

List of patient groups

Country	Patient Associations	Support from Affiliates
<p style="text-align: center;">HQ Allschwil</p>	<p>For 2009 Pulmonary Hypertension Association (PHA) Scleroderma Foundation Caring Voice Coalition (CVC) Lupus Foundation of America (LFA) International Scleroderma Network (ISN) PHCentral National Organization of Rare Diseases (NORD) Scleroderma Research Foundation National Niemann-Pick Disease Foundation Pulmonary Hypertension Association Europe</p>	<p>Unrestricted grants for all PAs</p>

**HQ
Allschwil**

Federation of European Scleroderma Associations (FESCA)

For UK: Niemann-Pick Disease Group (NPDG)

For US: National NP-C Disease Foundation (NNPDF)

For Italy: Associazione Italia Niemann-Pick

For 2010

Pulmonary Hypertension Association (PHA)

Pulmonary Hypertension Association Europe

Federation of European Scleroderma Associations (FESCA)

For Italy: Associazioni Italia Niemann-Pick

For Spain: Fundacion de Niemann-Pick Espana

For UK: European Gaucher Alliance

Unrestricted grants for all
PAs

Grant: 10000 CHF

Austria

For 2009

Austrian PAH association (71.830 Euros incl. VAT)

www.lungenhochdruck.at

Austrian association for children with congenital heart failures
(5000 Euros)

www.kinderherz.at

For 2010

Austrian PAH association (16.519 excl. VAT)

www.lungenhochdruck.at

Austrian association for children with congenital heart failures
(8.350 excl. VAT)

www.kinderherz.at

Morbus Gaucher Austria (3.000 excl. VAT)

Funded with a yearly amount as a basic support for the office and secretary. This amount is based on an agreement with other sponsors to guarantee the yearly patient's support by the association's office. Other financial support is only provided on a project's basis, e.g. for awareness campaigns, educational sessions, patient's meetings, promotion activities & events.

Sponsorship for special projects 2010: - regular patient meetings, - phone costs for a patient-support-hotline, -PH newsletter and - PH Research Foundation Project (buying a milestone with personally engraved names and motto's for a dedicated PH place in the "Prater" in Vienna), - "Youthsummercamp" for children with congenital heart failures

Austria

For 2011

Austrian PAH association

18 101 EUR grants covering specific projects: webpage, information folder, relaxing days and coaching for patients

Austrian Association for children with congenital heart failures

12 000 EUR grant covering specific projects: mothers/fathers weekend, youth group founding

Morbus Gaucher Austria

1 500 EUR: annual patient association meeting support

Austrian patients associations for Scleroderma

4 048 EUR: support for meetings of the self-help groups 2011

CF Austria

750 EUR support grant for the 6th education day pulmonology 2011 (organizer: clinic Wels-Grieskirchen)

Kinder PPH Forschungsverein
(Children PPH Research Foundation)

10 560 EUR: grant covers specific research topic (non-invasive measurement of cardiac output)

Belgium

For 2009
BOKS vzw

Support daily activities from the association

PH VZW

Support daily activities from the association

APSB - Association des Patients Sclérodermiques de Belgique

Participation at the 10th anniversary from the association

For 2010
CIB-liga

Support lunch World Lupus Day and World Scleroderma day + logo on flyers for World Scleroderma Day and on back of magazine in September

For 2011
A.P.S.B

DVD, participation Journée CLAIR and preparation of the Franco-Belge organization of Sclérodermie in Tournai

BCR (Belgian Congress of Rheumatology)

participation as an exhibitor

Belgium

BSC (Belgian Society of Cardiology)

Organization of satellite symposium on the 30th annual scientific meeting of the Belgian Society of Cardiology

BWGNICI

support of the 1-day congress on Non Invasive Cardiac Imaging

CIB Liga

Benefit for FWRO and celebrate 30 Year CIB in Antwerp

PH VZW/B.P.P.H

10th anniversary from the association and the Jossie Habets-award

Canada

For 2011

CORD - Canadian Organization for Rare Disorders

Regroupement Québécois pour les maladies orphelines –
RQMO

Canadian chapter of the National Niemann Pick Disease
Association

National Gaucher Foundation

Eczema Society of Canada

Pulmonary Hypertension Association of Canada

Sclerodermie Québec / Canada

Canadian Congenital Heart Association

Unrestricted Educational
Grant to all PAs

**Czech
Republic**

For 2009

The civil association of parents of children and adults disabled with Gauchers Disease
Mladeznika, 36005 Karlovy Vary

Research and Educational Grant

The Civil association of patients with pulmonary hypertension II internal clinic of General Teaching Hospital, 12802 Prague

Research and Educational Grant

For 2010

The Civil association of patients with pulmonary hypertension Nabrezie Ivana Krasku 4, 921 12 Piestany, Slovakia

Research and Educational Grant : 10 000 EUR

For 2011

META,o.s
Darovaci smlouva

20 000 CZK: deed of gift

Zdruzenie pacientov s PH o.z.
Darovaci smlouva

10 000 EUR: deed of gift

Asociace pacientu PAH
Darovaci smlouva

30 000 CZK: deed of gift

France

For 2009

HTAP France
(French PAH Association)

Association des Sclérodermiques de France (ASF)
(French Scleroderma Association)

ASF & HTAP France “Communications workshop”

The grants cover specific projects linked to information dissemination:

- annual meetings for members of patient associations
- 2 special races for HTAP France to raise awareness of PAH in the general public (the funds help to produce communication materials, advertising and general organizational costs)
- special family week-ends for children suffering from PAH (workshops, activities and psychological support groups for families)
- production of information leaflets for patients and their families

Any additional funds go to the general running costs of the associations

Professional training module provided for representatives on communication techniques (public address in Dec. 08)

France

For 2010

Association des Sclérodermiques de France (ASF)
(French Scleroderma Association)

25 000 EUR grant covering specific projects linked to information dissemination:

- annual meetings for members of PA
- improvement of the PA Internet Site
- new production of information leaflets
- carry on local meetings and giving helping hand to PA

15 000 EUR grant allowing production of a newspaper by the PA and contribution towards meals and hospitality during the annual meeting for members of this PA

HTAP France
(French PAH Association)

40 000 EUR grant covering specific projects linked to information dissemination:

- to fund research in PAH
- to fund workshops during the annual meeting or local meetings for the patients and their families
- to fund special family weekends

France

ANCC
(Association Nationale des Cardiaques Congénitaux)

- to fund the internal organization of the association
- to fund the raise awareness of PAHH in the general public

3000 EUR for financial support of the annual meeting and of the printing of " A coeur ouvert" , the newspaper of the association

Financial support to local meetings for patients and for the internal organization of the association

VML
(Vaincre les maladies Lysosomales)

7000 EUR for financial support in view to improve the information relative to the lysosomal diseases mainly through a meeting named "les Clés du lysosome"

Financial support to prepare a document for patients

Alliance Maladies Rares

5000 Euros to fund an awareness and information campaign for the general

France

For 2011

HTAP France
(French PAH Association)

Association des Sclérodermiques de France (ASF)
(French Scleroderma Association)

Public to communicate on Rares Diseases mainly during the "Telethon"

40 000 EUR grant :

- support research on PH and promote development of information activities (during general and regional meetings) to patients with PAH and their families
- fund assistance in organizing the WEEF
- support to the inner workings of association

25 000 EUR grant covering specific projects linked to information dissemination:

- bring support under the national reorganization of the management of research protocols
- fund the creation of banners for each regional delegation
- support the organization of General Assembly 2011

Germany

For 2009
GGD

Deutsches Rheuma Forschungs Zentrum Berlin

Verband Organtransplantierter Dt. e.V

Berliner Interessengemeinschaft Phenylketonurie

Pulmonale Hypertonie e.V

ASIM

Interessengemeinschaft Organtransplantierter Patienten

Niemann-Pick Selbsthilfegruppe e.V.

For 2010

Sklerodermie Selbsthilfegruppe

Verein Elterninitiative Bad Qeynhausen

Grant for the Balance Award
Promotion of public health

Unrestricted donation

Promotion of public health:
donation

Unrestricted donation

Membership fee
Promotion of public health:
donation

Promotion of science

Promotion of public health:
donation

Promotion of public health:
donation

Promotion of public health;
donation 2500 EUR

Unrestricted donation

Germany

Verein zur Förderung der Erforschung u. Bekämpfung rheumatischer Erkrankungen

Unrestricted donation: 5000 EUR

Projekt Teddybär Uniklinikum Freiburg

Unrestricted donation: 3000 EUR

Rene Baumgart Stiftung

Unrestricted donation: 5300 EUR

Achse e.V

Sponsoring: 2140 EUR

Ph e.V

Sponsoring: 29 090 EUR

Rheumazentrum Magdeburg e.V

Sponsoring: 1011 EUR

ASIM

Sponsoring: 1050 EUR

DDS Dt Stiftung Sklerodermie

Unrestricted donation: 1500 EUR

GGD

Unrestricted donation: 5000 EUR

Herzklopfen Elterninitiative

Unrestricted donation: 500 EUR

Niemann-Pick Selbsthilfegruppe e.V.

Membership fee: 200 EUR

Orphan Frühchen- Team e.V.

Unrestricted donation: 1000 EUR

Germany

For 2011

Patient organisations:

Pulmonale hypertonie (ph) e.V.
Unrestricted donation
Membership fee Promotion of public health: donation

Patient organisations:

16 000 EUR

Rheumastiftung
Unrestricted donation
Membership fee Promotion of public health: donation

10 000 EUR

Medical societies / university hospitals

Charite
Collegium Dermatitis atopica e.V.
Dt. Gesellschaft für Angiologie
HDZ NRW
Klinikum Ernst von Bergmann gGmbH
Krankenhaus Bethanien gGmbH
LMU München
Nationales Register für angeborene Herzfehler
Universitätsklinikum Essen
Universitätsklinikum Hamburg-Eppendorf
Universität des Saarlandes

11 250 EUR

20 000 EUR

10 000 EUR

40 000 EUR

15 000 EUR

10 000 EUR

11 000 EUR

10 000 EUR

12 000 EUR

17 000 EUR

18 000 EUR

Greece

For 2009

The Greek Alliance for Rare diseases

The Greek PA for Pulmonary Hypertension

For 2010

Greek Alliance of Rare Diseases (PESPA)

Hellenic Patient Association of Pulmonary Hypertension

Cyprus League against Rheumatism

Hellenic Patient Association of Systemic Autoimmune Diseases

Hellenic Patient Association of "Child's Heart"

Sponsorship of meetings or conventions; donations

Sponsorship of educational meetings and disease awareness campaign and Sponsorship of disease and educational printed materials and PA's official journal

Hungary

For 2010

Hungarian Scleroderma Association
with its registered seat in Hungary, 7632 Pécs,
Aidinger János u. 40 entered in the register of associations,
other voluntary and vocational organizations, foundations, and
social establishments of health care under number 2554

Unrestricted Grant

Pulmonary Vasculature Association with its registered seat in
Hungary, Cházár András u. 19/B, Budapest, 1146, entered in
the register of associations, other voluntary and vocational
organizations, foundations, and social establishments of health
care under number 13037

Unrestricted Grant

For 2011

Pulmonary Vasculature Association with its registered seat in
Hungary, Cházár András u. 19/B, Budapest, 1146
Tax Number: 18197048 - 1 - 42

Grant : 1'000 000 HUF

Hungarian Scleroderma Association
with its registered seat in Hungary, 7632 Pécs,
Aidinger János u. 40
Tax Number: 18326639 - 1 - 02

Unrestricted Grant

Italy

For 2008

Italian Niemann-Pick Patients Association (responsible also for gangliosidosis)

Associazione Italiana Niemann Pick ONLUS
Via Cafasse, 28 - 10074 - Lanzo T.se - TO

Italian Gaucher Patients Association
Associazione Italiana Gaucher ONLUS
Località Il Cellalio, 51/B - 50066 - Reggello - FI

Italian PAH Patients Association
AMIP
Via Bagnoregio 51
00189 ROMA

Italian SSc Patients Association
AILS
Associazione Italiana Lotta alla Sclerodermia (AILS)
Via Famagosta 46
20142 MILANO

Italian PAH Patients Association
API Onlus
Via Vigoni 5
20122 Milano

APMAR
Associazione Pugliese Malati Reumatici
Via Molise 16
73100 Lecce

All mentioned patient associations received an economic support according their own statute (filed at Italian Affiliate HQs) for what concerns the rational donation

Italy

Italian SSc Patients Association
GILS
Gruppo Italiano per la Lotta alla Sclerodermia
Via F. Sforza, 35
Padiglione Litta c/o Ospedale Maggiore Policlinico Mangiagalli
e Regina Elena
20122 Milano

Italian SSc Patients Associations
ALOMAR ONLUS
Associazione Lombarda Malati Reumatici
P.zza Cardinal Ferrari, 1
20122 Milano

Associazione Teramana per la Lotta contro le Malattie
Reumatiche
Via del Vaticano 7
64042 Colledara (Teramo)

APIMAR Sez.Cuneo
Associazione Piemontese Malati Reumatici
C/o Divisione Medicina I° - Ospedale S: Croce
Via M. Coppino, 15
Cuneo

For 2009

Cometa Sardegna ONLUS
Via Ciro Menotti 70
09045 Quartu S.Alena- Cagliari

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Italy

Fondazione Asrales ONLUS
Via G.Moscati 31
00168 Roma

Associazione Amici del Cuore
Via G. Marchi 10
45100 Rovigo

Fondazione Salus Pueri ONLUS
Via Galilei 49
35128 Padova

Associazione Italiana per il progresso della Cardiologia e della
Cardiochirurgia ONLUS
Via Baccarani 6
60125 Ancona

Associazione Lotta alla Trombosi ONLUS
Via Cesare Correnti 14
20123 Milano

Associazione Amici del Cuore ONLUS
Viale Bracci
53100 Siena

AMAR UMBRIA ONLUS
Via Papini 35
06081 Assisi

Associazione Amici del Cuore Terraferma ONLUS
Via Ca' Rossa 10/C
30174 Mestre

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Italy

A.N.T.I.A.G.E. ONLUS
Via Cassia 600
00189 Roma

ASMAR onlus
Via G. Cesare 59
09028 Sestu – Cagliari

CROI
C.SO Luigi Einaudi 18/A
10126 Torino

Associazione Italiana Diffusione Ricerca Cardiopatie dell'
Anziano
Via S.Giovanni Livraghi 1
00152 Roma

Associazione per lo Studio della Trombosi in Cardiologia
P.Le Golgi 2
27100 Pavia

Associazione Italiana Pneumologi Ospedalieri
Via A. Da Recanate 2
20124 Milano

FADOI- Federazione delle Associazioni dei Dirigenti
Ospedalieri Internisti
Via Rodolfo Lanciani 2
00162 Roma

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Italy

Comitato per la Promozione della Ricerca sulle Malattie Rare
Viale A. Diaz 60
33100 Udine

Associazione Malattie respiratorie A.MA.RE.
Via Pessina 8
22100 Como

Associazione per la Ricerca in Reumatologia
P.Zzle Giulio Cesare
70124 Bari

Centro Studi Integrità Salute Milano
Via F.Corridoni 11
60123 Ancona

Associazione Cuore e Ricerca
Via P.Toselli40
95100 Catania

Associazione italiana per lo studio e la terapia del fenomeno di
Raynaud
Via Val D'Aosta 102
00199 Roma

Amici della Cardiocirurgia di Pavia
C/O Policlinico S.Matteo
27100 Pavia

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Italy

Associazione Ipertensione Polmonare Italiana ONLUS
Via San Rocco 5
40122 Bologna

For 2010

C.I.S.M.I. Centro studi integrità salute materno infantile
c/o Clinica Pediatrica Università di Ancona
Via Corridoni 11
60123 Ancona

Fondazione SMEM Studio Malattie Endocrino Metaboliche
Corso Bramante 59/6
10126 Torino

Associazione Malattie Autoimmuni MARIO ROSSI ONLUS
Via Aretina 155
50136 Firenze

Fondazione Italiana Ricerca sull' Artrite ONLUS
Piazza Duse 2
20122 Roma

Associazione Malati Ipertensione Polmonare ONLUS
Via Bagnoregio 51
00189 Roma

Associazione Malati Reumatici Arezzo ONLUS
c/o Ospedale San Donato Sez. Reumatologia
Via P. Nenni 23
52100 Arezzo

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Italy

Associazione Oncologica Assistenza e Ricerca ONLUS
Via dell'Annunziata 131
00147 Roma

Associazione Brianza per il cuore ONLUS
Villa Serena Via Donizetti 106
20052 Monza

Associazione Amici del Cuore Piemonte ONLUS
c/o Ospedale Molinette Rep. Cardiologia 2
Corso Bramante 88
10126 Torino

Brains for Brain Foundation ONLUS
c/o Dipartimento di Pediatria Salus Pueri
Via Giustiniani 3
35121 Padova

Associazione Studio Sclerosi Sistemica e Malattie Fibrosanti
ONLUS
C/O AOU Careggi Sez. Reumatologia
Villa Monna Tessa Viale Pieraccini 18
50139 Firenze

Associazione Sarda Malati Reumatici ONLUS
Via G. Cesare 59
09028 Sestu

For 2011

Associazione Italiana Niemann pick ONLUS
Via Cafasse 28
10074 Lanzo Torinese

All mentioned patient associations received an economic support according their own statute (filed at Italian Affiliate HQs) for what concerns the rational donation

70 000 EUR

Italy

Gruppo Italiano per la lotta alla Sclerodermia ONLUS Via F. Sforza 35 20122 Milano	6 500 EUR
Associazione Malati Reumatici Arezzo ONLUS Via P. Nenni 23 52100 Arezzo	2 500 EUR
Associazione Lotta alla Trombosi ONLUS Via Ludovico da Viadana 5 20122 Milano	16 500 EUR
Associazione Italiana dei Cardiopatici Congeniti Adulti AICCA ONLUS Via Pascoli 37 20097 San Donato Milanese	3 000 EUR
Associazione Italiana Lotta Sclerodermia AILS ONLUS Via Pini, 9 20122 Milano	40 000 EUR
Associazione Malattie Autoimmuni Rare AMAR ONLUS Via Oriani, 1 47100 Forlì	2 000 EUR
Associazione Malati Reumatici AMaR Umbria Onlus Via G. Papini, 35 06081 Assisi	10 000 EUR

Italy

Associazione Amici della Cardiochirurgia di Pavia c/o Policlinico S. Matteo 27100 Pavia	5 000 EUR
Associazione Amici del San Gerardo di Monza Via Donizetti, 106 20052 Monza	14 000 EUR
Associazione Malati di Ipertensione Polmonare AMIP ONLUS Via Bagnoregio, 51 00189 Roma	5 000 EUR
Associazione Pugliese Malatti Reumatici A.P.MA.R Onlus Via Forlanini, 26 73100 Lecce	10 000 EUR
Associazione per lo Studio delle Infezioni nell'Ospite Immunocompromesso ASIOI ONLUS Piazzale L. A. Scuro, 10 37134 Verona	9 000 EUR
Associazione Toscana Malati Reumatici - Prato A.T.Ma.R Onlus Via delle Rose, 30 59100 Prato	3 500 EUR
Association Columbus Via G. Moscati, 31 00168 Roma	11 000 EUR

Italy

Associazione Cuore Vivo Onlus Via della Montagnola, 81 60131 Ancona	1 000 EUR
Società Italiana di Ecografia Cardiovascolare SIEC Via Boscovich, 61 20124 Milano	2 300 EUR
Lega Italiana Sclerosi Sistemica Via C. Mecenate, 6 20138 Milano	3 000 EUR
Associazione Unione Malattie Rare U.M.A.R. Onlus Via S. Pansini, 5 80131 Napoli	20 000 EUR
Associazione Malattie Metaboliche Congenite AMMeC Onlus Via Luca Giordano, 13 50132 Firenze	5 000 EUR
Associazione Ipertensione Polmonare Italiana ONLUS Via G. Vigoni, 13 20122 Milano	25 000 EUR

<p style="text-align: center;">Mexico</p>	<p>For 2011 Asociación Mexicana de Hipertensión Arterial Pulmonar, A.C.</p>	<p>Up to December 2nd, no grants has been gifted, it is expected to give an unrestricted grant of \$15,000 MXP during the rest of the year.</p>
<p style="text-align: center;">Netherlands</p>	<p>For 2008/2009/2010 and 2011 Stichting PHA Nederland Nationale Vereniging L.E. Patiënten (NVLE) Volwassenen, Kinderen en Stofwisselingsziekten (VKS)</p>	<p>Unrestricted financial donations</p>

Nordic Countries

For 2011

Swedish Association of Heart and Lung disease

Financial support to specific events;
March 2011 Heart focus month : 25 000 SEK

Swedish Association of Heart and Lung disease & Swedish Patient Network

Financial support to specific events;
Patient association information meeting
Linköping March 2011: 75 000 SEK

Nordic Baltic Gaucher Association

Financial support to Specific event: April 2011; 50 000 SEK

Norwegian PAH Association

Financial support to Specific event 2011; 50 000 NOK

Danish SSc Patient Association

Financial support to specific event 2011; 25 000 DKK

For 2012

Rare Diseases Sweden

Financial support to specific events; 7 lectures in Sweden between Nov 2011 and Dec 2012; 50 000 SEK

Nordic Baltic Gaucher Association

Financial support to specific educational event: 2012; 25 000 SEK

Portugal

For 2009

Associação Portuguesa de Hipertensão Pulmonar (APHP)

Website and annual meeting sponsorship; publications to patients

Liga Portuguesa contra as Doenças Reumáticas (LPCDR)

Annual meeting sponsorship: support of symposia costs related to the annual event

Raríssimas

Punctual sponsorship: financial support of some symposia events

Associação Portuguesa das Doenças do Lisosoma (APDL)

Annual meeting sponsorship and website sponsoring

For 2010

Federação das doenças raras de Portugal (FEDRA)

financial support to specific events

Aliança Portuguesa de Associações de doenças raras (Aliança)

financial support to specific events

For 2011

Same as for 2010

Poland

For 2010

Stowarzyszenie Chorych na Niemann-Picka i Choroby Pokrewne "Życ nadzieją" ("Living on Hope" Society of Niemann-Pick and Related Illnesses Patients)

Financial donation for organizing the association's meeting (including KOLs participation).

Donation amount: 20 000 PLN

For 2011

Stowarzyszenie Chorych na Niemann-Picka i Choroby Pokrewne "Życ nadzieją" ("Living on Hope" Society of Niemann-Pick and Related Illnesses Patients)

Financial donation for organizing the association's meeting (including KOLs participation).

Donation amount: 20 000 PLN

<p style="text-align: center;">Russia</p>	<p>For 2010 National association of patients' organizations for Rare Diseases. http://www.rarediseases.ru/</p> <p>For 2011 National association of patients' organizations for Rare Diseases. http://www.rarediseases.ru/</p> <p>Russian Union of patients and patients organization for Rare Diseases http://www.rare-diseases.ru/</p>	<p>Participation in the organization of First All-Russian Conference for Rare Diseases and Rarely Used Medical Technologies. symposiums for PAH and NP-C were organized</p> <p>Participation in the organization of Rare Disease Day. Participation in the organization of Second All-Russian Conference for Rare Diseases and Rarely Used Medical Technologies.</p> <p>Participation in the organization of Russian Conference for Rare Diseases.</p>
<p style="text-align: center;">Slovakia</p>	<p>For 2010 Zdruzenie pacientov s plucnou hypertenziou o.z. Registered seat at: Lucenska 31, 990 01 Velky Krtis, Slovak Republic ID No: 42189535</p>	<p>Research and Educational grant :10 000 EUR</p>

Spain

Fundación Niemann-Pick. It includes all Niemann-Pick patients and relatives (regardless of type A, B and C)

Asociación Nacional de Hipertensión Pulmonar [Pulmonary Hypertension National Association] (<http://www.hipertensionpulmonar.es/>). Spanish association providing support to patients affected with PH and their relatives

Corazones Atendidos: Asociación de Afectados por Cardiopatías Congenitas y Adquiridas (Helped Hearts: Association of Patients with Congenital or Acquired Heart Diseases) (<http://www.corazonesatendidos.org/>). It provides support to heart disease patients and their relatives

FEDER (Federación Española de Enfermedades Raras) (Spanish Federation for Rare Diseases) (<http://www.enfermedades-raras.org/>). Umbrella body for more than 140 orphan disease patient's associations

Fundación Menudos corazones (Foundation for the Tiny Hearts) (<http://www.menudoscrazones.org/index.php>)
Foundation for the help of children with heart problems

For 2010

Asociación Española de Esclerodermia
Spanish association providing support to scleroderma patients and their relatives

All mentioned patient associations received unrestricted grants through a donation. The donation certificate states the donation nature of the grant. The final use of the funds is entirely to the respective patient association

<p style="text-align: center;">Spain</p>	<p>Fundación Española de Hipertensión Pulmonar Spanish association providing support to pulmonary hypertension patients and their relatives</p> <p>Asociación Española de Enfermos y Familiares de Gaucher (AEEFEG) Spanish patient association of Gaucher patients</p>	<p>All mentioned patient associations received unrestricted grants through a donation. The donation certificate states the donation nature of the grant. The final use of the funds is entirely to the respective patient association</p>
<p style="text-align: center;">Switzerland</p>	<p>For 2008 Vaincre les Maladies Lysosomales/ VML Suisse http://www.vml-asso.org Goal of the organisation : Support of patients with lysosomal storage diseases and their families</p> <p>HTAP Revivre Association des patients Suisse Romande http://www.sgph.ch/SuisseRomande#HTAP Goal of the organisation : Support of patients with pulmonary arterial hypertension and their families</p> <p>PPH Selbsthilfegruppe Schweiz http://www.lungenhochdruck.ch/php/index.php Goal of the organization: Contact forum for concerned patients and interested persons</p>	<p>General support with 1000 CHF</p> <p>Support of the general assembly with 1000 CHF</p> <p>Support of the patient meeting with 2200 CHF</p>

Switzerland

For 2009

Cuore matto

Vereinigung für Jugendliche und Erwachsenen mit angeborenem Herzfehler

<http://www.cuorematto.ch/>

For 2010

Cuore matto

Vereinigung für Jugendliche und Erwachsenen mit angeborenem Herzfehler

<http://www.cuorematto.ch/>

HTAP Revivre

Association des patients Suisse Romande

Hypertension pulmonaire

<http://www.sgph.ch/SuisseRomande#HTAP>

Goal of the organisation :

Support of patients with pulmonary arterial hypertension and their families

Schweizer PH Verein (SPHV)

<http://www.lungenhochdruck.ch/php/index.php>

Goal of the organization:

Contact forum for concerned patients and interested persons

Donation in year of jubilee with 5500 CHF

Financial support for Action "Baden zeigt Herz" with 2300 CHF

General support with 2000 CHF

Support of the General Assembly with 3000 CHF

General support with 3000 CHF

Switzerland

For 2011

Cuore Matto

Vereinigung für Jugendliche und Erwachsene mit angeborenem Herzfehler

<http://www.cuorematto.ch/>

HTAP Revivre

Association des patients Suisse Romande hypertension pulmonaires

<http://www.sgph.ch/SuisseRomande#HTAP>

PPH Selbsthilfegruppe Schweiz / Primäre Pulmonale Hypertonie

Kontaktforum betroffener Patienten und interessierter Personen

<http://www.lungenhochdruck.ch/php/index.php>

Elternvereinigung für das herzkrankte Kind

<http://www.evhk.ch/>

Organisation für Patienten, die an Sklerodermie oder einer verwandten Krankheit leiden.

<http://www.sclerodermie.ch>

Cost for mailing : 1100 CHF

Support of the General Assembly with 1000 CHF

General support with 1000 CHF

Support of the General Assembly with 500 CHF

Support on the occasion of the "Welt-Sklerodermietages" with 3500 CHF
Support of film project 10000 CHF

Turkey

For 2009

Pulmonary Hypertension Association: A Support Group for PH, Scleroderma and Eisenmenger Patients
www.phdernegi.org.tr

Sponsorship frame agreement with PH Association in 2009. Unrestricted yearly educational grant for office and maintenance, and project-based financial support for congress participation, patient educational materials and meetings, awareness campaigns are provided, in line with local regulations and Actelion TR PharmaCode

For 2010/11
Same status

UK

For 2009

Irish Raynaud's and Scleroderma Society

Sponsorship of materials and postage for the European Scleroderma Day on June 2009

For 2010

Pulmonary Hypertension Association (PHA-UK)

Just Walk 2010 donation
National PH Pharmacist Meeting, 7th Oct

Raynauds & Scleroderma Association (RSA)

Sponsorship
- for Doctor to attend patient meeting
- of educational materials, regional meetings, annual conferences
Letter and packs for Rheumatologists

Irish Raynauds & Scleroderma Society (IRSS)

Sponsorship of annual Conference / Dublin 2010
Dog sled challenge donation
Printing of patient Ed Booklets

Scleroderma Society

Sponsorship of patient info leaflets and annual pt conference

UK

Niemann Pick Disease Group (UK) NPDG

Support of Nurses to attend international Congresses
Sponsorship of Family's Day
Patient Support Programme
Sponsorship of annual conference & interactive workshop on NPD.
Sponsorship of clinical Management and New techniques for Patients with LSD
Sponsorship of patient meetings

Gaucher Association GA

Production of Patient information Booklets
Patient support Programme
Choices and challenges for the Gaucher community – stand, 2 delegates-

For 2011

Irish Raynauds and Scleroderma Society

A grant of 1000 EUR towards the 2011 Annual conference

UK

Raynauds and Scleroderma Association

A grant of 2000 GBP towards the 2011 Annual conference
A grant of 16 600 GBP as part of a jointworking agreement for a Digital Ulcer Disease Awareness programme which included media outreach and an information pack for Rheumatologists

Scleroderma Society

A grant of 1000 GBP towards the 2011 Annual conference

Pulmonary Hypertension Association UK

A grant of 29 065 GBP provided for the production and printing of a patient booklet 'Listening to me, listening to you: A guide to living with the emotional effects of PH'
A grant of 7 250 GBP for the National PH Nurse/Pharmacist group meeting (organised by the PHA UK)
A grant of 4 500 EUR for finding and referring PAH patients and carers for the

UK

PHA Ireland

Actelion sponsored Global PAH survey

A grant of 3000 EUR towards the 2011 Annual conference

Grown Up Congenital Heart Patients Association

A grant of 54 260 GBP towards a joint working project to determine a best practice 'model of care' to improve the management of PAH in patients with GUCH

Niemann Pick C Disease Group (NPDG UK)

Funding of 5000 GBP for a stand space at the British Paediatric Neurology Association meeting
A grant of 107 643 GBP towards a patient support programme which includes materials for patients and carers
Travel expenses of 207 GBP for NPDG committee members to attend a meeting as part of the patient support programme
Funding of 23 347 GBP towards the NPDG family conference

US

For 2011

National Gaucher Foundation, Inc.

Newark Beth Israel Medical Center Foundation

Congenital Heart Walk

National Gaucher Foundation, Inc.

Adult Congenital Heart Association

Pulmonary Hypertension Association

Scleroderma Foundation

Educational Meetings

Heart & Sole Walk

2011 Twin Cities Congenital Heart Walk

Educational Meetings

Heart to Heart (H2H) Program

Heart to Heart Program

Year 4 Medical Education Fund non-CME Program (PHA on the Road/PHA Classroom)

Patient Support and Advocacy

Central Fund for Chapter and Regional Initiatives

US

Pulmonary Hypertension Association

Actelion Community of Hope
Patient Scholarship Fund

10 International PH
Conference and Scientific
Sessions

PH Awareness Month 2012

2012 Special Event Central
Fund

2012 Support Group Central
Fund

The International Scleroderma Network

Development of Patient
Education Content for the
www.sclero.org website
including PAH Patient
Education

Infuse sclero.org with
Modern Web-based
Technologies