

List of patient groups 2013

Country	Patient Associations	Support from Affiliates
<p style="text-align: center;">HQ Allschwil</p>	<p>Pulmonary Hypertension Association Europe (PHA EUROPE)</p>	<ul style="list-style-type: none"> - 80 000 EUR for core funding of the organizations' activities - 55 000 EUR for the partnership with Ironman Triathlon to support World Pulmonary Hypertension Day activities - 30'000 CHF fundraising as a result of World PH Day 2013 event at Actelion - 1'000 EUR - patient group advisory board - 120'000 EUR for core funding of the organisation's activities

HQ
Allschwil

Pulmonary Hypertension Association Europe (PHA)

- 13'000 CHF - fundraising as a result of World PH Day 2013 event at Actelion
- 1'300 US\$ - patient group advisory board

Pulmonary Hypertension Association (PHA UK)

- 10'000 CHF - fundraising as a result of World PH Day 2013 event at Actelion
- 900 £ - patient group advisory board

Federation of European Scleroderma Associations (FESCA)

40 000 EUR:
- 30 000 EUR World Scleroderma Day, Platinum Sponsorship
- 10 000 EUR Patient conference at the 3rd Systemic Sclerosis World Congress (Rome, February 2014), Silver Sponsorship

Associazione Ipertensione Polmonare Italiana Onlus (AIPI)

1'000 EUR - unrestricted grant to support the project MASKS

Hungarian Pulmonary Hypertension Patient Association (Tüdőér Egylet)

Donation of five (5) second-hand laptop computers

<p style="text-align: center;">HQ Allschwil</p>	<p>Associação Portuguesa de Hipertensão Pulmonar (APHP)</p> <p>Cystic Fibrosis Trust</p>	<p>5'000 EUR - unrestricted grant for provision of services to patients and their families affected by pulmonary hypertension</p> <p>900 £ - patient group advisory board</p>
<p style="text-align: center;">Australia</p>	<p>HeartKids NSW</p> <p>Pulmonary Hypertension Australia</p> <p>HeartKids Australia</p> <p>Scleroderma Australia</p>	<p>Donation: AUD\$ 2 000 \$</p> <p>UEG for PAH awareness event held in November: AUD\$6000</p> <p>10 000 Donation for Annual Education Day. AUD\$ 10 000</p> <p>UEG for purpose of supporting attendance at Third World Systemic Sclerosis Congress 2014: AUD \$5,000</p>

<p style="text-align: center;">Austria</p>	<p>Austrian PAH Association (Initiative Lungenhochdruck)</p> <p>CF Patient Organization Upper Austria</p> <p>SSc Patient Organizations Styria and Upper Austria</p>	<p>EUR 31'300.00: Office support, Patient meetings, Sport events</p> <p>EUR 500.00: Organizational costs</p> <p>EUR 1'831.00: 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>Sponsoring: help of organizing the "8ème journée des Affections Inflammatoires Rhumatismales " of March 9th 2013. Amount: 1000 EUR</p> <p>Help for the participation to the Patient Days of October 12th and 13th 2013. Amount: 350 EUR</p> <p>Help for the organization of the Patient Days of October 12th and 13th 2013. Amount: 4000 EUR</p>

Brasil

	Donations / financial support for educational meetings for All PAs
Associação Brasileira de Pacientes de Esclerose Sistêmica	11 000 BRL
Associação Gaúcha de HAP	1 500 BRL
Associação Bras. Amigos e Familiares dos portadores de HAP	5 000 BRL
Associação de Assistência a mucoviscidose no Paraná	8 000 BRL
Associação Novo Rumo	12 000 BRL
Associação dos amigos do hospital de clínicas do Paraná	380 BRL
Associação Cearense de Prof. Atuantes em doenças genéticas, familiares e voluntários	12 000 BRL
Ass. N. P. doença Gaucher	60 000 BRL

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 style="text-align: center;">China</p>	<p>I SEEK PH</p>	<p>H1 2013: RMB 73K 1) Sponser 05.05.2013 WPHD Activities in China 2) Sponser "Blue Lips" Journal</p>
<p style="text-align: center;">Czech Republic</p>	<p>Sdruzeni pacientu s plicni hypertenzi" The Civic association of patients with pulmonary hypertension</p> <p>Medical newspaper: Medical Tribune</p>	<p>Research and Educational Grant : 80 000,-CZK</p> <p>Sponsoring projects - "Miniatlas-PAH": 49.000,- CZK - creation and administration of web page: "www.miniatlas-pah.cz": 17.000,-CZK</p>

France

Vaincre les maladies Lysosomales (VML)

15 000 EUR : financial support for patients's specific projects and for further research

Association nationale des Cardiaques Congénitaux (ANCC)

5000€ for financial support to local events for patients with congenital heart diseases and for the internal organization of the association.

Association des Sclérodermiques de France (ASF)

- 3000€ for financial support to participate at the Sclerodermia meeting in Italy in February 2014
- 4500€ to support the publication of a brochure for patients relative to DU disease

HTAP France (french PAH association)

- 2000€ for financial support to patients congress organization

<p style="text-align: center;">Germany</p>	<p>Pulmonale hypertonie (ph) e.V.</p> <p>KID e.V.</p> <p>Niemann-Pick shG e.V.</p> <p>Achse e.V</p> <p>Skleroderma Liga e.V.</p> <p>Räume für Frauen e.V.</p> <p>Stiftung Atemweg</p>	<p>17 750 EUR: membership Fee and donation</p> <p>500 EUR: donation</p> <p>4 700 EUR: donation</p> <p>5 000 EUR: donation</p> <p>500 EUR: donation</p> <p>800 EUR: donation</p> <p>1000 EUR: donation</p>
<p style="text-align: center;">Greece</p>	<p>Hellenic Pulmonary Hypertension</p> <p>Association of Support and Mutual Help for PH Patients</p>	<p>Support the production of PH Disease leaflet for public: 2 260 EUR</p> <p>Support the organization of Press Conference & Press Release for World PH Day, May 5th: 3 600 EUR</p>

Greece

Association for the protection, information & assistance to children with Heart diseases

Support the awareness activities for the CHD day 14/2/13. (Disease leaflet, stand and t-shirts): 1 600 EUR

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

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

The Greek Alliance of Rare diseases

- 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

Patients Assotiation "Krikos Zois"

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

Országos Scleroderma Egyesület
Patient association of Scleroderma patients

500 000 HUF: financial support for the National Scleroderma Day event

GD Patient Organization (Gauche Disease)

300.000 HUF: financial support for the functioning of the organization

Hungarian PAH patient organization (Tüdőér Egylet)

- 1 Million HUF: financial support given in September for the activities of the organization
- 500.000 HUF: financial support given in November for foundation activity

Italy

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

60 000 EUR

Gruppo Italiano per la lotta alla Sclerodermia GILS ONLUS
Via F. Sforza 35
20122 Milano

5 000 EUR

Associazione Italiana dei Cardiopatici Congeniti Adulti AICCA ONLUS
Via Pascoli 37
20097 San Donato Milanese

10 000 EUR

Lega Italiana Sclerosi Sistemica Onlus
Via C. Mecenate, 6
20138 Milano

3 000 EUR

Associazione Ipertensione Polmonare Italiana AIPI ONLUS
Via G. Vigoni, 13
20122 Milano

25 000 EUR

Italy

Associazione Italiana Pneumologi Ospedalieri AIPO Via D. Da Recanate,2 20124 Milano	30 000 EUR
Associazione Alessandro Lupoli Onlus Via Sarzanese Valdera 137 56030 Cascine di Buti	16 000 EUR
Associazione Malati di Ipertensione Polmonare AMIP ONLUS Via Bagnoregio, 51 00189 Roma	5 000 EUR
Associazione Ligure Malati Reumatici A.L.Ma.R Onlus Via XX Settembre, 36/14 16121 Genova	10 000 EUR
Associazione Malattie Metaboliche Congenite AMMeC Onlus Via Luca Giordano, 13 50132 Firenze	10 000 EUR
Brains for Brain Foundation - Onlus Via Giustiniani, 3 35121 Padova	20 000 EUR
Associazione Cometa Sardegna Onlus Via Ciro Menotti, 70 09045 Quartu Sant'Elena	3 000 EUR

Italy

Associazione CardioTrapiantati Italiani ACTI Onlus Viale Bracci – Osp. Le Scotte 53100 Siena	€ 1'000
Associazione Italiana Lotta Sclerodermia AILS ONLUS Via Pini, 9 20122 Milano	€ 40'000
Associazione Amici del San Gerardo di Monza Onlus Via Donizetti, 106 20900 Monza	€ 18'000
Associazione Malati Reumatici AMaR Umbria Onlus Via Luigi Rizzo, 23 06128 Perugia	€ 10'000
Associazione Persone con Malattie Reumatiche A.P.MA.R Onlus Via Miglietta, 5 73100 Lecce	€ 6000
Unione Italiana Lotta alla Distrofia Muscolare UILDM Onlus V.le Diaz, 60 33100 Udine	€ 10'000

<p style="text-align: center; color: red; font-weight: bold; font-size: 1.5em;">Japan</p>	<p>PHA Japan</p> <p>Association of study for PH</p>	<p>-Donation: 100 000 JPY - Production fee of Japanese version of PH Patients Survival Guide by Pulmonary Hypertension Association in US : 8 Million JPY</p> <p>Donation: 100 000 JPY</p>
<p style="text-align: center; color: red; font-weight: bold; font-size: 1.5em;">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; color: red; font-weight: bold; font-size: 1.5em;">Mexico</p>	<p>Asociación Mexicana de Hipertensión Arterial Pulmonar, A.C.</p> <p>Proyecto Pide un Deseo México, i.a.p</p>	<p>Unrestricted grant of MXN \$60,000.00 per year for communication activities with patients</p> <p>Unrestricted grant of MXN \$189,702 M.N. each semester for general activities, proper of the institution</p>

<p style="text-align: center;">Netherlands</p>	<p>Nationale Vereniging L.E. Patiënten (NVLE)</p>	<p>Financial support Patient Advisory Board and Patient Day: 1750 EUR</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>Mb Gaucher Sweden</p> <p>The Wille Foundation</p> <p>Mb Gaucher Sweden</p>	<p>Financial support for specific event 2013: creation of leaflets; approx. 50 000 SEK</p> <p>Financial support for start-up event 2013: 30 000 DKK</p> <p>Financial support for start-up event 2013: 20 000 NOK</p> <p>Financial support for specific event, April-13: 30 000 SEK</p> <p>Financial support for specific event, Dec -13, 10.000 SEK</p> <p>Financial support for specific event, Dec -13, 30.000 SEK</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>19 434 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>Associação Portuguesa das Doenças do Lisosoma (APDL)</p>	<p>Sponsorship Meeting in October: 2 500 EUR</p> <p>Sponsorship registration SSc Symposium 2012: 1 000 EUR</p> <p>Donation for event on Int. PH Day: 1 000 EUR</p> <p>Annual grant to support PA yearly activity: 1 000 EUR</p>
<p style="text-align: center;">Russia</p>	<p>National association of patients' organizations for Rare Diseases. http://www.rarediseases/</p>	<p>Participation in the organization of Rare Disease Day</p>

<p style="text-align: center;">Russia</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. Participation in the organization of All Russian Conference on PAH “World Pulmonary Hypertension Day”</p> <ul style="list-style-type: none"> - Participation in the organization of Rare Disease Day - Participation in All-Russia Congress of Patients 25-26 November: 450 000 roubles
<p style="text-align: center;">Slovakia</p>	<p>“Zdruzenie pacientov s plucnou hypertenziou o.z.” The Civic association of patients with pulmonary hypertension</p> <p>The Civil Association of Patients with PH</p> <p>Medical newspaper: Medical Tribune</p>	<p>Research and Educational Grant: 3000,- EUR</p> <p>Support of science and education: 1 000 EUR</p> <p>Sponsoring projects</p> <ul style="list-style-type: none"> - "Minitlas-PAH": 49.000,- CZK - creation and administration of web page: "www.minitlas-pah.sk": 9.000,-CZK

Spain

Fundación Niemann-Pick (www.fnp.org)

- Niemann Pick National Day (February):
3.000€ Financial support
- Niemann Pick National Event (November):
5.000€ 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: 4920€ Financial support

Fundación contra la Hipertensión Pulmonar

- Research activities:
12.000€ Financial support
- General Association's activities: 5.000€ Financial support

Asociación Nacional Esclerodermia

- Awareness Campaign:
5.300€ Financial
- Educational Activities of the Association:
2.500€ Financial support

Switzerland

HTAP Revivre
Association des patients Suisse Romande
Hypertension pulmonaire
<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>

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

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

General support with
CHF 500

General support with
CHF 13 000

Grant of CHF 5 000 towards
the 1 day Workshop to be
held at the Conference
“Genetics of NPC Disease”
in March 2014

<p style="text-align: center;">Taiwan</p>	<p>Taiwan Association of Caring PAH</p> <p>NCKUH PH Patient Group</p> <p>Taiwan Foundation for Rare Disorders</p> <p>Rheumatic Diseases Caring Society of Taiwan</p>	<p>50,000 NTD: Gathering of the patient and carers</p> <p>30,000 NTD: Launch party of the patient group</p> <p>44,600 NTD: Book publication</p> <p>200,000 NTD: For core funding of the organization's activities</p>
<p style="text-align: center;">Turkey</p>	<p>Pulmonary Hypertension Association: A Support Group for PH, Scleroderma and Eisenmenger Patients www.phdernegi.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>

<p style="text-align: center; color: red; font-weight: bold;">UK</p>	<p>Raynauds & Scleraderma Association UK Conference</p> <p>Raynauds & Scleraderma Association Eire Conference</p> <p>Niemann-Pick Disease Group (Annual Families Conference)</p> <p>Royal Free, Young Adults SSc</p>	<p>£2'000: Contribution to conference fund</p> <p>Euro 1000: Contribution to conference fund</p> <p>£10'000: Contribution to families conference</p> <p>£300: Contribution to charity</p>
<p style="text-align: center; color: red; font-weight: bold;">US</p>	<p>Pulmonary Hypertension Association</p>	<ul style="list-style-type: none"> - \$675'000 : Year 6 PHA Medical Education and Central Fund - \$10'000: "Charity Donation Project" PAH Change Perspective. - \$20'000: "O2 Breathe" Empowering hope to cure PH. Evening Honoring Dr Robyn Barst and raising awareness to fight PH. We were Platinum sponsors - \$15'000: "O2 Breathe". Additional funding to Robyn Barst Pediatric Research.

US

NORD

National Gaucher's Foundation

- \$919.15: "World PH Day". Money was raised to fight PH.
- \$20'000 : "Reach for the Stars": promote awareness

\$15'000 : "Gala Sponsorship": NORDS's 30th Anniversary Celebration. Gold level sponsor.

- \$5'000: "Educational Meetings": providing patients and families with most up-to-date information as well as provide a forum in which to ask questions
- \$5'000: "Education & Awareness": Patients, caregivers and HCPs to become familiar with the symptoms of Guacher's disease, leading to testing and treatment, if necessary of individuals who are misdiagnosed or underdiagnosed

US

International Scleroderma Network

- \$12'500: "Education & Awareness": Patients, caregivers and HCPs to become familiar with the symptoms of Guacher's disease, leading to testing and treatment, if necessary of individuals who are misdiagnosed or underdiagnosed

- \$20'000: Enhanced Digital Support and Education for Scleroderma and PAH Patients

- \$5'000: Enhanced Digital Support and Education for Scleroderma and PAH Patients. Redesign, modify and improve "sclero.org". And redesign, modify and improve the overall online educational environment on sclero.org

US

ACHA

- \$100'000: "Heart to Heart (H2H)": The goals of the H2H Program are to reduce health risks associated with CHD, provide direct educational opportunities for adults with CHD and their families, help physicians educate their patients through specialized brochures on ACHD health risks, educate the CHD community about the need for specialized ACHD care, and increase awareness of CHD in the general public

- \$50'000: "ACHA, Where You Live": The goals of each ACHA Where You Live event includes: 1) offering face-to-face education to adults with CHD and their families in collaboration with local ACHD medical programs, 2) providing adults with CHD and their families with ACHA educational materials,

US

Cutaneous Lymphoma Foundation

3) increasing participation in ACHD education by securing non-ACHA member attendance and encouraging free ACHA membership, and 4) increasing ACHA member connection and engagement by creating a sense of community and local peer-to-peer support opportunities.

\$150'000: Education for patients, health care professionals and general community.