

# European Federation of Pharmaceutical Industries and Associations (EFPIA)

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This document details Baxalta support from July 1<sup>st</sup>, 2015 till December 31, 2015 to EU based patient organizations.

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**AUSTRIA**

<b>Patient organisation:</b>	<b>Business unit:</b>	<b>Amount</b>	<b>Summary of support:</b>
ÖHG - Österreichische Hämophilie Gesellschaft	Hematology	15,000 EURO	Contribution for educational/awareness/community patient events events and handouts.
Österreichische Selbsthilfegruppe für primäre Immundefekte - ÖSPID	Hematology	1,500 EURO	Donation of a video worth 1,500 Euros.
Österreichische Selbsthilfegruppe für primäre Immundefekte - ÖSPID	Hematology	1,000 EURO	Contribution for educational/awareness/community patient events and handouts.

**BELGIUM**

<b>Patient organisation:</b>	<b>Business unit:</b>	<b>Amount</b>	<b>Summary of support:</b>
Belgian Hemophilia Association (AHVH)	Hematology	20,000 EURO	Support of scientific, social and educational initiatives of AHVH focused on Haemophilia disease and community.

**DENMARK**

<b>Patient organisation:</b>	<b>Business unit:</b>	<b>Amount</b>	<b>Summary of support:</b>
Danmarks Bloderforening (The Danish Haemophilia Society)	Hematology	37,197 DKK	Educational meeting for patients and families. The overall topic was telemedicine and was carried out in cooperation with Danish physicians.

**FINLAND**

<b>Patient organisation:</b>	<b>Business unit:</b>	<b>Amount</b>	<b>Summary of support:</b>
Finnish Hemofili society (SHY)	Hematology	848,40 EUR	Educational meeting for patients and their families.

**FRANCE**

<b>Patient organisation:</b>	<b>Business unit:</b>	<b>Amount</b>	<b>Summary of support:</b>
AFH Regional Committee Pays de Loire et Poitou-Charentes - French Hemophilia patient association	Hematology	2,500 EURO	Donation related to the NPONon Profit Organisation status according to communication made regarding Hemophilia, Willebrand disease and other rare bleeding disorders, therapeutic patient education and its management, advocacy for patients, families of patients and their families, valuing scientific medical research.
IRIS (Immuno-Déficienc e Primitive Recherche, Information, Soutien)	Immunology	2,500 EURO	Sponsorship for a PID family day event including educational/ awareness/ community activities Sept 26, 2015 PACA area.

AFH (Association Française des Hémophilies)	Hematology	5,000 EURO	Sponsor AFH 60e anniversary celebration in 3 projects from August 2015 till July 2016:  Monthly posted videos illustrating the history of the Association including interviews and testimonies.  Communication from AFH on different medias: social network, website, Newsletter.
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## GERMANY

Patient organisation:	Business unit:	Amount	Summary of support:
Deutsche Hämophiliegesellschaft (DHG) e.V.	Hematology	30,000 EURO	Contribution for educational/awareness/community patient events and handouts.
Interessengemeinschaft Hämophilier e.V. (IGH)	Hematology	30,000 EURO	Contribution for educational/awareness/community patient events and handouts.
Hämophilie 2000 e.V.	Hematology	2,500 EURO	Sponsorship of a educational/awareness/community patient event.
Leben mit Hämophilie e.V.	Hematology	2,500 EURO	Sponsorship of a educational/awareness/community patient event.
dsai - Patientenorganisation für angeborene Immundefekte	Immunology	10,200 EURO	Sponsorship of educational/awareness/community events.
Kompetenz-Team ITP/Morbus Werlhof	Immunology	1,000 EURO	Sponsorship of congress attendance.

**IRELAND**

<b>Patient organisation:</b>	<b>Business unit:</b>	<b>Amount</b>	<b>Summary of support:</b>
Irish Haemophilia Society	Hematology	12,000 EURO	Patient Organisation Support : Annual Platinum Corporate Sponsorship.
Irish Haemophilia Society	Hematology	1,393 EURO	Personal Contribution (fundraising from charity bike ride): Annual Platinum Corporate Sponsorship.
Irish Cancer Society	Hematology	1,393 EURO	Contribution (fundraising from charity bike ride): Annual Platinum Corporate Sponsorship.



**ITALY**

<b>Patient organisation:</b>	<b>Business unit:</b>	<b>Amount</b>	<b>Summary of support:</b>
Fondazione Emo O.N.L.U.S.	Hematology	5,000 EURO	As per the association statute, contribution to activities including educational, awareness and community event.
AIL (Leukemia, Lymphomas and Myelomas Italian Association)	Hematology	10,000 EURO	As per the association statute, contribution to activities including educational, awareness and community event.
ARCE (Associazione Regionale Campania Emofilia) ONLUS	Hematology	6,000 EURO	As per the association statute, contribution to activities including educational, awareness and community event.
Association A.M.A.R.E Onlus	Hematology	7,000 EURO	As per the association statute, contribution to activities including educational, awareness and community event.
Cultural Association Onlus Giuseppe Dossetti	Hematology	40,000 EURO	Contribution for the organization of 2 events to be held in 2016 to enhance the awareness and attention to Rare Diseases.
Associazione per le Immunodeficienze Primitive- ONLUS	Immunology	40,000 EURO	Contribution for the "IDP network on the territory" set up in 4 Regions; the AIP project aiming to understand the PID real facts across Italy, to create a database of various important local stakeholders, and to map PID diseases as for number of diagnosed patients, time to diagnosis, and type.

**LATVIA**

<b>Patient organisation:</b>	<b>Business unit:</b>	<b>Amount</b>	<b>Summary of support:</b>
Latvia: Latvijas Hemofilijas biedrība (Latvia Hemophilia Society)	Hematology	7,500 EURO	Financial support for Bleeding disorders awareness and monitoring program.

**NORWAY**

<b>Patient organisation:</b>	<b>Business unit:</b>	<b>Amount</b>	<b>Summary of support:</b>
Norwegian Hemofili Society (FBIN)	Hematology	15,800 NOK	Nordic Patient organisation educational meeting.

**PORTUGAL: NO DONATIONS**

**SPAIN**

<b>Patient organisation:</b>	<b>Business unit:</b>	<b>Amount</b>	<b>Summary of support:</b>
Asociación de Hemofilia de la Comunidad Valenciana (ASHECOVA)	Hematology	10,000 EURO	Financial contribution to carry out an integral domiciliary service for patients with hemophilia in the Autonomous Community of Valencia, supporting the project "Homedelivering of medicines 2015".
Federación Española de Hemofilia (FEDHEMO)	Hematology	50,000 EURO	Annual contribution for the Spanish Federation of Hemophilia (FEDHEMO) for the development of different activities and actions which will contribute to the improvement of the quality of life of children and young people with disability for hemophilia or other congenital coagulopathies and to their relatives. These activities will be developed during the year 2015 and have an aim of continuity. Some examples are: formative and informative workshops of the disease and its treatment; training courses in the labor field; training for self-treatment of children with hemophilia; workshop for parents of children in early ages, affected of hemophilia, and workshops for hemophilia carriers, etc.
Asociación Gallega de Hemofilia (AGADHEMO )	Hematology	14,000 EURO	Annual donation for the Galician Association of Hemophilia (AGADHEMO) for the development of the project ' Saluditinere 2015 ' which consists in facilitating the access of patients to the hemo-derivatives products on an easy and quickly way, guaranteeing the improvement of their quality of life.
Hemophilia Association of Guipuzcoa (ASHEGUI)	Hematology	9,000 EURO	Annual donation, during the year 2015, to give support to the 'Hemophilia Association of Guipuzcoa' (ASHEGUI) for helping and support people affected of hemophilia, Von Willebrand and other congenital coagulopathies and to their relatives, focused on the project 'Psico-pedagogic Service', which main aim is to

			give response to the bio-psico-social needs of the members of the association.
Asociación Malagueña de Hemofilia	Hematology	15,000 EURO	Grant to support two projects of this Patient Association: 'III Convivencia Autotrataamiento (3rd Meeting for self-treatment) & VIII Jornadas de formación en Hemofilia (8th Training session in Hemophilia).
AHEMADRID - Asociación de Hemofilia de la Comunidad de Madrid	Hematology	6,726.85 EURO	Economical Contribution to support the project of the association proyecto "VIII taller para familias con niños recién diagnosticados de hemofilia" (Workshop for parents with children recently diagnosed with Hemophilia).
Grupo Español de Pacientes con Cáncer - GEPAC	Oncology	5,500 EURO	Co-Sponsorship of the World Pancreatic Cancer Day.

## SWEDEN

Patient organisation:	Business unit:	Amount	Summary of support:
Swedish Hemofili society (FBIS)	Hematology	50,000 SEK	Twin-project meeting between Nepal hemophilia Society and Swedish hemophilia Society.
Swedish Hemofili society (FBIS)	Hematology	50,000 SEK	Family conference for patients with inhibitors.

## SWITZERLAND

Patient organisation:	Business unit:	Amount	Summary of support:
GBS & CIDP Initiative	Immunology	75,000 EURO	Contribution for educational/awareness/community patient events and handouts.
IPOPI	Immunology	20,000 EURO	Financial support to develop a PI Principles of Care Implementation Package.
IPOPI	Immunology	75,000 EURO	Financial support to two projects: (1) the IPOPI Patient Information Materials Project and (2) the IPOPI Patient Testimonials Project ("Activity).
IPOPI	Immunology	95,000 EURO	IPOPI Core Sponsorship Platinum Level and IPOPI TV Channel sponsorship.
EHC – European Haemophilia Consortium	Hematology	137,500 EURO	Financial support to following projects: -Membership of the Corporate Giving Program at Platinum level -Support of the Round Tables of Stakeholders at Gold level -Support of the Youth Leadership Workshop at co-sponsorship level - Support of the New Technologies Workshop at co-sponsorship level -Support of the Leadership Conference pilot as one of three sponsors EHC is involved in and responsible for EHC education & advocacy programmes for its member organisations, and EHC shall use the grant applied for as part of these ongoing efforts encapsulated in the different projects detailed.
EHC – European Haemophilia Consortium	Hematology	295,100 USD	Financial support for following projects: The EIN programme which has four primary objectives: •To nurture the creation of a community for PWI under the auspices of the EHC that enables often isolated PWI and their caregivers to find a natural 'home' in the wider haemophilia space by building connections with those who face similar challenges and circumstances; •To build and maintain a social

			network for PWI to allow direct, peer-to-peer communication in person and online in order to address and focus on key issues that are specific to this community; <ul style="list-style-type: none"> <li>•To work at European level together with other partners (e.g. EAHAD) to develop consensus standards for the treatment and care for PWI; and</li> <li>•To identify and develop specific advocacy tools, materials, strategies and programmes to best represent the needs of PWI to payers, policymakers and other authorities.</li> </ul>
Schweizer Hämophilie-Gesellschaft	Hematology	21,000 EUROS	As per the association status, contribution for educational/awareness/community patient events.
Schweizer Hämophilie-Gesellschaft	Hematology	14,215 EUROS	Product donation.
EuropaColon	Oncology	9,500 EURO	Financial support for meeting in Prague on the 21st April 2015 which aimed at helping educating EuropaColon's patient advocates to understand the issues for patients with pancreatic cancer and to help them expand into offering support for these patients. Meeting includes an in-depth discussion of the current knowledge of the causes, diagnosis and treatment of the cancer and some of the psycho-social issues patients with pancreatic cancer and their families face post diagnosis.

## THE NETHERLANDS

<b>Patient organisation:</b>	<b>Business unit:</b>	<b>Amount</b>	<b>Summary of support:</b>
Dutch Society of Haemophilia Patients	Hematology	14,750 EURO	Support of scientific, social and educational initiatives of Dutch Society of Haemophilia Patients focused on Haemophilia disease and community.
Stichting voor afweerstoornissen (SAS)	Immunology	5,000 EURO	Support for awareness campaign "altijdziek".
Vereniging Spierziekten Nederland (VSN)	Immunology	1,500 EURO	Support information film Guillain Barré and Strohl.

UK

Patient organisation:	Business unit:	Amount	Summary of support:
Haemophilia Society	Hematology	22,400 GBP	Haemophilia Society. A grant requested for the purpose to develop a package of support to meet the needs of their inhibitor community and produce evidence based impact data for services and share with the wider Haemophilia community.
Pancreatic Cancer UK	Oncology	1,500 GBP	Sponsorship for Pancreatic Cancer UK to support The Annual HPB Nurse National Study Day. The purpose of Study Day to share best practices for HPN Nurses and the professional development of HPN Nurse, in their delivery of care to patients with HPB.
Genetic Alliance UK	Oncology Hematology Immunology	10,000 GBP	Unrestricted grant to Genetic Alliance UK To part fund a project which includes a meeting in Scotland with key stakeholders including Payers, Policy makers, Patients and Professionals to help patients to understand access to treatment policy issues in Scotland. The project team at Genetic Alliance UK will write up the meeting outputs and recommendations as a 'patient charter' which Genetic Alliance UK will disseminate.
Pancreatic Cancer UK	Oncology	5,000 GBP	In line with Pancreatic Cancer UK charter, unrestricted grant to organise educational/awareness/community events for patients.



**GAPP-EMEA**

<b>Patient organisation:</b>	<b>Business unit:</b>	<b>Amount</b>	<b>Summary of support:</b>
European Patients' Forum (EPF)	ALL	10.000 EURO	Support for the EPF Work plan 2015.
Eurordis	ALL	10.000 EURO	Support for Eurordis Roundtable of Companies 2015 (ERTC).