

List of patient groups 2014

Country	Patient Associations	Support from Affiliates
<p style="text-align: center;">HQ Allschwil</p>	<p>Pulmonary Hypertension Association Europe (PHA EUROPE)</p>	<p>105'000 EUR to support World Pulmonary Hypertension Day activities:</p> <ul style="list-style-type: none"> - 75'000 EUR for the partnership with Ironman Triathlon - 30'000 EUR for the participation of PHA Europe member association in the Ironman events - 100'000 EUR for core Funding of the organisation's Activities - 40'000 EUR for the dissemination of the Patient and Carer Dialogue Tools among and by the member associations ("Time-to-Talk")

HQ
Allschwil

Pulmonary Hypertension Association Europe (PHA)

- 15'000 EUR: fundraising during the ESC and ERS congresses 2014 with the aim to raise awareness about pulmonary arterial hypertension
- 4'000 CHF: fundraising for participation in Basel Marathon 2014 as a part of Actelion's World PH Day 2014 event
- 1'196 EUR: patient group advisory board/workshop

Federation of European Scleroderma Associations (FESCA)

10'000 EUR: Platinum sponsorship of the book "Hope Springs Eternal" for raising awareness of pulmonary hypertension

30'000 EUR: World Scleroderma Day (Platinum Sponsorship)

European Organisation for rare Diseases (EURORDIS)

15'000 EUR: EURORDIS Gala Dinner (Silver Sponsorship)

HQ
Allschwil

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

34'800 USD: translation and adaptation of Pulmonary Hypertension Association (PHA)'s "Patient's Survival Guide »

International NPC patient association INPDA

4'000 EUR: attendance and activities with families and patients associations during an International event in Pediatrics

Schweizer PH-Verein (SPHV)

8'000 CHF: fundraising for participation in Basel Marathon 2014 as a part of Actelion's World PH Day 2014 event

Association HTAP Revivre

3'500 CHF: fundraising for participation in Basel Marathon 2014 as a part of Actelion's World PH Day 2014 event

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

120'000 CHF Educational grant for PH Resource Website provided as payment in kind

Pulmonary Hypertension Association, US

10'588 EUR: patient group advisory board/workshop

Asociación Nacional de Hipertensión Pulmonar (ANHP)

1'726 EUR: patient group advisory board/workshop

HQ
Allschwil

Association HTAP France

1'236 EUR patient group advisory board/workshop

PHA Norway

2'221 EUR patient group advisory board/workshop

Pulmonary Hypertension Association (PHA UK)

1'894 EUR: patient group advisory board/workshop

Pulmonale Hypertonie e.v.

1'695 EUR: patient group advisory board/workshop

Hungarian PH Patient Association (Tüdóér Egylet)

1'662 EUR: patient group advisory board/workshop

Polish PH Patient Association

Provided video "What is PAH" from PAHuman eBook without any consideration / free of charge

<p style="text-align: center;">Australia</p>	<p>Arthritis South Australia</p> <p>Scleroderma Association of New South Wales</p>	<p>\$600- unrestricted funding to support Scleroderma Seminar</p> <p>\$2'000- Donation</p>
<p style="text-align: center;">Austria</p>	<p>Austrian PAH Association (Initiative Lungenhochdruck)</p> <p>Pro rare Austria</p> <p>SSc Patient Organizations Styria and Upper Austria</p>	<p>13'636,36 EUR: Office support, Patient meetings, Sport events</p> <p>4'500 EUR: Working program, Annual report 2013</p> <p>1'391,66 EUR: Travel grants (Patient meeting)</p>

<p style="text-align: center;">Belgium</p>	<p>Association des Patients Sclérodermiques de Belgique (A.P.S.B asbl)</p> <p>Association de Patients souffrant d'Hypertension Artérielle Pulmonaire en Belgique asbl</p> <p>Belgische Patiëntenvereniging voor Pulmonale Hypertensie VZW</p>	<p>3'000 EUR for Sponsoring: help of organizing the "6ème journée Franco-Belge de la Sclerodermie " of October 18, 2014.</p> <p>978 EUR: help for the organization and participation to different meetings during the year</p> <p>4'000 EUR: Support of the organization of the Patient Days of November 15, 2014</p>
<p style="text-align: center;">Brasil</p>	<p>ABRAF</p> <p>ABRAPES</p> <p>ANPB Associação Brasileira de Portadores NP-C</p> <p>Associação Eu Luto pela Vida</p>	<p>2 000 BRL: science and educational support</p> <p>2 000 BRL: financial support for activities of the organization</p> <p>30 000 BRL: financial support for specific event in September</p> <p>15 000 BRL: financial support for activities of event called "Muitos comos raros"</p>

<p style="text-align: center;">Brasil</p>	<p>AFAG</p> <p>ACDG</p>	<p>25 000 BRL: assist in the support and dissemination of materials on rare disease awareness</p> <p>10 000 BRL: assist in the support and dissemination of materials on Gaucher disease awareness</p>
<p style="text-align: center;">Canada</p>	<p>CORD - Canadian Organization for Rare Disorders</p> <p>Regroupement Québécois pour les maladies orphelines – RQMO</p> <p>Canadian chapter of the National Niemann Pick Disease Association</p> <p>National Gaucher Foundation</p> <p>Eczema Society of Canada</p> <p>Pulmonary Hypertension Association of Canada</p> <p>Sclerodermie Québec / Canada</p>	<p>Unrestricted Educational Grant to all PAs</p>

<p style="text-align: center;">Canada</p>	<p>Canadian Adult Congenital Heart Network</p> <p>Fondation en Coeur</p> <p>Edmonton Pulmonary Arterial Hypertension Society (EPAHS)</p> <p>Fondation Hypertension Artérielle Pulmonaire Québec (HTAPQ)</p>	<p>Unrestricted Educational Grant to all PAs</p>
<p style="text-align: center;">China</p>	<p>Rare Disease</p> <p>ISEEK</p>	<p>Sponsorship RMB100,000</p> <p>Grant of RMB 50'000</p>
<p style="text-align: center;">Czech Republic</p>	<p>The Civil association of patients with Pulmonary Hypertension</p>	<p>Research and Educational Grant : 100 000,-CZK</p>

<p style="text-align: center;">France</p>	<p>Vaincre les maladies Lysosomales (VML)</p> <p>Association nationale des Cardiaques Congénitaux (ANCC)</p> <p>Association des Sclérodermiques de France (ASF)</p> <p>HTAP France (French PAH association)</p>	<p>15'000 EUR: financial support for research</p> <p>6'000 EUR: financial support for research and specific patient's projects</p> <p>30'000 EUR: financial support for a scientific meeting and for specific projects</p> <p>30'000 EUR: financial support For PAH research and educational activities for patients with PAH</p>
<p style="text-align: center;">Germany</p>	<p>Allianz Chronischer Seltener Erkrankungen (ACHSE) e.V</p> <p>Arbeiterwohlfahrt KV Freiburg e.V..</p> <p>Bundesvereinigung JEMAH e.V.</p> <p>Gaucher Gesellschaft Deutschland e.V. (GGD)</p> <p>Niemann-Pick Selbsthilfegruppe e. V.</p>	<p>Unrestricted grants for all mentioned PAs</p> <p>5'000 EUR</p> <p>2'000 EUR</p> <p>4'000 EUR</p> <p>5'000 EUR</p> <p>5'200 EUR</p>

<p style="text-align: center;">Germany</p>	<p>Pulmonale hypertonie (ph) e.v.</p> <p>Raum für Frauen e.V. Bickenbach</p> <p>René Baumgart-Stiftung</p> <p>Scleroderma Lige e.V</p>	<p>Unrestricted grants for all mentioned PAs 16'800 EUR</p> <p>1'000 EUR</p> <p>2'500 EUR</p> <p>1'500 EUR</p>
<p style="text-align: center;">Greece</p>	<p>Patient Association with Rare Disease</p> <p>Association of Support and Mutual Help for PH Patients</p> <p>Association for the protection, information & assistance to children with Heart diseases</p>	<p>Support the activities during the World Day of Rare Diseases organized by PESPA, February 28th: EUR 1'000</p> <p>Support activities for World PH Day organized by the association, May 29th: EUR 34'600</p> <p>Support the awareness activities for the CHD day 14/2/13. (Disease leaflet, stand and t-shirts): 1 600 EUR</p>

Greece

Hellenic Association against Rheumatism Diseases
(EL.E.AN.A)

The Greek Alliance of Rare diseases

Patients Assotiation "Krikos Zois"

Support the production of a
SSc Disease leaflet for
public: 1 100 EUR

- Sponsorship for the
Celebration of World Day for
Rare Diseases of "Greek
Alliance of Rare Diseases",
named "Rare disorders
without borders" on
February 28th: 1 000 EUR
- Support the Rare Disease
Congress, took place on
October 11-12th in
Thessaloniki: 500 EUR

500 EUR: Supporting the
Patients Association to meet
current needs and direct
costs for the operation of the
Patients Association, given
as an example by the
annual cost of housing / part
of the rent

Hungary

Hungarian PAH Patient Organization (Tüdöér Egylet)

-1 Million HUF: organization of World PAH Day events
- 1 Million HUF: organization of the National PAH Patient org. meeting
- 500 000 HUF: financial support

GD Patient Organization (Gauche Disease)

250.000 HUF: financial support for the Patient Meeting

Országos Scleroderma Egyesület
Patient association of Scleroderma patients

-300 000 HUF: financial support for the National Scleroderma Day event
- 1 000 000 HUF financial support for the organization of the World Day of Scleroderma

Italy

Associazione Italiana Niemann pick ONLUS/No-Profit
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

60 000 EUR

Gruppo Italiano per la lotta alla Sclerodermia GILS ONLUS/No-Profit
Via F. Sforza 35
20122 Milano

11 000 EUR

Associazione Italiana dei Cardiopatici Congeniti Adulti AICCA ONLUS/No-Profit
Via Pascoli 37
20097 San Donato Milanese

7 000 EUR

Lega Italiana Sclerosi Sistemica Onlus/No-Profit
Via C. Mecenate, 6
20138 Milano

3 000 EUR

Associazione Ipertensione Polmonare Italiana AIPI ONLUS/No-Profit
Via G. Vigoni, 13
20122 Milano

25 000 EUR

<p style="text-align: center;">Italy</p>	<p>Associazione Abbruzzese Malati Reumatici “M.Alberti” Onlus/No-Profit Pescara</p> <p>Associazione Malati Reumatici Arezzo Onlus/ No-Profit Milano</p> <p>Lega Regionale Ligure contro le malattie reumatiche Genova</p>	<p>10 000 EUR</p> <p>26 000 EUR</p> <p>3 000 EUR</p>
<p style="text-align: center;">Japan</p>	<p>PHA Japan</p> <p>Association of study for PH</p>	<p>Donation: 100 000 JPY</p> <p>Donation: 100 000 JPY APJ sponsored seminars: 1,200,000 JPY</p>
<p style="text-align: center;">Korea</p>	<p>Pulmonary Hypertension Association Korea (PHA Korea)</p>	<p>30,000,000 KRW : financial support for the activities of the organization</p>

<p style="text-align: center;">Mexico</p>	<p>Asociación Mexicana de HAP.</p> <p>Sociedad Mexican de Epilepsia</p> <p>Organización Mexicana de Enfermedades Rara</p>	<p>April 2014: Unrestricted grant of 15,000 Mexican Pesos</p> <p>May 2014: Unrestricted grant of 10,000 Mexican Pesos</p> <p>October 2014: unrestricted grant of 12,000 Mexican Pesos</p>
<p style="text-align: center;">Netherlands</p>	<p>Stichting PHA</p> <p>NHV</p> <p>VKS</p>	<p>Sponsorship EUR 3000</p> <p>Sponsorship EUR 1400</p> <p>One time grant for EUR 3750</p>

<p style="text-align: center;">Nordic Countries</p>	<p>Swedish PAH network</p> <p>Danish PAH network</p> <p>Norwegian PAH network</p> <p>Systemic Sclerosis Patient Association</p> <p><i>For more specifics regarding the support, please contact medinfo_nordic@actelion.com</i></p>	<p>Financial support for production of educational material 2014: 2 000 EUR</p> <p>Financial support for printed material: 500 DKK and 6525 DKK. Support in association with start-up/general assembly: 11 085 DKK</p> <p>Financial support for specific event 2014: 15 000 NOK</p> <p>Financial support for two lectures: 600 EUR</p>
<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>40 000 PLN: Donation for organizing of the patients' meeting</p>

<p style="text-align: center;">Portugal</p>	<p>Liga Portuguesa contra as Doenças Reumáticas (LPCDR)</p> <p>Associação Portuguesa de Doentes com Esclerodermia (APDE)</p> <p>Associação Portuguesa de Hipertensão Pulmonar (APHP)</p>	<p>Sponsorship Meeting in October: 2 500 EUR</p> <p>Sponsorship registration SSc Symposium: 1 000 EUR</p> <p>5 000 EUR: unrestricted grant for provision of services to patients and their families affected by pulmonary hypertension</p>
<p style="text-align: center;">Romania</p>	<p>Pulmonary Hypertensive Patients Association Romania</p>	<p>Financial support by paying registration fee for the establishment of the association: 250 EUR</p>

<p style="text-align: center;">Russia</p>	<p>National association of patients' organizations for Rare Diseases. http://www.rarediseases/</p> <p>All Russian Union of Orphan Diseases http://www.rarediseases.ru/</p> <p>All Russian Union of Patients and Patients organization of orphan Diseases (SPIPORZ) http://spiporz.ru/</p>	<p>Participation in the organization of Rare Disease Day</p> <p>Participation in the organization of Rare Disease Day.</p> <p>Participation in the organization of Rare Disease Day</p>
<p style="text-align: center;">Slovakia</p>	<p>The Civil association of Patients with Pulmonary Hypertension</p>	<p>Educational Grant: EUR 3'000</p>

Spain

Fundación Niemann-Pick (www.fnp.org)

- Niemann Pick National Event (November):
6.000€ Financial support

Asociación Española de Enfermos y Familiares de Enfermedad de Gaucher (www.aeefegaucher.es)

Gaucher Disease National Patients Meeting (October):
12.000€ Financial support

Asociación Nacional Hipertensión Pulmonar

Patient and Carers Support Program: 4000€ Financial support

Fundación contra la Hipertensión Pulmonar

Research activities: 12.000€ Financial support

Asociación Nacional Esclerodermia

Educational Activities of the Association:
1.500€ Financial support

Federación Española de Enfermedades Raras (FEDER)

Rare Disease Day: 5.000€ Financial support

Switzerland

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

Schweizerische Niemann Pick Vereinigung
<http://www.npsuisse.ch/>

SPHV Schweizer PH-Verein
<http://www.lungenhochdruck.ch/php/index.php>

HTAP Revivre – Association des patients Suisse Romande
Hypertension pulmonaire
<http://www.sgph.ch/SuisseRomande#HTAP>

General support with CHF
5'000

Support of Film project with
CHF 20'000

- Sponsoring lecture for association with CHF 1'400
- Fundraising as a result of Basel Marathon CHF 8'000
- Support of travel to patients assembly in Germany with CHF 1'099
- 8'000 CHF: fundraising for participation in Basel Marathon 2014 as a part of Actelion's World PH Day 2014 event

- Fundraising as a result of Basel Marathon CHF 3'500
- 3'500 CHF: fundraising for participation in Basel Marathon 2014 as a part of Actelion's World PH Day 2014 event

<p style="text-align: center;">Taiwan</p>	<p>Taiwan Association of Caring PAH</p> <p>Taiwan Rare Disease Foundation</p>	<p>- NT\$ 557'265: for website and app development - NT\$ 30'000: for patient gathering</p> <p>NT\$ 100'000: for book publication and movie production</p>
<p style="text-align: center;">Turkey</p>	<p>Pulmonary Hypertension Association: A Support Group for PH, Scleroderma and Eisenmenger Patients www.ph dernegi.org.tr</p>	<p>Based on the sponsorship frame agreement with PH Association, financial support includes unrestricted yearly educational grant, project-based support for congress participations, patient educational materials and meetings, and PAH awareness campaigns run by the association, in line with local regulations and Actelion TR PharmaCode 20 000 TL</p>

US

ACHA

Cutaneous Lymphoma Foundation

- \$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

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