoring the scientific event "10. Fachtagung Jugend und Sucht" on 10.03.2016 in Deggendorf. | 700.00 | EUR | |
| Germany | Teb e.V. Selbsthilfe | Sponsoring World Pancreatic Cancer Day (WPCD) am 17.11.2016 in Ludwigsburg. | 10,000.00 | EUR | |
| Germany | Urticaria Network e.V | Donation to support objectives of patient organization | 300,000.00 | EUR | |
| Germany | Verein Freunde und Förderer der Kinderklinik und der Sozialpädiatrie am St. Marien-Hospital e.V. | Donation to support objectives of patient organization | 30,000.00 | EUR | |



Shire Patient Organization Funding
For the Period: January 1, 2016 through December 31, 2016

| Country | Name of Organization | Description of the Activity/Purpose | Amount | Currency | Total per Country |
|-----------------------|---|---|--------------|------------|----------------------|
| Germany Total: | | | | EUR | 608,100.00 |
| Greece | PESPA | World Rare Diseases day activities. | 5,000.00 | EUR | |
| Greece | PESPA | Donation for the creation of patients registry. | 4,000.00 | EUR | |
| Greece | PESPA | Annual Scientific Meeting of PESPA. | 5,000.00 | EUR | |
| Greece | PO Solidarity | Awareness meeting of GD patients- other activities. | 14,000.00 | EUR | |
| Greece Total: | | | | EUR | 28,000.00 |
| Hungary | Foundation for the Prevention of Angioedematous Disease | 10th C1 inhibitor Deficiency Workshop. | 51,000.00 | EUR | |
| Hungary | Foundation for the Prevention of Angioedematous Disease | Donation to support objectives of patient organization | 102,000.00 | EUR | |
| Hungary | FRIENDS OF HEMOPHILIACS (Hemofíliások Baráti Köre) | Support to the educational and rehabilitation camp organized for the hemophilic patients in 2016. | 5,000,000.00 | HUF | |
| Hungary | FRIENDS OF HEMOPHILIACS (Hemofíliások Baráti Köre) | Support to the educational and rehabilitation camp organized for the hemophilic patients in 2017. | 6,000,000.00 | HUF | |
| Hungary | Hungarian Haemophilia Society (Magyar Hemofília Egyesület) | Financial support for the rehabilitative summer camp of haemophilic children in 2016. | 2,000,000.00 | HUF | |
| Hungary | Hungarian Haemophilia Society (Magyar Hemofília Egyesület) | Financial support to organize the rehabilitation camp for haemophilic children in 2017. | 2,000,000.00 | HUF | |
| Hungary Total: | | | | EUR | 153,000.00 |
| | | | | HUF | 15,000,000.00 |
| Ireland | Epilepsy Ireland | Fund educational meetings organised by Epilepsy Ireland. | 16,800.00 | EUR | |



Shire Patient Organization Funding
For the Period: January 1, 2016 through December 31, 2016

| Country | Name of Organization | Description of the Activity/Purpose | Amount | Currency | Total per Country |
|-----------------------|---|---|-----------|------------|-------------------|
| Ireland | Irish Haemophilia Society | Healthcare Education Grant Sponsorship of accommodation only for Irish Haemophilia Society Staff at WFH, Orlando Florida 24th-28th July 2016 | 6,090.00 | EUR | |
| Ireland | Irish Platform for Patient Organisations, Science & Industry (IPPOSI) | Educational funding for IPPOSI. | 450.00 | EUR | |
| Ireland | Irish Platform for Patient Organisations, Science & Industry (IPPOSI) | Annual membership fee. | 7,500.00 | EUR | |
| Ireland | Irish Society for Mucopolysaccharide Diseases | Fund educational meetings for patients and families with MPS diseases organised Irish MPS society. | 2,000.00 | EUR | |
| Ireland | HADD Ireland, for people affected by ADHD | Funding to support patient support programs | 10,000.00 | EUR | |
| Ireland Total: | | | | EUR | 42,840.00 |
| Italy | A.E.L. Associazione degli Emofilici del Lazio - ONLUS | Funding to support patient support programs | 7,000.00 | EUR | |
| Italy | A.I.A.F. - Associazione Italiana Anderson Fabry | Activities aimed at supporting and protecting the patients of Anderson-Fabry Disease. | 20,000.00 | EUR | |
| Italy | AICE- Associazione Italiana Centri Emofilia | 2016 Annual Contribution. | 8,000.00 | EUR | |
| Italy | Aip -Associazione Immunodeficienze Primitive Onlus | Support to social assistance and social health; Support Health care; Scientific research | 60,000.00 | EUR | |
| Italy | APPI Associazione Per Pazienti con Ipoparatiroidismo | Funding to support patient educational programs | 15,000.00 | EUR | |
| Italy | Ass.Bambini E Giovani Con Emofilia Onlus | Support the scientific research , promote events for families living with the disease. | 2,500.00 | EUR | |



Shire Patient Organization Funding
For the Period: January 1, 2016 through December 31, 2016

| Country | Name of Organization | Description of the Activity/Purpose | Amount | Currency | Total per Country |
|---------------------|---|--|--------------|------------|-------------------|
| Italy | Associazine UN FILO PER LA VITA ONLUS | Donation to support objectives of patient organization | 15,000.00 | EUR | |
| Italy | Associazione (onlus) emofilici e talassemici vincenzo russo serdoz | Supports the activities and initiatives between patients and doctors who deal with hemophilia and thalassemia. | 25,000.00 | EUR | |
| Italy | ASSOCIAZIONE ITALIANA GAUCHER - Onlus | Support the organization of conference for parents- Patients. | 20,000.00 | EUR | |
| Italy | Associazione Italiana Mucopolisaccaridosi e Malattie Affini - ONLUS | Funding to support patient educational programs | 15,000.00 | EUR | |
| Italy | CIDP Italy Onlus | Funding to support patient educational programs | 41,000.00 | EUR | |
| Italy | Fedemo-Federazione delle Associazioni Emofilici | Support to the XII Global Day of Hemophilia. | 7,500.00 | EUR | |
| Italy | Fondation Paracelso | "Disease: Transform it into Energy" (Malattia- Trasformiamola in Energia). | 7,000.00 | EUR | |
| Italy | Italian Association for Primary Immunodeficiency (AIP) | WPIW Awareness Campaign 2016. | 60,000.00 | EUR | |
| Italy | Italy Rare Cancers Europe | Bronze Industry Support | 5,000.00 | EUR | |
| Italy | Un Filo per la Vita | Support the costs of conducting the PACIFHAN Meeting. | 1,256.00 | GBP | |
| Italy Total: | | | | EUR | 308,000.00 |
| | | | | GBP | 1,256.00 |
| Japan | Assoc of GD patients in Japan | Support event organized by patient organization | 1,200,000.00 | Yen (¥) | |
| Japan | Biwa Lake Family Respite | Support for patient organization activities | 100,000.00 | Yen (¥) | |
| Japan | CREATE | Support for patient organization activities | 1,000,000.00 | Yen (¥) | |
| Japan | Fabry Disease Patients Ass. | Support for patient organization activities | 500,000.00 | Yen (¥) | |
| Japan | Fabry NEXT | Support for patient organization activities | 400,000.00 | Yen (¥) | |



Shire Patient Organization Funding
For the Period: January 1, 2016 through December 31, 2016

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|----------------------|--|---|--------------|----------------|----------------------|
| Japan | Friends of Hematology National Network | Support for patient organization activities | 1,000,000.00 | Yen (¥) | |
| Japan | Japan Society of Hematology | Support for patient organization activities | 3,000,000.00 | Yen (¥) | |
| Japan | Japan Society of Inherited Metabolic Diseases | Donation in support of statutory activities. | 400,000.00 | Yen (¥) | |
| Japan | Kumamoto prefecture | Humanitarian Aid | 227,000.00 | Yen (¥) | |
| Japan | MPN Japan | Support for patient organization activities | 600,000.00 | Yen (¥) | |
| Japan | Short bowel syndrome alliance | Support for patient organization activities | 1,000,000.00 | Yen (¥) | |
| Japan | Solaputi Kids' Camp | Support for patient organization activities | 145,278.00 | Yen (¥) | |
| Japan | The 6th Int. Collaborative Forum of Human Gene Therapy for Genetic Disease | Support for patient organization activities | 500,000.00 | Yen (¥) | |
| Japan | Tokyo Medical University | Support for centennial commemoration project. | 1,000,000.00 | Yen (¥) | |
| Japan Total: | | | | Yen (¥) | 11,072,278.00 |
| Latvia | Latvia Hemophilia Society | World Hemophilia Day Activities: Patient Conference & Patient Survey. | 2,880.00 | EUR | |
| Latvia | Latvia Hemophilia Society | Support to attend WFH 2016. | 735.00 | EUR | |
| Latvia | Latvia Hemophilia Society | Annual Educational Meeting. | 2,645.00 | EUR | |
| Latvia | Society for Genetic hereditary diseases patients & peers Saknes | Support for patient organization activities | 10,000.00 | EUR | |
| Latvia Total: | | | | EUR | 16,260.00 |
| Lithuania | Lithuania People with Hemophilia Association | Support for Educational and Sport Camp. | 5,116.75 | EUR | |
| Lithuania | Lithuania People with Hemophilia Association | Support for EHC Annual Conference | 1,156.50 | EUR | |
| Lithuania | Lithuania People with Hemophilia Association | Patient Education Seminar. | 7,105.00 | EUR | |



Shire Patient Organization Funding
For the Period: January 1, 2016 through December 31, 2016

| Country | Name of Organization | Description of the Activity/Purpose | Amount | Currency | Total per Country |
|-------------------------|--|---|------------|---------------|-------------------|
| Lithuania Total: | | | | EUR | 13,378.25 |
| Mexico | Asociación Mexicana de Atención de las Enfermedades Raras A.C. | Activities for the disease awareness. | 700,000.00 | Mexican pesos | |
| Mexico | Asociación Mexicana de Atención de las Enfermedades Raras A.C. | Patient support activities | 110,000.00 | Mexican pesos | |
| Mexico | Asociación Mexicana de Atención de las Enfermedades Raras A.C. | Support for Disease awareness programs | 600,000.00 | Mexican pesos | |
| Mexico | Colegio Mexicano de Inmunología Clínica y Alergia A.C. | Legislative Forum for Hereditary Angioedema. | 60,000.00 | Mexican pesos | |
| Mexico | Grupo Fabry de México I.A.P. | Support for Disease awareness programs | 800,000.00 | Mexican pesos | |
| Mexico | Grupo Fabry de México I.A.P. | Support for Disease awareness programs | 600,000.00 | Mexican pesos | |
| Mexico | Grupo Fabry de México I.A.P. | Support for Disease awareness programs | 250,000.00 | Mexican pesos | |
| Mexico | MPS JAJAX A.C.-Enfermedades Lisosomales | Support for Physician & Public health programs | 350,000.00 | Mexican pesos | |
| Mexico | MPS JAJAX A.C.-Enfermedades Lisosomales | MPS Day celebration. | 50,000.00 | Mexican pesos | |
| Mexico | Palito y Toto Piden un Deseo A.C. | Support for Physician & Public health programs | 500,000.00 | Mexican pesos | |
| Mexico | Palito y Toto Piden un Deseo A.C. | Legislative activities with health authorities, Physicians and patients. | 306,704.65 | Mexican pesos | |
| Mexico | Palito y Toto Piden un Deseo A.C. | Hereditary Angioedema awareness, communication with HAE global NGO's and patients activities. | 92,300.00 | Mexican pesos | |



Shire Patient Organization Funding
For the Period: January 1, 2016 through December 31, 2016

| Country | Name of Organization | Description of the Activity/Purpose | Amount | Currency | Total per Country |
|---------------------------|---|--|-----------|----------------------|---------------------|
| Mexico Total: | | | | Mexican pesos | 4,419,004.65 |
| Netherlands | Fsign-Fabry Support and Information Group | Sponsorship Lustrum 2016. | 5,500.00 | EUR | |
| Netherlands | HAEI-International Patient Organization for C1 Inhibitor Deficiencies | Sponsorship meeting + newsletter. | 1,302.00 | EUR | |
| Netherlands | MetaKids | Sponsorship digital environment (Website). | 10,000.00 | EUR | |
| Netherlands | Nederlands Vereniging voor Hemofilie Patienten | Sponsoring Jong Adult weekend. | 7,500.00 | EUR | |
| Netherlands | SAS- Dutch PID Organization | WPIW Awareness Activities. | 6,000.00 | EUR | |
| Netherlands | Spierziekten Nederland | Sponsoring Symposium and 2 video's to increase awareness around GBS and CIDP. | 5,300.00 | EUR | |
| Netherlands | Stichting het Hunter Syndroom | Sponsorship patient day. | 750.00 | EUR | |
| Netherlands | Stichting voor afweerstoornissen | Sponsoring for activities during World PI week. | 6,000.00 | EUR | |
| Netherlands | VKS-Volwassenen, Kinderen en Stofwisselingsziekten | Support for patient organization activities | 10,000.00 | EUR | |
| Netherlands Total: | | | | EUR | 52,352.00 |
| Norway | NORILCO | Publication support. | 14,300.00 | NOK | |
| Norway | FBIN-Foreningen for blødere i Norge | Support for Educational meeting | 55,000.00 | NOK | |
| Norway | FBIN-Foreningen for blødere i Norge | Support for Educational meeting | 8,000.00 | SEK | |
| Norway | Nordic hypoPARA Organisation | Sponsorship to contribute to the costs of translation, design and printing of a patient leaflet on Hypopara. | 32,800.00 | NOK | |
| Norway Total: | | | | NOK | 102,100.00 |
| | | | | SEK | 8,000.00 |



Shire Patient Organization Funding
For the Period: January 1, 2016 through December 31, 2016

| Country | Name of Organization | Description of the Activity/Purpose | Amount | Currency | Total per Country |
|---------|--|---|-----------|----------|-------------------|
| Poland | Fudacja "Parent Project Muscular Dystrophy" | Financial support for the organisation of the conference on rare diseases "Rare diseases around us" for HCPs and patients. | 16,000.00 | PLN | |
| Poland | Fundacja Watch Health Care | Funding to help organize "Rare and ultrarare diseases - access to treatment", a medical and scientific event in Insytut Biocybernetyki i Inżynierii Biomedycznej in Warsaw on 22 March 2016 | 12,300.00 | PLN | |
| Poland | Immunoprotect Society | Support for the Regional patients educational workshops in order to increase knowledge on Primary Immunodeficiency in March 12, 2016. | 1,000.00 | PLN | |
| Poland | Polskie Stowarzyszenie Pomocy Chorym z obrzękiem Naczynioruchowym PIĘKNIE PUCHNĘ | Support of regional meeting of the association combined with self-injection training for HAE patients and their cares organized by the Polish Association of Angioedema Patient's Aid. | 5,289.00 | PLN | |
| Poland | Polskie Stowarzyszenie Pomocy Chorym z obrzękiem Naczynioruchowym PIĘKNIE PUCHNĘ | Financial support for educational conference for HAE patients and HCPs | 24,600.00 | PLN | |
| Poland | Potrąfię Pomóc Sp. z o. o. | Financial support for Inherited metabolic diseases educational event | 4,059.00 | PLN | |
| Poland | Stowarzyszenie Apetyt na Życie | Support the costs of conducting the PACIFHAN Meeting. | 1,256.00 | GBP | |
| Poland | Stowarzyszenie Chorych na(MPS) Mukopolisacharydozę i Choroby Rzadkie | Financial support for Rare Disease educational event | 30,000.00 | EUR | |



Shire Patient Organization Funding
For the Period: January 1, 2016 through December 31, 2016

| Country | Name of Organization | Description of the Activity/Purpose | Amount | Currency | Total per Country |
|----------------------|---|--|-----------|------------|-------------------|
| Poland | Stowarzyszenie Chorych na(MPS) Mukopolisacharydozę i Choroby Rzadkie | Financial support for Rare Disease educational event | 38,385.00 | PLN | |
| Poland | Stowarzyszenie Pomocy Chorym z Obrzekiem | Support of regional meeting of the association combined with self-injection training for HAE patients and their cares organized by the Polish Association of Angioedema Patient's Aid. | 10,578.00 | PLN | |
| Poland | Stowarzyszenie Pacjentów Leczonych Żywieniowo Apetyt na Życie | Financial support for educational event on Short Bowel Syndrome issues and on Parenteral Nutrition. | 25,000.00 | PLN | |
| Poland Total: | | | | EUR | 30,000.00 |
| | | | | PLN | 137,211.00 |
| | | | | GBP | 1,256.00 |
| Portugal | Aliança Port.Assoc.Doen. Raras | Support for patient organization activities | 1,500.00 | EUR | |
| Portugal | APH - Associação Portuguesa de Hemofilia e de outras Coagulopatias Congénitas | Support for patient organization activities | 19,260.00 | EUR | |
| Portugal | APOFEN-ASSOCIAÇÃO PORTUGUESA DA FENILCETONÚRIA E OUTRAS DOENÇAS METABÓLICAS | Support for patient organization activities | 2,000.00 | EUR | |
| Portugal | Fedra-Federação das Doenças Raras de Portugal | Support for patient organization activities | 7,000.00 | EUR | |
| Portugal | Raríssimas- Portuguese National Association for Rare and Mental Disorders | Support for patient organization activities | 10,000.00 | EUR | |



Shire Patient Organization Funding
For the Period: January 1, 2016 through December 31, 2016

| Country | Name of Organization | Description of the Activity/Purpose | Amount | Currency | Total per Country |
|------------------------|---|---|--------------|------------|-------------------|
| Portugal | Raríssimas- Portuguese National Association for Rare and Mental Disorders | Support for patient organization event | 2,752.94 | EUR | |
| Portugal Total: | | | | EUR | 42,512.94 |
| Romania | National Alliance for Rare Diseases | Support for patient organization event | 2,400.00 | EUR | |
| Romania | National Alliance for Rare Diseases | Financial support for hemophilia educational event to increase the awareness for rare hemophilia. | 17,810.40 | RON | |
| Romania | National Alliance for Rare Diseases | Support for educational event focused on raising awareness for rare disease for patients | 8,989.80 | RON | |
| Romania | National Alliance for Rare Diseases | Support for educational event focused on raising awareness for rare disease for patients | 10,836.61 | RON | |
| Romania | National Association of Hemophilia Patients | Support for organizing the National Hemophilia Day | 26,800.80 | RON | |
| Romania | National Association of Hemophilia Patients | Support for educational event focused on raising awareness for Hemophilia for patients | 53,601.60 | RON | |
| Romania | Romanian Association for Children with Cancer | Support for organizing the Medical Conference Pediatric Hemophilia | 6,700.20 | RON | |
| Romania | Romanian Association of Hematology | Support for organizing the "Summer School for Resident Physicians" | 4,460.00 | RON | |
| Romania | Romanian Association of Pediatric Surgery | Support for organizing the 8th National Pediatric Surgery Congress | 4,466.80 | RON | |
| Romania | THE ASSOCIATION "ASOCIATIA PENTRU PROMOVAREA ECONOMIEI CUNOASTERII" | Support for the costs of publication of a medical student handbook | 16,202.52 | RON | |
| Romania Total: | | | | RON | 149,868.73 |
| Romania Total: | | | | EUR | 2,400.00 |
| Russia | All Russian Hemophilia Society | Support for organizing Patient Education Days (Schools). | 2,800,000.00 | RUB | |



Shire Patient Organization Funding
For the Period: January 1, 2016 through December 31, 2016

| Country | Name of Organization | Description of the Activity/Purpose | Amount | Currency | Total per Country |
|---------|--|--|--------------|----------|-------------------|
| Russia | All-Russian Society of Hemophilia | Support for Information Programs of the Patient Organization | 565,000.00 | RUB | |
| Russia | All-Russian Society of Hemophilia | Support for Programs of the Patient Organization | 384,000.00 | RUB | |
| Russia | Autonomic Non-commercial Organization Center for Patients' Support "Genome" | Support for Regional RD Patient support and Regular Regional RD Patient events | 500,000.00 | RUB | |
| Russia | Autonomic Non-commercial Organization Helping Patients with Short Bowel Syndrome and Metabolic Disorders "Wind of Hope" | Support for Programs and Activities of the Foundation | 100,000.00 | RUB | |
| Russia | Komi Regional non-profit children charity foundation "Power Of Good" | Support for Programs and Activities of the Patient Organization | 500,000.00 | RUB | |
| Russia | Multi-Regional Charity Public Organization "Hunter Syndrome" | Support for Programs and Activities of the Patient Organization | 7,700,000.00 | RUB | |
| Russia | Multi-Regional Public Organization "Patients' community with Hereditary Angioedema" | Support for Programs and Activities of the Patient Organization | 1,170,000.00 | RUB | |
| Russia | Multi-Regional Public Organization "Support for disabled patients since childhood, suffering from Gaucher disease, and their families" | Support for Regional patient events, Gaucher Information Service, Gaucher Patients day | 1,036,396.40 | RUB | |



Shire Patient Organization Funding
For the Period: January 1, 2016 through December 31, 2016

| Country | Name of Organization | Description of the Activity/Purpose | Amount | Currency | Total per Country |
|----------------------|--|--|--------------|------------|----------------------|
| Russia | Multi-Regional Public Organization "Trust" (Patients with inflammatory bowel disease) | Support for Programs and Activities of the Patient Organization | 860,000.00 | RUB | |
| Russia | Multi-Regional Public Organization "Union of Patients and Patient's Organizations With Rare Diseases" | Support for Fabry/Gaucher diseases working group creation and support, Patients support, Regular Fabry/Gaucher events for HCPs and Patients, publications and Expert advisory boards | 7,715,000.00 | RUB | |
| Russia | Multi-Regional Public Organization for Fabry Disease and other RD patients "Road to life" | Support for Rare disease dedicated events, Web site design and support and Patient support activities | 1,310,000.00 | RUB | |
| Russia | Regional Charity Public Organization "Hunter Syndrome" (Patients with Hunter Syndrome, other types of MPS and other rare genetic diseases) | Support for patient events and Patient support activities | 100,000.00 | RUB | |
| Russia Total: | | | | RUB | 24,740,396.40 |
| Serbia | National Organization for Rare Diseases of Serbia (local name: Nacionalna organizacija za retke bolesti Srbije - NORBS) | Financial support for "Help line for rare diseases" to improve patient access to services | 1,710,186.98 | RSD | |
| Serbia | Serbian Hemophilia Society | Donation for organization of Summer Hemophilia camp. | 646.43 | EUR | |
| Serbia | Serbian Hemophilia Society | Donation for organization of Youth Hemophilia camp. | 3,200.00 | EUR | |
| Serbia Total: | | | | EUR | 3,846.43 |



Shire Patient Organization Funding
For the Period: January 1, 2016 through December 31, 2016

| Country | Name of Organization | Description of the Activity/Purpose | Amount | Currency | Total per Country |
|------------------------|---|--|-----------|------------|-------------------|
| | | | | RSD | 1,710,186.98 |
| Slovakia | Association for Patients with Primary Immunodeficiency | Donation to support multiple patient organization programs. | 7,500.00 | EUR | |
| Slovakia | NPO- Association for Patients with Primary Immune Deficiency | Donation to support multiple patient organization programs. | 6,800.00 | EUR | |
| Slovakia | Slovak Hemophilia Society | Support for organizing Autumn Meeting with Specialists, Autumn Intensive Rehabilitation-Reconditioning Stay for Adult Haemophiliacs | 7,280.00 | EUR | |
| Slovakia | Slovak Hemophilia Society | Support for organizing educational conference for patients | 9,344.72 | EUR | |
| Slovakia | Slovak Hemophilia Society | Support for organizing educational events for children and adult hemophiliacs and their family members: understanding of disease, modern way of treatment. | 5,000.00 | EUR | |
| Slovakia Total: | | | | EUR | 35,924.72 |
| Slovenia | Association for patients with blood diseases | Donation for organization of educational meeting for patients and their families, as well as for preparation and publication of guide for patients. | 2,000.00 | EUR | |
| Slovenia | Slovenian Hematology Society | Donation for organization of professional meeting for doctors of all specialties, nurses and healthcare professionals, pharmacists and hemophiliacs from the region, as well as for production of educational video animation. | 10,000.00 | EUR | |
| Slovenia Total: | | | | EUR | 12,000.00 |
| Spain | Ashemadrid- Asociacion de hemofilia de la Comunidad de Madrid | Support for organizing educational summer camp for children | 6,700.00 | EUR | |
| Spain | Asociación Asperger de Ibiza y Formentera | Sponsorship "Workdays 2016 Association Asperger Ibiza". | 431.82 | EUR | |
| Spain | Asociación D'GENES | Sponsorship for Congress D'GENES 2016 round table. | 4,000.00 | EUR | |



Shire Patient Organization Funding
For the Period: January 1, 2016 through December 31, 2016

| Country | Name of Organization | Description of the Activity/Purpose | Amount | Currency | Total per Country |
|---------|---|--|-----------|----------|-------------------|
| Spain | Asociación de Ayuda al Déficit de Atención con más o menos Hiperactividad (ADAHI) | Shire Scholarship "Active in TDAH". | 6,000.00 | EUR | |
| Spain | Asociación de Enfermos y Familiares de la Enfermedad de Gaucher (AEEFEG) | Support for updating the website. | 3,000.00 | EUR | |
| Spain | Asociación de Enfermos y Familiares de la Enfermedad de Gaucher (AEEFEG) | Sponsorship for the organization and logistics of the XVIII National Meeting of the Association. | 15,000.00 | EUR | |
| Spain | Asociación de Enfermos y Familiares de la Enfermedad de Gaucher (AEEFEG) | Non-financial support agency communication in association's events (donation of time). | N/A | N/A | |
| Spain | Asociación de la Mucopolisacaridosis y síndromes relacionados (MPS) | Sponsorship for XI International Scientific-Family Congress MPS Spain. | 5,000.00 | EUR | |
| Spain | Asociación de la Mucopolisacaridosis y síndromes relacionados (MPS) | Sponsorship and assistance of activities during 2016 on Fabry disease. | 20,000.00 | EUR | |
| Spain | Asociación de la Mucopolisacaridosis y síndromes relacionados (MPS) | Support for patient organization organized events | N/A | N/A | |
| Spain | Asociación Española de Angioedema Familiar (AEDAF) | Donation for activities related to the World Day of Hereditary Angioedema in 2016. | 6,000.00 | EUR | |



Shire Patient Organization Funding
For the Period: January 1, 2016 through December 31, 2016

| Country | Name of Organization | Description of the Activity/Purpose | Amount | Currency | Total per Country |
|---------|--|--|-----------|----------|-------------------|
| Spain | Asociación Española de Angioedema Familiar (AEDAF) | Support for patient organization organized events - "Patient School". | 6,000.00 | EUR | |
| Spain | Asociación Española de Angioedema Familiar (AEDAF) | Sponsorship of the HAE Global Conference (Madrid, 19-22 May 2016). | 1,000.00 | EUR | |
| Spain | Asociación Española de Angioedema Familiar (AEDAF) | Support for patient organization organized events | N/A | N/A | |
| Spain | Asociación fallo intestinal (NUPA) | Donation beneficial calendar 2016. | 500.00 | EUR | |
| Spain | Asociación fallo intestinal (NUPA) | Donation Campaign support and visibility in adult patients. | 10,000.00 | EUR | |
| Spain | Asociación fallo intestinal (NUPA) | Donation NUPA Awareness Campaigns. | 15,000.00 | EUR | |
| Spain | Asociación fallo intestinal (NUPA) | Non-financial support agency communication in association's events (donation of time). | N/A | N/A | |
| Spain | Federación Española de Asociaciones de Ayuda al Déficit de Atención e Hiperactividad (FEAADAH) | Donation IV National Meeting of Associations of Aid to TDAH. | 6,000.00 | EUR | |
| Spain | Federación Española de Enfermedades Raras (FEDER) | Donation for publication of the final report of the AcogER project. | 1,536.00 | EUR | |
| Spain | Federación Española de Enfermedades Raras (FEDER) | Sponsorship for VII Race for Hope. | 7,000.00 | EUR | |
| Spain | Federación Española de Enfermedades Raras (FEDER) | Donation for the realization of the project "World Day of Rare Diseases" 2016. | 10,000.00 | EUR | |



Shire Patient Organization Funding
For the Period: January 1, 2016 through December 31, 2016

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|---------------------|---|--|-----------|------------|-------------------|
| Spain | Federación Española de Enfermedades Raras (FEDER) | Non-financial support agency communication in association's events (donation of time). | N/A | N/A | |
| Spain | FEDHEMO-Federación Española de Hemofilia | Educational Talks: Inhibitors in Children. | 50,000.00 | EUR | |
| Spain | Fundación privada ADANA | Sponsorship for XIII workdays of Adana Foundation "TDA, beyond childhood". | 2,000.00 | EUR | |
| Spain | Fundación privada ADANA | Sponsorship for XIV workdays of ADANA Foundation Conference. | 2,000.00 | EUR | |
| Spain | Galacian Association of Hemophilia | Briefings for People with Hemophilia. | 12,399.45 | EUR | |
| Spain | GEPAC-El Grupo Español de Pacientes con Cáncer | Informative Guide on Pancreatic Cancer. | 20,000.00 | EUR | |
| Spain | GEPAC-El Grupo Español de Pacientes con Cáncer | World Cancer Day Pancreas. | 3,000.00 | EUR | |
| Spain | GEPAC-El Grupo Español de Pacientes con Cáncer | Informative Guide on ALL. | 5,000.00 | EUR | |
| Spain | Hemophilia Association of the Valencian Community | Awareness and Patient Training Program. | 10,000.00 | EUR | |
| Spain | Hemophilia Patient Association of Balaeres | Patient Education on the Personalization of Hemophilia. | 850.00 | EUR | |
| Spain Total: | | | | EUR | 228,417.27 |
| Sweden | Blodcancerförbundet- Blood cancer PO | Sponsoring of an ALL network meeting. | 60,000.00 | SEK | |
| Sweden | Dravets Syndrome Association Sweden | Sponsorship to cover costs for an educational event on Dravets Syndrome. | 34,250.00 | SEK | |
| Sweden | FBIS-The Swedish Hemophilia Society | Educational material translation. | 47,900.00 | SEK | |
| Sweden | FBIS-The Swedish Hemophilia Society | Educational grant- sponsoring of annual educational meeting. | 40,000.00 | SEK | |



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|----------------------|---|--|------------|------------|-------------------|
| Sweden | FBIS-The Swedish Hemophilia Society | Honorariums/speaker fees during an vWD-education in conjunction with WFH. | 14,700.00 | SEK | |
| Sweden | FBIS-The Swedish Hemophilia Society | Honorariums/speaker fees- Nordic patient organization report/presentation Iceland. | 5,000.00 | SEK | |
| Sweden | FBIS-The Swedish Hemophilia Society | Honorariums/speaker fees- internal education on vWD. | 3,600.00 | SEK | |
| Sweden | PALEMA- Pancreatic cancer PO | Sponsoring of an educational meeting and educational materials. | 67,000.00 | SEK | |
| Sweden | PIO- Swedish Patient Organization for Primary Immunodeficiency | WPIW Education Meeting. | 20,000.00 | SEK | |
| Sweden | Svenska HPN-Föreningen Barn & Ungdom | Support the costs of conducting the PACIFHAN Meeting. | 1,256.00 | GBP | |
| Sweden Total: | | | | GBP | 1,256.00 |
| | | | | SEK | 292,450.00 |
| Switzerland | Fabrysuisse | Donation to support patient organization activities in 2016 | 21,500.00 | CHF | |
| Switzerland | GBS & CIDP Initiative Schweiz | Contribution towards the mail distribution of invitation flyers for the organisation's bi-annual patient meeting (sent to >700 HCPs). | 2,500.00 | CHF | |
| Switzerland | HAEI-International Patient Organization for C1 Inhibitor Deficiencies | National/Regional Access Support Global State of HAE Management Report 2016 HAE Global Conference HAE day Regional Workshops Global Member Organization Advocacy Training | 400,000.00 | USD | |
| Switzerland | HAEI-International Patient Organization for C1 Inhibitor Deficiencies | HAE Global Conference Sponsorship. | 200,000.00 | USD | |



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|---------------------------|---|---|-----------|------------|-------------------|
| Switzerland | International Myelofibrosis Advocates Network | MPN Horizons Meeting 2016, on 28.08.2016 in Belgrade. | 8,813.68 | EUR | |
| Switzerland | Proraris | Donation to support multiple patient organization programs | 10,000.00 | CHF | |
| Switzerland | Schweizerische Hämophilie Gesellschaft (SHG) (Swiss Hemophilia Society) | Sponsorship of Congress Attendance (NHF and WFH, Orlando, USA) | 3,970.00 | CHF | |
| Switzerland | Schweizerische Hämophilie Gesellschaft (SHG) (Swiss Hemophilia Society) | Sponsorship of Congress Attendance (Hamburger Hämophilie Symposion, Hamburg, Germany) | 1,703.00 | CHF | |
| Switzerland | Schweizerische Hämophilie Gesellschaft (SHG) (Swiss Hemophilia Society) | Donation for realization of information materials | 26,000.00 | CHF | |
| Switzerland Total: | | | | CHF | 65,673.00 |
| | | | | EUR | 8,813.68 |
| | | | | USD | 600,000.00 |
| Turkey | MPS TURK | Financial Support for patient Support and Social Media Projects. | 69,129.00 | TRY | |
| Turkey Total: | | | | TRY | 69,129.00 |
| | | Patient organisations: financial support, and significant non-financial support | | | |
| UK | ADHD Foundation | Support for the Immune Deficient Patients' group and running the annual patients' educational evening . | 500.00 | GBP | |
| UK | Adult ADHD NI | To support and provide advocacy for patients affected by Adult ADHD. | 10,000.00 | GBP | |



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|---------|--|---|-----------|----------|-------------------|
| UK | Bile Acid Malabsorption (BAM) Support UK | To provide a forum for patients with BAM to share their experiences and provide support for patients, by the form of written literature and educational talks. | 480.00 | GBP | |
| UK | Crohn's and Colitis UK | To support the extension of their support lines and new patient information packs. | 10,000.00 | GBP | |
| UK | Crohn's and Colitis UK | Provision of Radar Keys for use in the patient information packs (in kind). | 2,000.00 | GBP | |
| UK | Europacoln | To support Expert Patient advisor group meeting which supports us to have discussions with our Medical staff to discuss developments in Pancreatic cancer and metastatic colorectal cancer trials and development and to update needed educational materials for patients | 5,000.00 | EUR | |
| UK | EGA- International Alliance of Patients' Organizations | Core Support for the EGA related to their work programme: Humanitarian aid database Raising awareness and supporting access EGA biennial meeting Advocacy training National websites development EGA code of ethics translation Young Doctors Programme Nueronopathic Gaucher Disease treatment EGA materials International Gaucher Day International Meeting attendance | 49,500.00 | GBP | |
| UK | Fabry International Network (FIN) | Core Support to facilitate collaboration between Fabry Patient Organisations to support those affected by Fabry Disease. | 26,000.00 | GBP | |
| UK | Genetic Alliance UK Ltd | Final Steering Group Consultation | 13,200.00 | GBP | |



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|---------|--|---|-----------|----------|-------------------|
| UK | HAE UK | To support their patient day, updating patient organization website and support other activities of the patient organization | 35,000.00 | GBP | |
| UK | Hypopara UK | To support website development, online forums, telephone helplines and local groups. To support development of leaflets on Hypopara in pregnancy, children with Hypopara, having a parathyroidectomy, the treatment journey and a GP information booklet. | 15,000.00 | GBP | |
| UK | Immune Deficiency Patients Group | Support towards running the annual patients educational evening. | 500.00 | GBP | |
| UK | IPOPI-International Association of Patients with Primary Immune Deficiency | To support the Global Principles of Care Workshop 2016. | 20,000.00 | EUR | |
| UK | IPOPI-International Association of Patients with Primary Immune Deficiency | To support IPOPI EU PID Policy Forum 2016. The grant will be used to cover specialised public affairs consultants support, analysis work and mapping out key treatment issues at national level. | 30,000.00 | EUR | |
| UK | IPOPI-International Association of Patients with Primary Immune Deficiency | To support IPOPI EU PID Policy Forum 2016. The support will be used to cover specialised public affairs consultants support, analysis work and mapping out key treatment issues at national level. | 35,000.00 | EUR | |
| UK | IPOPI-International Association of Patients with Primary Immune Deficiency | To support IPOPI World Primary Immunodeficiencies Week Policy Event. | 40,000.00 | EUR | |
| UK | IPOPI-International Association of Patients with Primary Immune Deficiency | To support the Corporate Partnership Programme. | 65,000.00 | EUR | |



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For the Period: January 1, 2016 through December 31, 2016

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|--|---|---|--|------------|-------------------|
| UK | MPS Society | To provide financial support for the All Ireland Advocacy Support Post. | 15,000.00 | GBP | |
| UK | MPS Society | Funding MPS Conference May 2016. | 8,000.00 | GBP | |
| UK | MPS Society | Funding MPS Symposium Bonn July 2016. | 10,000.00 | GBP | |
| UK | MPS Society | Support for MPS Awareness Day May 2016. | 1,000.00 | GBP | |
| UK | MPS Society | England, Scotland, Wales Advocacy Support Post. | 25,000.00 | GBP | |
| UK | PINNT-Patients On Intravenous & Nasogastric Nutrition Therapy | To carry out survey of their patient membership with Short Bowel Syndrome (SBS) on Home Parenteral Nutrition (HPN). To capture data on a number of issues related to burden of illness, impact of quality of life on patient and family/carers. | 26,000.00 | GBP | |
| UK | PINNT-Patients On Intravenous & Nasogastric Nutrition Therapy | Support the costs of conducting the PACIFHAN Meeting. | 1,256.00 | GBP | |
| UK | Short Bowel Survivor and Friends | Shire Patient Association Development Workshop. | 224.00 | GBP | |
| UK | The Gauchers Association | This project will provide real world data of the impact of Gauchers Disease on patients. This will help to direct how patients are cared for in order to help them to live a life as normal as possible. | 20,000.00 | GBP | |
| UK | The Pituitary Foundation | To support the pituitary foundation helpline operator training. | 3,000.00 | GBP | |
| UK | UK ADHD Partnership (UKAP) | Support the activities of the patient organization | 15,000.00 | GBP | |
| UK | UK Society for Mucopolysaccharide | Wales Information Day MPS. | 2,000.00 | GBP | |
| Subtotal Patient Organization financial support, and significant non-financial support: | | | | GBP | 288,660.00 |
| | | | | EUR | 195,000.00 |
| | | | Patient Organisation Service Payments | | |
| UK | Crohn's and Colitis UK | Speaker Fees. | 83.50 | GBP | |
| Subtotal: | | | | GBP | 83.50 |



Shire Patient Organization Funding
For the Period: January 1, 2016 through December 31, 2016

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|------------------|---|---|----------|------------|-------------------|
| UK | European Gauchers Alliance | Speaker Fees. | 219.10 | GBP | |
| Subtotal: | | | | GBP | 219.10 |
| UK | Haemophilia Society | Speaker Fees. | 1,000.00 | GBP | |
| | | | | GBP | 1,000.00 |
| UK | HAE UK | Speaker Fees: talk on the impact of lack of disease awareness and appropriate services has impacted HAE care. | 180.00 | GBP | |
| UK | HAE UK | Speaker Fees: talk on living with HAE with particular focus on the impact of having an attack on the quality of life. | 70.00 | GBP | |
| Subtotal: | | | | GBP | 250.00 |
| UK | Hypopara UK | Hypopara Patient Speaker for Zug lunch and learn. | 340.00 | GBP | |
| UK | Hypopara UK | Advisory Board Fees | 1,120.00 | | |
| UK | Hypopara UK | Patient Assistance related to Advisory Board | 1,113.61 | | |
| Subtotal: | | | | GBP | 2,573.61 |
| UK | Genetic Alliance UK Ltd | Speaker Fees | 577.20 | GBP | |
| Subtotal: | | | | GBP | 577.20 |
| UK | The Gauchers Association | Shire Patient Association Development Workshop. | 75.00 | GBP | |
| UK | The Gauchers Association | Shire Patient Association Development Workshop. | 58.90 | GBP | |
| Subtotal: | | | | GBP | 133.90 |
| UK | The MPS Society | Support for Pedigree Lunch and Learn event | 200.00 | GBP | |
| Subtotal: | | | | GBP | 200.00 |
| UK | PINNT-Patients On Intravenous & Nasogastric Nutrition Therapy | Advisory Board Fees | 831.83 | GBP | |
| UK | PINNT-Patients On Intravenous & Nasogastric Nutrition Therapy | Speaker Fees | 240.85 | GBP | |
| Subtotal: | | | | GBP | 1,072.68 |



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For the Period: January 1, 2016 through December 31, 2016

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|--|---|--|------------|----------|-------------------|
| Subtotal Patient Organization Services: | | | | GBP | 6,109.99 |
| UK Total: | | | | EUR | 190,000.00 |
| | | | | GBP | 294,769.99 |
| Ukraine | All-Ukrainian public organization "The Union of MPS invalids" | Support for costs related to organizing International MPS Day, designing and printing of booklets on rare diseases, International Conference of rare diseases, Workshop on Treatment and rehabilitation of patients with MPS and PKU for doctors and patients and International Children's Day | 397,255.00 | UAH | |
| Ukraine | Private "Fund mucopolysaccharidosis patients" welfare fund | Promotion, Development and Support of science and research, in particular implementation of disease awareness educational activities about the mucopolysaccharidosis. | 273,697.00 | UAH | |
| Ukraine Total: | | | | UAH | 670,952.00 |