

List of patient groups 2016

Country	Patient Associations	Support from Affiliates
<p style="text-align: center;">HQ Allschwil</p>	<p>Pulmonary Hypertension Association Europe (PHA EUROPE)</p>	<p>250'000 EUR grant to support 2016 projects/activities:</p> <ul style="list-style-type: none"> • 40'000 EUR Core funding of organisation's activities • 60'000 EUR Annual PH European Conference • 40'000 EUR World Pulmonary Hypertension Day • 45'000 EUR Advocacy • 50'000 EUR Fellowship and White Spots programs • 15'000 EUR Publications <p>1'259 CHF Multidisciplinary Workshop "Exploring the Communication Gaps in PAH Patient Care" - consultancy and travel</p>

Pulmonary Hypertension Association Europe (PHA EUROPE)

Donation of 530 PAHuman patient diaries for 2017 (10 CHF per diary)

Federation of European Scleroderma Associations (FESCA)

30'000 EUR: World Scleroderma Day 2016 Global Campaign

15'000 EUR: 4th Patient World Scleroderma Congress

European Organisation for rare Diseases (EURORDIS)

35'000 EUR: EURORDIS Black Pearl Evening (Platinum partnership level)

BLACKSWAN Foundation

10'000 CHF: RE(ACT) Congress

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

25'000 US\$: World PH Day Workshops in Buenos Aires, Argentina

Schweizer PH-Verein (SPHV)

9'000 CHF: fundraising for participation in Basel Marathon 2016

Cuore Matto

10'000 CHF: fundraising for participation in Basel Marathon 2016

Initiative Lungenhochdruck

30'000 EUR for organisation's operational activities

HQ
Allschwil

Pulmonary Hypertension Association, US

4'990 CHF Multidisciplinary Workshop "Bridging the communications gaps in PAH patient care" - consultancy and travel

Asociación Nacional de Hipertensión Pulmonar (ANHP)

1'647 CHF Multidisciplinary Workshop "Bridging the communications gaps in PAH patient care" - consultancy and travel

Pulmonale Hypertonie e.v.

1'682 CHF Multidisciplinary Workshop "Bridging the communications gaps in PAH patient care" - consultancy and travel

Association HTaP France

1'858 CHF Multidisciplinary Workshop "Bridging the communications gaps in PAH patient care" - consultancy and travel

PHA Norway

2'254 CHF Multidisciplinary Workshop "Bridging the communications gaps in PAH patient care" - consultancy and travel

<p>HQ Allschwil</p>	<p>Hungarian PH Patient Association (Tüdóér Egylet)</p> <p>Associação Portuguesa de Hipertensão Pulmonar (APHP)</p>	<p>1'828 CHF Multidisciplinary Workshop “Bridging the communications gaps in PAH patient care” - consultancy and travel</p> <p>1'673 CHF Multidisciplinary Workshop “Bridging the communications gaps in PAH patient care” - consultancy and travel</p>
<p>Australia</p>	<p>Pulmonary Hypertension Association of Australia</p> <p>Scleroderma Australia</p>	<p>Unrestricted Educational Grant for assistance to attend US Pulmonary Hypertension Association Conference - \$10,000 AUD</p> <p>Unrestricted Educational Grant for assistance to attend PHSANZ Annual Scientific Meeting - \$3,000 AUD</p> <p>Donation to enable Association's website to be updated - \$4,080 AUD</p> <p>Donation for Scleroderma Australia newsletter preparation - \$3,000 AUD</p>

Austria	<p>SHG Lungenhochdruck</p> <p>Pro rare Austria</p> <p>Pharmig OKIDS</p> <p>SHG SSc/DU</p>	<p>25.000 EUR: Support and Maintenance Agreements - core funding of the organisation's activities</p> <p>5'000 EUR: Core funding</p> <p>5'000 EUR: Sponsoring for organisation's activities</p> <p>3.500 EUR: Sponsoring of Patient group meetings</p>
Belgium	<p>vzw PH België</p> <p>HTAP Belgique asbl</p> <p>Association des Patients Sclérodermiques de Belgique (A.P.S.B asbl)</p>	<p>5'000 EUR: Sponsoring organization of the Patient Association Activities and PH awareness activities in 2016</p> <p>1'500 EUR: Sponsoring participation to congresses / seminars, support to the LUSS meetings & meetings with patient associations of patients in the hospitals</p> <p>1'500 EUR: Sponsoring to develop educational material (comic book digital ulcers, folio oral care and scleroderma, printing costs newspaper)</p>

Brasil

Assoc. Paulista de MPS e DR	15 000 BRL: Donation
Assoc. Mineira Port. Amigos Gaucher - AMPAG	10 000 BRL: Donation
Assoc. Amigos Hosp. Universitário Pedro Ernesto - AMHOPE	89 000 BRL: Donation
ANPB- Assoc. Niemann Pick Brasil	70 000 BRL: Assist in the support and dissemination of materials on rare disease awareness
AFAG	100 000 BRL: Assist in the support and dissemination of materials on rare disease awareness
Assoc. de Assit. Criança Deficiente - AACD	6 000 BRL: Donation
Casa Hunter	90 000 BRL: Assist in the support and dissemination of materials on rare disease awareness

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)

Scleroderma Association of British Columbia

British Columbia "Pulmonary Hypertension Society

Unrestricted Educational Grant to all PAs

China	CORD (Chinese Organization for Rare Disorders)	Roll out PAH patient care program 2016. Actelion China pays all program associated expense. Provides RMB 150,000 to CORD as partnership fee.
Croatia	No support given in 2016	
Czech Republic	The Civil association of patients with Pulmonary Hypertension	Science and Educational Grant: 80 000,-CZK

France

Vaincre les maladies Lysosomales (VML)

15,000 Euro : financial support for social and psychological support for parents of sick young patients and adult patients

HTAP France (French PAH association)

30'000 EUR for financial support:
- to PAH medical research
- to improve the information carrier
- to update the association's Website
- to organize weekend for PAH sick patients

Association des Sclérodermiques de France (ASF)

2,000 EUR : financial support

25'000 EUR for Financial Support to cover:
- part of the attendee's hospitality during the ASF general meeting
- a specific part of the ASF general meeting

Germany

Allianz Chronischer Seltener Erkrankungen (ACHSE) e.V

Funding of public health care and scientific research:
5'000 EUR

Arbeitsgemeinschaft für angeborene Stoffwechselstörungen in der Inneren Medizin – ASIM

Funding of public health care and scientific research: 25 EUR

Niemann-Pick Selbsthilfegruppe e. V.

Charitable grant to support medical education: 7'700 EUR

Offene Fachschaft Medizin eV

Funding of public health care and scientific research:
1'000 EUR

Pulmonale hypertonie (ph) e.V.

Funding of public health care and scientific research:
19'133 EUR

NEMO eV

Funding of public health care and scientific research:
1'000 EUR

Greece

Hellenic Pulmonary Hypertension Greek Association

8'500 EUR: support the activities during the World Day for Pulmonary Hypertension (May 5th, 2016)

4'000 EUR : support the activities during the PAH Awareness Month (Nov 2016)

1'620 EUR: support with purchase of 150 books dedicated to PAH, Nov 2016

500 EUR: Support with purchase of 50 calendars 2017, Nov 2016

PESPA (Greek Alliance for Rare Diseases)

1'000 EUR: support the activities during the World Day of Rare Diseases (February 29th, 2016)

1'000 EUR: support the activities during the 9th Annual Panhellenic Congress of PESPA, 7-8 October 2016

Association of Patients with Rheumatic Diseases of Patra

2'000 EUR: support the activities during the World Scleroderma Day, June 29th, 2016

<p>Hungary</p>	<p>Hungarian PAH Patient Organization (Tüdöér Egylet)</p> <p>Scleroderma Patient Organization (Országos Scleroderma Egyesület)</p>	<p>550'000 HUF: financial support (April 2016)</p> <p>1' 500 000 HUF: financial support (November 2016)</p> <p>1' 500 000 HUF: financial support (December 2016)</p> <p>300'000 HUF: realization of foundation goals</p>
<p>Israel</p>	<p>Haverim Lerefua ID Number 580408748</p> <p>Pulmonary hypertension patients association ID Number 580368041</p>	<ul style="list-style-type: none"> - Donation: 7,000 ILS - Free good: 2 tracleer 62.5 Mg 13 Zavesca 100 Mg - Donation: 92,500 ILS - Lecture by the association CEO: 1,500 ILS - Purchase of 36 books published by the association and spreading them in hospitals: 1,800 ILS

Italy

	All mentioned patient associations received an economic support according their own statute for what concerns the rational donation
ASSMAF - Associazione per lo Studio della Sclerosi Sistemica e delle Malattie Fibrosanti	60'000 EUR
Associazione Italiana Niemann Pick ONLUS	60'000 EUR
Lega Italiana Sclerosi sistemica ONLUS	6.500 EUR
Associazione Alessandro Luppoli ONLUS	10.000 EUR
AIPI Associazione Ipertensione Polmonare Italiana ONLUS	25.000 EUR
AMEGEP Associazione Malattie metaboliche e Genetiche Puglia ONLUS	1.500 EUR
Associazione per la lotta alle malattie cardiovascolari e aiuto alimentare ONLUS	5.000 EUR
Le.Li.Co.Ma.R. ONLUS - Lega Regionale Ligure contro le Malattie reumatiche e per l'aiuto dei malati reumatici	6.000 EUR
GILS Gruppo Italiano per la Lotta alla Sclerodermia ONLUS	12.000 EUR

<p style="text-align: center;">Italy</p>	<p>ASAMPA Associazione Sarda Malati di Parkinson - ONLUS</p> <p>AILS Associazione Italiana Lotta alla Sclerodermia ONLUS</p> <p>ACTI Associazione Cardiotrapiantati Italiani ONLUS</p> <p>ALT Associazione Lotta Trombosi Malattie Cardiovascolari ONLUS</p>	<p>23.000 EUR</p> <p>35.000 EUR</p> <p>12.000 EUR</p> <p>10.000 EUR</p>
<p style="text-align: center;">Japan</p>	<p>Pulmonary Hypertension Association Japan (PHA Japan)</p> <p>Okayama Pulmonary Hypertension Association</p> <p>Tokyo Pulmonary Hypertension Association</p> <p>Osaka Pulmonary Hypertension Association</p>	<p>200,000 JPY: financial support</p> <p>100,000 JPY: financial support</p> <p>100,000 JPY: financial support</p> <p>10,000 JPY: financial support</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>

Mexico	Patient Association "Palito y Toto Piden un Deseo, A.C." Patient Association OMER (Mexican Organization for Rare Diseases)	\$ 38,350.80 Mexican pesos: Financial support for different educational activities on the rare disease day \$ 60,000 Mexican pesos: Financial unrestricted support
Netherlands	in 2016: no sponsoring	

Nordic Countries

FOR SWEDEN

PAH Association Sweden

Rare Diseases Sweden

FOR FINLAND

No support given during 2016

FOR DENMARK

PAH Association Denmark

Financial support for 3 educational meetings for patients and caretakers: 1542 Euro

Rare disease Day support. Aim to increase awareness and educate: 2665 Euro

4541 DKK: board member at the Danish PAH Patient Association, attendance to PHA International PH Conference in Dallas June 17th – 19th 2016

10.000 DKK: Sponsorship to 2016 Seminar for members of the Danish PAH Patient Association

5376 DKK: Sponsorship for meeting for the members of the Danish PAH Patient Organisation to be held on October 22nd 2016

<p>Nordic Countries</p>	<p>FOR NORWAY LHL Norge</p>	<p>NOK 8.333: PAH Awareness Day May 5th 2016</p>
<p>Poland</p>	<p>The Polish Association of People with Pulmonary Arterial Hypertension and Their Friends (Polskie Stowarzyszenie Osób z Nadciśnieniem Tętniczym i ich Przyjaciół)</p>	<p>20 000 PLN: Donation for organizing regional meeting for PH patients, October 15, 2016</p>
<p>Portugal</p>	<p>Associação Portuguesa de Doentes com Esclerodermia (APDE)</p> <p>Portuguese Association for Patients with Scleroderma</p>	<p>Donation of 1'000 EUR on 16 February 2016. Contribution to participate in the 4th SSc World Congress</p> <p>Donation of EUR 2,000 on 5 September 2016. Contribution to sponsor activities related to International Scleroderma Day</p>

Romania	Pulmonary Hypertension Patients Association in Romania (Asociatia Pacientilor Hipertensivi Pulmonari din Romania)	Wet Painting Event on October 14th, 2016. All the funds were donated to Romanian PAH Patients Association. Sponsorship Value: - Financial: RON 27,022 - Materials for painting: RON 5,166 Participation fees to PAH FORUM Barcelona 2016 for Mr. Bogdan Burduja (President of the Association): RON 4241.78
Russia	No financial support in 2016	

<p style="text-align: center;">Slovakia</p>	<p>The Civil Association of Patients with Pulmonary Hypertension</p>	<p>Educational Grant: 3'000 EUR</p>
<p style="text-align: center;">Slovenia</p>	<p>Društvo za pljučno hipertenzijo Slovenije (Patient Association Group for PH) Dbph.slovenije@gmail.com</p> <p>Društvo bolnikov z Gaucherjevo boleznijo Slovenije (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 2016 : 1000 EUR</p> <p>Support for organization of local patient activities (organization of patient meeting at Gaucher day): 300 EUR</p>

Spain

Fundación Niemann-Pick (www.fnp.org)

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

Asociación Nacional Hipertensión Pulmonar

Patient and Caregivers Support Program:
10.548€ Financial support

Fundación contra la Hipertensión Pulmonar

Research activities: 21.200€
Financial support

Federación Española de Enfermedades Raras (FEDER)

Rare Disease Day: 7.000€
Financial support

Fundación Española para el Estudio y Tratamiento de la Enfermedad de Gaucher y otras lisosomales

Rare Disease Day: 7.000€
Financial Support

Asociación Juntos Podemos Vencer

Race to support rare diseases: 500€ Financial support

Asociación Niemann Pick de Fuenlabrada

Niemann Pick National Event: 1.000€ Financial Support

Asociación Española de Esclerodermia

Patient and Caregivers Financial Support: 1.500€

Asociación de las Mucopolisacaridosis y Síndromes Relacionad

Patient and Caregivers Financial Support: 2.000€

<p style="text-align: center;">Switzerland</p>	<p>Cuore Matto http://www.cuorematto.ch/</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> <p>Schweizerische Niemann Pick Vereinigung http://www.npsuisse.ch/</p> <p>Herznetz.ch https://www.herznetz.ch/</p>	<p>Fundraising as a result of Basel Marathon CHF 10'000</p> <p>General support: CHF 7'000</p> <p>Fundraising as a result of Basel Marathon: CHF 9'000</p> <p>General support: CHF 500</p> <p>General support: CHF 5'000</p> <p>Printing material / patient cards CHF 6000.00</p>
<p style="text-align: center;">Taiwan</p>	<p>Taiwan Association of Caring PAH</p> <p>Taiwan Rare Disease Foundation</p>	<p>NT\$ 100,000: for disease awareness campaign (feel breathless campaign)</p> <p>NT\$ 200,000: for patient vaccination program</p>

Turkey	no support provided during 2016	
UK	Scleroderma and Raynauds UK Pulmonary Hypertension Association UK	Donation of £2,000 towards Annual Conference Donation of £950 from speaker fees waived by HCPs Donation of £1,800 from advisory fees waived by HCPs Donation of £30,000 to support the establishment of the PHocus 2021 group Donation of £22,500 towards PHA UK Communications programme

UK

Scottish Pulmonary Vascular Unit

Charitable donation of £1,000 from employee fundraising event

Donation of £3,000 towards Patient day

The Somerville Foundation

Charitable donation of £1,000 from employee fundraising event

PHA Ireland

Donation of £1,000 towards Annual Patient and Family meeting

Charitable donation of £1,000 from employee fundraising event

Neimann-Pick Disease Group

Donation of £20,000* towards International Scientific and Families weekend

* £10,000 from Actelion UK

Charitable donation of £1,000 from employee fundraising event

US

For New Jersey

National Multiple Sclerosis Society

Scleroderma Foundation

Bike to shore ride \$7,500
Booth Sponsor, \$710
Registration and donations
for employee participants

Stepping out to cure
Scleroderma walk \$1,000

For San Francisco

American Heart Association

American Lung Association in KY

\$10,000: Black-tie gala for
heart disease awareness/
silent auction fundraiser

\$3,000: Kentucky Derby
Gala for lung disease
awareness

Bike PHifty, Inc

\$2,000: Bike PHifty
Fundraiser

Blue Lips Foundation

\$5,000: Blue Lips
Foundation Gala

HHT Foundation, International

\$2,500: 18th HHT National
Patient & Family
Conference

Newark Beth Israel Medical Center Foundation

\$5,000: Heart & Sole Walk

US

Pulmonary Hypertension Association

\$2,500: All Hearts On Deck-Casino Night PHor A Cure

\$4,000: Second Annual Right Heart Fight OKC- PHA 5K Run/Walk and Family Picnic

\$1,296,000: PHA's 2016 Corporate Giving Prospectus. Multi-program patient support

\$2,000: Escape from Alcatraz Triathlon

Team PHenomenal Hope

\$100,000: Team PHenomenal Hope Sponsorship- Provide patient education, community events, create opportunities for patients/ caregivers

\$3,500: PHriends4Life SoCal Walk

US

UPHill Journeys

\$2,000: 10th Annual "Swinging Fore a Cure" Golf Tournament

Vera Moulton Wall Center at Stanford (The Board of Trustees of the Leeland Stanford University)

\$25,000: 16th Annual Race Against Pulmonary Hypertension

CMDAT Research Foundation

\$2,400: Free information brochures focused on pulmonary arterial hypertension and Gaucher disease for Russian-speaking patients in Denver, CO

Cutaneous Lymphoma Foundation

\$5,000: CL Foundation 2-Day Patient Education Program

Orange County Breast Feeding Coalition

\$5,000: Patient educational symposium on PAH