

List of patient groups 2015

Country	Patient Associations	Support from Affiliates
<p style="text-align: center;">HQ Allschwil</p>	<p>Pulmonary Hypertension Association Europe (PHA EUROPE)</p>	<p>100'000 EUR for core funding of the organisation's activities</p> <p>150'000 EUR grant to support 2015 projects:</p> <ul style="list-style-type: none"> • 30'000 EUR Annual PH European Conference • 50'000 EUR World Pulmonary Hypertension Day and IRONMAN • 40'000 EUR Advocacy • 20'000 EUR Fellowship and White Spots programs • 10'000 EUR Publications <p>2'500 EUR speaker fees for the participation at 14th</p>

HQ
Allschwil

Pulmonary Hypertension Association Europe (PHA EUROPE)

International Pulmonary Hypertension Forum

5'000 EUR – fundraising at EULAR congress 2015

5'000 EUR – fundraising at ERS congress 2015

1'315 EUR World PH Day 2015 Panel Discussion

Federation of European Scleroderma Associations (FESCA)

30'000 EUR World Scleroderma Day 2015 Global Campaign

5'000 EUR – fundraising during the EULAR congress 2015

European Organisation for rare Diseases (EURORDIS)

25'000 EUR EURORDIS Black Pearl Dinner (Gold partnership level)

Pulmonary Hypertension Latin Society – Sociedad Latina de Hipertension Pulmonar (SLHP)

6'000 US\$ attendance at ERS congress 2015

Schweizer PH-Verein (SPHV)

9'000 CHF - fundraising for participation in Basel Marathon 2015

HQ
Allschwil

Association HTAP Revivre

4'500 CHF - fundraising for participation in Basel Marathon 2015

Initiative Lungenhochdruck

20'000 EUR costume run in the Vienna Prater ("Ghostrun")

41'000 EUR for the organisation's operational activities

Pulmonary Hypertension Association Europe (PHA Europe) and Pulmonary Hypertension Association, US

80'000 CHF Educational grant for PH Resource Website provided as payment in kind

Pulmonary Hypertension Association, US

9'846 CHF Multidisciplinary Workshop "Exploring the Communication Gaps in PAH Patient Care" – consultancy and travel

Asociación Nacional de Hipertensión Pulmonar (ANHP)

1'541 CHF Multidisciplinary Workshop "Exploring the Communication Gaps in PAH Patient Care" - consultancy and travel

Pulmonale Hypertonie e.v.

1'785 CHF Multidisciplinary Workshop "Exploring the Communication Gaps in PAH

HQ
Allschwil

Pulmonary Hypertension Association (PHA UK)

Patient Care” - consultancy
and travel

2'047 EUR World PH Day 2015
Panel Discussion

552 EUR Patient Group
Workshop - travel costs

1'617 CHF Multidisciplinary
Workshop “Exploring the
Communication Gaps in PAH
Patient Care” - consultancy
and travel

Association HTAP France

750 EUR World PH Day 2015
Panel Discussion

PHA Norway

1'783 EUR World PH Day 2015
Panel Discussion

504 EUR Patient Group
Workshop - travel costs

Slovenian PH Patient Association ("Društvo Za Pljučno
Hipertenzijo Slovenije")

1'415 EUR World PH Day 2015
Panel Discussion

APH Moment Plus ("Asocijacija za Pulmonalna Hipertenzija
Moment Plus")

2'438 EUR World PH Day 2015
Panel Discussion

<p>HQ Allschwil</p>	<p>Hungarian PH Patient Association</p> <p>Bulgarian Society of Patients with Pulmonary Hypertension</p> <p>PAH Patientforeningen Denmark</p>	<p>213 EUR Patient Group Workshop - travel costs</p> <p>543 EUR Patient Group Workshop - travel costs</p> <p>536 EUR Patient Group Workshop - travel costs</p>
<p>Australia</p>	<p>Pulmonary Hypertension Australia</p> <p>Scleroderma Australia</p>	<p>\$2500 (excl GST) - Unrestricted Educational Grant for assistance to attend PHSANZ Annual Scientific Meeting</p> <p>\$2500 (excl GST) - Unrestricted Educational Grant for assistance to attend World Systemic Sclerosis Congress</p>

<p style="text-align: center;">Austria</p>	<p>Selbsthilfegruppe Lungenhochdruck F</p> <p>Pro rare Austria</p> <p>Pharmig</p>	<p>13'636,36 EUR: Office support</p> <p>5'000 EUR: Working program 2015</p> <p>5'000 EUR: Okids</p>
<p style="text-align: center;">Belgium</p>	<p>vzw PH België</p> <p>HTAP Belgique asbl</p> <p>Association des Patients Sclérodermiques de Belgique (A.P.S.B asbl)</p>	<p>4'000 EUR: Sponsoring organization of the Patient Days of 2015</p> <p>1'100 EUR: Sponsoring participation to congresses / seminars / workshop EUPATI, Patient Rights Day, EPHA and HAM PHA EunethHTA and the EMA meeting, support to the LUSS meetings & meetings with patient associations of patients in the hospitals</p> <p>1'500 EUR for Sponsoring to develop educational material for Scleroderma patients</p>

Brasil

Assoc. Paulista de MPS e DR

15 000 BRL: Donation, in this case Actelion Brasil don't interfere in the propose

Assoc. Mineira Port. Amigos Gaucher - AMPAG

10 000 BRL: Donation, in this case Actelion Brasil don't interfere in the propose

Assoc. Amigos Hosp. Universitário Pedro Ernesto - AMHOPE

6 600 BRL: Donation, in this case Actelion Brasil don't interfere in the propose

ANPB- Assoc. Niemann Pick Brasil

40 000 BRL: assist in the support and dissemination of materials on rare disease awareness

AFAG

50 000 BRL: assist in the support and dissemination of materials on rare disease awareness

Assoc. de Assit. Criança Deficiente

5 000 BRL: Donation, in this case Actelion Brasil don't interfere in the propose

Centro de Estudos de Pneumologia

9 000 BRL: Donation, in this case Actelion Brasil don't interfere in the propose

Canada

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 Adult Congenital Heart Network

Fondation en Coeur

Edmonton Pulmonary Arterial Hypertension Society (EPAHS)

Fondation Hypertension Artérielle Pulmonaire Québec
(HTAPQ)

Unrestricted Educational
Grant to all PAs

<p>China</p>	<p>ISEEK</p>	<p>Sponsorship of 90,000 RMB for “See blue lips” public photography exhibition press conference on 2015 PH Day</p>
<p>Croatia</p>	<p>Hrvatski savez za rijetke bolesti (Croatian Association of Rare Disease)</p>	<p>Support for organization conference for rare disease and other activities (e.g. covering costs for education of members of association) during year 2015 6'000 HRK</p>
<p>Czech Republic</p>	<p>The Civil association of patients with Pulmonary Hypertension</p>	<p>Research and Educational Grant : 80 000,-CZK</p>

France

Vaincre les maladies Lysosomales (VML)

15'000 EUR: financial support for research to build support to parents of children or adults with NP-C.
5,000 EUR : Financial support of the organization of a Day NP-C.

HTAP France (French PAH association)

32,000 EUR : Financial support for the making of a movie entitled "Draw me PAH".
30'000 EUR for financial Support:
- to PAH medical research
- to better inform patients with PAH and their families
- to publish specific documents for patients with PAH and their families

Association des Sclérodermiques de France (ASF)

2,000 EUR : financial support for the writing of a brochure relative to the patients with DU.
25'000 EUR for Financial support:
- to cover a part of the Attendee's hospitality during the ASF general meeting

<p style="text-align: center;">France</p>		<p>- for the publication of the association's newspaper and other documents for patients and their families</p>
<p style="text-align: center;">Germany</p>	<p>Allianz Chronischer Seltener Erkrankungen (ACHSE) e.V</p> <p>Arbeitsgemeinschaft für angeborene Stoffwechselstörungen in der Inneren Medizin – ASIM</p> <p>Mukoviszidose e.V. –</p> <p>Niemann-Pick Selbsthilfegruppe e. V.</p> <p>Offene Fachschaft Medizin</p> <p>Pulmonale hypertonie (ph) e.v.</p> <p>René Baumgart-Stiftung</p>	<p>Funding of public health care and scientific: 5'000 EUR</p> <p>- Charitable grant to support medical education: 5'000 EUR</p> <p>- Charitable grant to support medical education: 25 EUR</p> <p>Funding of public health care and scientific: 300 EUR</p> <p>Funding of public health care and scientific: 5'200 EUR</p> <p>Charitable grant to support medical education: 1'000 EUR</p> <p>Charitable grant to support medical education: 16'500 EUR</p> <p>Charitable grant to support medical education: 1'200 EUR</p>

	Scleroderma Lige e.V	Charitable grant to support medical education: 1'000 EUR
Greece	<p>Hellenic Pulmonary Hypertension Greek Association</p> <p>PESPA (Greek Alliance for Rare Diseases)</p>	<p>10'000 EUR: support the activities during the World Day for Pulmonary Hypertension (May 5th)</p> <p>3'500 EUR : support the activities during the PAH Awareness Month (November 2015)</p> <p>500 EUR: support the activities during the World Day of Rare Diseases (February 28th) organized by PESPA</p> <p>15'000 EUR: support the activities during the World Scleroderma Day (June 29th) organized by PESPA</p> <p>500 EUR: support the activities during the 8th Annual Panhellenic Congress of PESPA, 16-17 October 2015</p>

Hungary	<p>Hungarian PAH Patient Organization (Tüdöér Egylet)</p> <p>Scleroderma Patient Organization (Országos Scleroderma Egyesület)</p>	<p>300'000 HUF: financial support</p> <p>1' 500 000 HUF: organization of the National PAH Patient org. meeting</p> <p>500'000 HUF: financial support</p>
Israel	<p>pulmonary hypertension patients association</p>	<p>50,000 ILS : donation to the association</p>

Italy

ASSMAF - Associazione per lo Studio della Sclerosi Sistemica e delle Malattie Fibrosanti ONLUS
Viale Pieraccini, 18 Firenze

All mentioned patient associations received an economic support according their own statute for what concerns the rational donation

12'000 EUR

ATMAR - Associazione Toscana Malati Reumatici ONLUS
Via. Viale Bracci, Siena

4'000 EUR

Lega italiana Sclerosi Sistemica ONLUS/No-Profit
Via Mecenate 6, Milano

5'500 EUR

ACAPMR - Associazione Calabrese Assistenza Pediatrica Malattia Rara ONLUS
Via Il Traversa Milano, 5 Catanzaro

22'000 EUR

GILS - Gruppo Italiano per la Lotta alla Sclerodermia ONLUS
Via Sforza, 35 Milano

12'000 EUR

Associazione Alessandro Lupoli ONLUS
Via Sarzanese Valdera, 141 Cascine di Buti (PI)

21'000 EUR

ACTI - Associazione Cardiotrapiantati Italiani ONLUS
Viale Bracci, Siena

5'000 EUR

Italy

Associazione Italiana Niemann Pick e Malattie Affini ONLUS Via Marchese della Rocca, 30 Lanzo Torinese	70'000 EUR
AAMAR - Associazione Abruzzese Malati Reumatici ONLUS Via Fonte Romana, 8 Pescara	10'000 EUR
AIPi - Associazione Ipertensione Polmonare Italiana ONLUS Via G Vigoni, 13 Milano	25'000 EUR
ALMAR - Associazione Ligure Malati Reumatici ONLUS Via Benedetto XV, 6 Genova	10'000 EUR
ASAMPA - Associazione Sarda Malati Parkinson ONLUS Via Riva Villasanta, 222/B Cagliari	24'000 EUR
AMARV - Associazione Malati Reumatici del Veneto – ONLUS Piazzale San Lorenzo Giustiniani, 6 Mestre	10'000 EUR
AMIP - Associazione Malati Ipertensione Polmonare ONLUS Via Bagnoregio, 51 Roma	10'000 EUR
AILS - Associazione Italiana Lotta alla Sclerodermia ONLUS Via Pini, 9 Milano	40'000 EUR

Japan	Pulmonary Hypertension Association Japan (PHA Japan) Okayama Pulmonary Hypertension Association	200 000 JPY: financial support for the activities of the organization 100 000 JPY: financial support for the activities of the organization
Korea	Pulmonary Hypertension Association Korea (PHA Korea)	30,000,000 KRW : financial support for the activities of the organization

<p style="text-align: center;">Mexico</p>	<p>Organización Mexicana de Enfermedades Raras (OMER)</p>	<p>60,000 Mexican Pesos: unrestricted support</p>
<p style="text-align: center;">Netherlands</p>	<p>SSc weekend "De Zonneroos" Hart voor Longen Zaandam</p>	<p>One time grant of 8604 EUR One time sponsoring EUR 5000 + EUR 1221 fundraising actively realized for the PAH Nederland Foundation during the 24h walk event</p>
<p style="text-align: center;">Nordic Countries</p>	<p>Swedish PAH network Danish PAH network</p>	<p>Financial support for production of educational material 2014-2016; a total 2'000 EUR over 2 years Financial support for a patient rehabilitation project: 7000 DKK, May – October 2015</p>

Nordic Countries

Danish Scleroderma and Raynaud Association

Financial support for a PAH Awareness campaign; 15000 DKK, Oct 2015

Financial Support for Activities at the World Scleroderma Day June 29th 2015. 2 lectures of 300 Euro: in total 600 EUR

Norwegian Association for Heart and lung diseases

Financial support for patient meeting in collaboration with the Feiring rehab clinic, June 2015. NOK 10 000

Financial support for a stand at the Cardiology Fall Meeting Oct 22-24 2015, NOK 18.667

International Childrens Heart Foundation, Memphis

Financial support for specific charity work / contribution for Danish nurse to the pulmonary team 2015, 5000 DKK

For more specifics regarding the support, please contact medinfo_nordic@actelion.com

<p style="text-align: center;">Poland</p>	<p>The Polish Association of People with Pulmonary Arterial Hypertension and Their Friends (Polskie Stowarzyszenie Osób z Nadciśnieniem Tętnicznym i ich Przyjaciół)</p>	<p>35 000 PLN: Donation for organizing of World PH Day, May 16, 2015</p>
<p style="text-align: center;">Portugal</p>	<p>Associação Portuguesa de Doentes com Esclerodermia (APDE):</p> <p>Associação Portuguesa de Hipertensão Pulmonar (APHP)</p> <p>Raríssimas</p>	<p>- Donation of 1'000 EUR on 2015/01/29. Contribution to participate in the 2015 FESCA Congress</p> <p>- Donation of 2'000 EUR on 2015/05/20. Contribution to sponsor activities related to International Scleroderma Day</p> <p>Donation of 2'500 EUR on 2015/06/11. Contribution to sponsor activities related to World Pulmonary Hypertension Day</p> <p>Donation of 1'500 EUR on 2015/10/08. Contribution to sponsor VII Int. Congress on Cornelia de Lange Syndrom</p>

<p>Russia</p>	<p>No any financial support to anyone.</p>	
<p>Slovakia</p>	<p>The Civil Association of Patients with Pulmonary Hypertension</p>	<p>Educational Grant: 3'000 EUR</p>
<p>Slovenia</p>	<p>Društvo za pljučno hipertenzijo Slovenije Slovenska 29, 1000 Ljubljana Dbph.slovenije@gmail.com</p> <p>Slovenian Association of patient for Gaucher disease</p>	<p>Support to organise national PAH day and other activities (e.g. printing/delivering PAH booklets for patients, covering costs for education of members of PAH patient association) during year 2015 : 500,00 EUR</p> <p>Support for organization of local patient activities (organization of patient meeting at Gaucher day) 100,00 EUR</p>

<p style="text-align: center;">Spain</p>	<p>Fundación Niemann-Pick (www.fnp.org)</p> <p>Asociación Nacional Hipertensión Pulmonar</p> <p>Fundación contra la Hipertensión Pulmonar</p> <p>Federación Española de Enfermedades Raras (FEDER)</p>	<p>Niemann Pick National Event (November): 5.000 EUR Financial support</p> <p>Patient and Carers Support Program: 13,640 EUR Financial Support</p> <p>Research activities: 6,500 EUR Financial support</p> <p>Rare Disease Day: 8,000 EUR Financial support</p>
<p style="text-align: center;">Switzerland</p>	<p>SPHV Schweizer PH-Verein http://www.lungenhochdruck.ch/php/index.php</p> <p>HTAP Revivre – Association des patients Suisse Romande Hypertension pulmonaire http://www.sgph.ch/SuisseRomande#HTAP</p>	<ul style="list-style-type: none"> - General support with CHF 5'200 - Fundraising as a result of Basel Marathon CHF 9'000 - Fundraising as a result of Basel Marathon CHF 4'500 - General support with CHF 500

<p style="text-align: center;">Taiwan</p>	<p>Taiwan Association of Caring PAH</p> <p>Taiwan Rare Disease Foundation</p> <p>Taiwan CHD Care Association</p> <p>Cheng-Hsing Medical Foundation</p> <p>Taiwan Heart Foundation</p>	<ul style="list-style-type: none"> - NT\$ 100,000: for disease awareness campaign - NT\$ 100,000: for patient gathering and disease education - NT\$ 100,000: #ActForBlue campaign donation/pledge <p>NT\$ 200,000: for patient vaccination program</p> <p>NT\$ 40,000: for patient gathering and disease education</p> <p>NT\$ 50,000: for patient gathering and disease education</p> <p>NT\$ 100,000: #ActForBlue campaign donation/pledge</p>
<p style="text-align: center;">Turkey</p>	<p>no support provided to patient associations in Turkey in 2015 as they stopped their activities and officially closed due to low interest from patients, physicians and industry.</p>	

UK

Raynaud's & Scleroderma Association

- Grant of £473.54 to support Chief Exec. to attend the 3rd World Congress in Scleroderma
- Sponsorship of £650 towards the 2014 annual conference

Scleroderma Society

Sponsorship of £662.52 towards the 2014 annual conference

Pulmonary Hypertension Association UK

- Grant of £31'000 provided for the production of a Layman's Guide to PAH, this grant was not paid directly to the patient organisation
- Grant of £72'718 provided towards the development of an online self-management programme for patients and carers, this grant was not paid directly to the patient organisation and was received as a "benefit in kind"

US

Scleroderma Foundation

- \$94,671: Central Fund Support (Chapter/Regional Initiatives)
- \$387,750: Patient Support & Advocacy
- \$50,000: Voice of the Patient, Leveraging Patient Advocates in Drug Development & Clinical Trials

ACHA

- \$390,000: Heart to Heart (H2H) Program
 - \$15,000: 2014 Congenital Heart Advocacy Program
 - \$79,200: 7th National Conference
 - \$80,000: Provider Action for Treating Congenital Hearts (PATCH) Program

T-Cell Leukemia Lymphoma Foundation

\$32,000: Patient Education Forums

National Comprehensive Cancer Network

- \$10,000: Value, Access, & Cost of Cancer Care Working Group

US

Cutaneous Lymphoma Foundation

- \$10,000: Patient Advocacy Summit: Value in Cancer Care; Patients

- \$5,000: 2015 Young Investigators award/Clarion's Research Award Reception
- \$175,000: Education for Patients, Healthcare Professionals and General Community

NORD

\$15,000: "Portraits of Courage Gala", Silver Sponsorship

American Lung Association

\$3,000: Kentucky Derby Gala

Global Genes

\$5,000: Corporate Alliance Sponsorship

JFK Tower Golf Association

\$5,000: JFK Tower 2015 Golf Tourney

PHA

-\$10,000: PHA NYC Breathless on Broadway 2015

US

PHA/Mayo Clinic/HHT Foundation

Scleroderma Foundation of Southern California

- \$1,000: Dewitt Take a Breath 2015
- \$2,000: PHA St. Louis Support Group Trivia Night Fundraiser
- \$500: PHA Woodlands CrawPHish Festival 2015
- \$5,000: PHA NYC 2015 Breathe Concert Series
- \$3,500: PHA Midwest Chapter Iowa Trivia PHun Extravaganza
- \$2,500: PHA Power for PH 4th PHun Walk for a Cure
- \$20,000: PHA Rochester Reach for the Stars Gala
- \$5,000: PHA Midwest Chapter The Force Awakens for PH
- \$2,500: Oklahoma Heart Hospital Kingrey OKC 5k Run

\$5,000: HHT Cure Walk 2015

\$10,000: Key to a Cure Gala 2015

US

Team Phenomenal Hope

-\$15,000: Team Phenomenal Hope 2015 Race
-\$2,000: Team Phenomenal Hope 2015 Race Kickoff

Maine Medical Center

- \$2,500: UPHill Journeys 9th Annual PH Golf Tournament

National Jewish Health

\$10,000: Walk with a Doc Program

PHAware

\$25,000: PHAware 2015

Stanford University

\$10,000: Race Against PH 2015