

## List of patient groups 2017

<b>Country</b>	<b>Patient Associations</b>	<b>Support from Affiliates</b>
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**HQ**  
**Allschwil**

Pulmonary Hypertension Association Europe (PHA EUROPE)

350'000 Euro grant to support 2017 projects/activities

Donation of 808 PAHuman patient diaries for 2018 (10 CHF per diary)

Federation of European Scleroderma Associations (FESCA)

30'000 Euro: World Scleroderma Day 2017 Global Campaign

European Organisation for rare Diseases (EURORDIS)

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

10'000 Euro: EURORDIS Round Table of Companies (ERTC) membership

**HQ**  
**Allschwil**

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

10'000 US\$: grant to support 2017 projects/activities

PH Serbia

841.75 British£: Participation in PH Serbia advisory board (Danjela Pesic: fee for service & Consultancy)

750 British£: Webinar presentation on how patient organizations can engage young adults living with PAH (Danjela Pesic: fee for service & Consultancy)

Team Phenomenal Hope

19'472 US\$: fundraising

PH Austria

20'000 Euro: fundraising Ghost Run

Phaware Global Association

29'209 US\$: for organization's operational activities

Oxford Health e Policy Forum CIC

20'000 British£: grant to support MS Policy Initiative

**Australia**

Autoimmune Resource and Research Centre

Donation to support educational material printing - \$7,500 AUD

HeartKids Australia

Donation to support development of factsheets and website updates - \$7,500 AUD

Pulmonary Hypertension Association of Australia

Donation to support production of patient videos - \$8,500 AUD

Donation to support attendance at Pulmonary Hypertension Conference in Australia - \$10,000 AUD

Donation for website updates - \$4,080 AUD

Lung Foundation Australia

Donation to support Pulmonary Hypertension awareness event in Parliament House Canberra - \$2,721.35 AUD

Grant to support multiple disease awareness activities and building collaborative relationships with the key patient support group - \$100,000 AUD

**Australia**

Pulmonary Hypertension Network Australia

Donation to support provision of patient education materials - \$12,000 AUD

**Austria**

SHG Lungenhochdruck

25.000 EUR: Support and Maintenance Agreements - core funding of the organisation's activities

Pro rare Austria

3'000 EUR: Core funding

Pharmig OKIDS

5'000 EUR: Sponsoring for organisation's activities

SHG SSc/DU

3.500 EUR: Sponsoring of Patient group meetings

## Belgium

vzw PH België

4'000 EUR: Sponsoring organization of the Patient Association Activities and PH awareness activities in 2017

HTAP Belgique asbl

1'500 EUR: Sponsoring participation to congresses / seminars, support to the LUSS meetings & meetings with patient associations of patients in the hospitals

Association des Patients Sclérodermiques de Belgique (A.P.S.B asbl)

1'500 EUR: Sponsoring to develop educational material, update the website, printing of envelopes and letters, printing of quarterly newsletters

<p style="text-align: center;"><b>Brasil</b></p>	<p>Assoc. Cearense de Doenças Raras - ACDG</p> <p>Assoc. Paulista de Amigos</p> <p>Assoc. Gaucha Pacientes Doença de Fabry e Familiares</p> <p>ABRAF - Assoc. Brasileira de Amigos e Familiares de HAP</p> <p>Assoc. Baiana dos Familiares e Amigos Portadores de Mucopolissacaridoses e Doenças raras ( ABAMPS)</p>	<p>3 000 BRL: Donation</p> <p>25 000 BRL: Donation</p> <p>20 000 BRL: Donation</p> <p>20 000 BRL: Donation</p> <p>3 000 BRL: Donation</p>
<p style="text-align: center;"><b>Brasil</b></p>	<p>ANPB- Assoc. Niemann Pick Brasil</p> <p>IGEIM - Instituto de Genética e Erros Inatos do Metabolismo</p> <p>Casa Hunter</p>	<p>95 000 BRL: Assist in the support and dissemination of materials on rare disease awareness</p> <p>20 000 BRL: Donation</p> <p>225 000 BRL: Assist in the support and dissemination of materials on rare disease awareness</p>



**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

Unrestricted Educational  
Grant to all PAs

**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

<b>China</b>	CORD (Chinese Organization for Rare Disorders)	Roll out PAH patient care program 2017. Actelion China pays all program associated expense. Provides RMB 159,000 to CORD as partnership fee and another RMB 27,500 for event of PAH Day
<b>Croatia</b>	Hrvatska udruga oboljelih od sklerodermije (Croatian Patient Association Group for Scleroderma)	Support the education of its members on educational meetings Amount: 1.000 EUR

<b>Czech Republic</b>	The Civil association of patients with Pulmonary Hypertension	Research and Educational Grant: CZK 70.000,-
<b>France</b>	HTAP France (French PAH association)	35,000 EUR for financial support: <ul style="list-style-type: none"><li>- to PAH medical research</li><li>- to improve the information carrier</li><li>- to update the association's Website</li><li>- to organize weekend for PAH sick patients</li></ul>

# France

Association des Sclérodermiques de France (ASF)

10,000 EUR: Financial support for design, printing and distribution of a self-assessment questionnaire entitled "Scleroderma, my Doctor and me!" given before consultation to patients

25,000 EUR: Financial support to cover:

- part of the attendee's hospitality during the ASF General Meeting
- a specific part of organization of the ASF General Meeting
- publication of Scleroderma Newsletter

Vaincre les maladies Lysosomales (VML)

15,000 EUR : financial support for social and psychological support for parents of sick young patients and adult patients with Lysosomal Diseases

Petit Cœur de Beurre

9,000 EUR : financial support for realize medical information activities for patients with congenital heart diseases

<b>France</b>	Association Nationale des Cardiaques Congénitaux (ANCC)	5,000 EUR : financial support for realize medical information activities for children suffer from congenital heart diseases
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**Germany**

Allianz Chronischer Seltener Erkrankungen (ACHSE) e.V

Funding of public health care and scientific research:  
€ 5'000,00

Niemann-Pick Selbsthilfegruppe e. V.

Funding of public health care and scientific research:  
€ 5'000,00

Pulmonale hypertonie (ph) e.V.

Funding of public health care and scientific research:  
€ 15'000,00

Funding of public health care and scientific research:  
€ 1'000,00

Funding of public health care and scientific research:  
€ 2'000,00

European Pediatric Pulmonary Vascular Disease Network e.V.

Funding of public health care and scientific research:  
€ 7.500,00

<b>Germany</b>	<p>Sklerodermie Selbsthilfe e.V.</p> <p>Raum für Frauen e.V. Bickenbach</p> <p>Pulmonale Hypertonie e.V. LV Sachsen</p>	<p>Funding of public health care and scientific research: € 1.000,00</p> <p>Funding of public health care and scientific research Meeting Selbsthilfegruppe PH Südbrandenburg € 1.000,00</p> <p>Funding of public health care and scientific research € 1.000,00</p>
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<p><b>Greece</b></p>	<p>Hellenic Patient Association for Pulmonary Hypertension</p> <p>PESPA (Greek Alliance for Rare Diseases)</p>	<p>5.000 EUR: support activities - World Day for Pulmonary Hypertension (May 5th, 2017)</p> <p>5.000 EUR: support activities - World PAH Awareness Month (November 2017)</p> <p>4.000 EUR: Support for the completion of a Guest House for PAH patients</p> <p>1.000 EUR: support activities - World Day of Rare Diseases (February 28th, 2017) organized by PESPA</p>
<p><b>Greece</b></p>		<p>500 EUR: support activities of the 5th Educational Seminar for Rare Diseases, 29 September 2017</p>

<p style="text-align: center;"><b>Hungary</b></p>	<p>Hungarian PAH Patient Organization (Tüdöér Egylet)</p> <p>Hungarian National Scleroderma Patient Organization</p>	<p>1.200.000 HUF: unrestricted grant (September 2017)</p> <p>500'000 HUF: unrestricted grant (April 2017)</p>
<p style="text-align: center;"><b>Israel</b></p>	<p>Haverim Lerefua ID Number 580408748</p> <p>Pulmonary hypertension patients association ID Number 580368041</p> <p>Patient Rights Association</p>	<p>Donation: 8,500 ILS</p> <p>Donation: 50,000 ILS</p> <p>Donation: 5,000 ILS</p>
<p style="text-align: center;"><b>Israel</b></p>	<p>Save the Child Heart - Wolfson Medical Center</p>	<p>Donation to association (not patient association) 6 Tracleer 62.5mg packs value of 50,478 ILS based on list price</p>

## Italy

A.MO.MA.R Associazione molisana malati reumatici per lo studio della sclerosi sistemica e delle malattie fibrosanti

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

2'500 EUR

A.B.A.R. Associazione bresciana artrite reumatoide ONLUS

12'000 EUR

APMAR Associazione nazionale persone con malattie reumatologiche e rare ONLUS

8'000 EUR

RespiriAmo Associazione di volontariato malattie del circolo polmonare

10'000 EUR

ALMAR Associazione laziale malati reumatici

3'000 EUR

AS.MA.RA. Associazione malattia rara sclerodermia ed altre malattie rare ONLUS

3'000 EUR

**Italy**

Associazione Italiana Niemann Pick ONLUS	50'000 EUR
Lega Italiana Sclerosi sistemica ONLUS	3'000 EUR
Associazione Alessandro Lupoli ONLUS	10'000 EUR
AIPi Associazione Ipertensione Polmonare Italiana ONLUS	25.000 EUR
Associazione per l'aiuto ai soggetti con s. di Prader Willi ed alle loro famiglie ONLUS	3'000 EUR
Associazione Magica ONLUS	10'000 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	8'000 EUR
AILS Associazione Italiana Lotta alla Sclerodermia ONLUS	5'000 EUR
ALT Associazione Lotta Trombosi Malattie Cardiovascolari ONLUS	20'000 EUR
ATMAR Associazione triestina malattie respiratorie ONLUS	30'000 EUR
Associazione Anziani ma sempre giovani ONLUS	2'500 EUR

<b>Japan</b>	<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>20,000 JPY: financial support</p>
<b>Korea</b>	<p>Pulmonary Hypertension Association Korea ( PHA Korea )</p>	<p>30,000,000 KRW : financial support for the activities of the organization</p>
<b>Mexico</b>	<p>in 2017: no support</p>	

<p><b>Netherlands</b></p>	<p>Stichting PHA Nederland</p>	<p>1'500 EUR sponsorship for "Heart for Phighters" sport shirts</p>
<p><b>Nordic Countries</b></p>	<p>FOR SWEDEN 2017 PAH Association Sweden</p> <p>FOR DENMARK 2017 PAH Association Denmark</p>	<p>Financial support patient brochure (production, printing and distribution) 45 000 SEK</p> <p>25.000 DKK: sponsor the yearly meeting for the members of the Danish PAH Patient Organisation to be held on May 27th – 28th 2017.</p>

**Nordic Countries**

FOR FINLAND 2017  
Finnish Scleroderma Association

FOR NORWAY 2017  
No support given

For more detailed info. Please contact:  
[medinfo\\_nordic@actelion.com](mailto:medinfo_nordic@actelion.com)

Support for Scientific  
meeting for Patients in th  
Rehabilitation center Apila  
24-26 of March 2017

**Poland**

The Polish Association of People with Pulmonary Arterial Hypertension and Their Friends (Polskie Stowarzyszenie Osób z Nadciśnieniem Tętnicznym i ich Przyjaciół)

- 60 000 PLN: Donation for organizing two regional meetings for PH patients: April 15, 2017 and September 30, 2017  
- 10 000 PLN: PAH Awareness Day May 5th 2017



<p style="text-align: center;"><b>Portugal</b></p>	<p>Portuguese Association for Patients with Scleroderma (APDE)</p>   <p>Portuguese Association for Pulmonary Hypertension (APHP)</p>	<p>Donation of 2'000 EUR - January 2017 Contribution to participate in the FESCA 2017 Congress</p> <p>Donation of EUR 2,000 - April 2017 Contribution to sponsor: 2 patient meetings in Lisbon and Oporto</p> <p>Donation of EUR 10,000 – November 2017 Contribution to Sponsor; several activities organized in 2017</p>
<p style="text-align: center;"><b>Romania</b></p>	<p>No financial support in 2017</p>	

<b>Russia</b>	No financial support in 2017	
<b>Serbia</b>	Plućna hipertenzija Srbija (Serbian Patient Association Group for PH)	Support the education of its members on educational meetings Amount: 1.500 EUR
<b>Slovakia</b>	The Civil Association of Patients with Pulmonary Hypertension	Research and Educational Grant: EUR 3.300,-

<p style="text-align: center;"><b>Slovenia</b></p>	<p>Društvo za pljučno hipertenzijo Slovenije (Patient Association Group for PH) Dbph.slovenije@gmail.com</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 2017 : 1.800 EUR</p>
<p style="text-align: center;"><b>Spain</b></p>	<p>Fundación Niemann-Pick</p> <p>Asociación Niemann-Pick Fuenlabrada</p> <p>Fundación de Medicamentos Huérfanos y Enfermedades Raras</p> <p>Hipertensión Pulmonar España Organización de Pacientes (HPE-ORG)</p> <p>Asociación Nacional de Hipertensión Pulmonar</p> <p>Fundación Contra la Hipertensión Pulmonar- FCHP</p>	<p>XVIII Scientific-family National Congress: 7.000€</p> <p>Scientific-family Conference: 1.000€</p> <p>International Congress 5.000€</p> <p>- Two Business meetings: 6000€</p> <p>- World PH Day: 3000€</p> <p>Projects and activities: 1.000€ + 5.848€</p> <p>Conference for patients 3.000€ + 5.000€</p>

<b>Switzerland</b>	<p>SPHV Schweizer PH-Verein  <a href="http://www.lungenhochdruck.ch/php/index.php">http://www.lungenhochdruck.ch/php/index.php</a></p> <p>Schweizerische Niemann Pick Vereinigung  <a href="http://www.npsuisse.ch/">http://www.npsuisse.ch/</a></p> <p>Herznetz.ch  <a href="https://www.herznetz.ch/">https://www.herznetz.ch/</a></p>	<p>General support: CHF 10'000.00</p> <p>General support: CHF 5000.00</p> <p>Printing material / patient cards CHF 3875.00</p>
<b>Taiwan</b>	<p>Taiwan Rare Disease Foundation</p> <p>Taiwan Association of Caring PAH</p>	<p>NT\$ 200,000: for patient all-spect caring program</p> <p>NT\$ 100,000: for confirmed patient caring program</p> <p>NT\$ 100,000: for confirmed patient caring program</p> <p>NT\$ 150,000: PAH education program</p> <p>NT\$ 100,000: PAH education program for HCP</p>

		NT\$ 100,000: VHG-KH PH Preceptorship
<b>Taiwan</b>		NT\$ 100,000: Education program for iPAH Patients outdoor activity
<b>Turkey</b>	no support provided during 2017	
<b>UK &amp; Ireland</b>	<p>Scleroderma and Raynauds UK (SRUK)</p> <p>Pulmonary Hypertension Association UK (PHA UK)</p>	<p>Donation of £5,000 towards Annual Conference and Mawdsley Memorial Lecture</p> <p>Donation of £2,150 from speaker and advisory fees waived by HCPs</p> <p>Donation of £85,000 towards PHA UK Communications</p>

		<p>programme</p> <p>Donation of £750 for PHA UK involvement in Actelion film</p>
<p><b>UK &amp; Ireland</b></p>	<p>Pulmonary Hypertension Association UK (PHA UK)</p>	<p>Travel expenses for PHA UK/Actelion May advisory meeting, £152.72</p> <p>Donation of £30,000 towards development of 'Café PHocus' self-management online programme</p> <p>Donation of £6,000 towards 3 PHA UK study days</p> <p>Donation of £1,500 for PHA UK involvement in Act on PAH meeting in November</p> <p>Donation of £450 for PHA UK involvement in advisory board</p> <p>Travel expenses for PHA UK/Actelion November advisory meeting, £143.31</p>

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<p style="text-align: center; color: red; font-weight: bold;">UK &amp; Ireland</p>	<p>PHA Ireland</p> <p>Neimann-Pick UK (NPUK)</p> <p>Shift MS</p>	<p>Donation of 4000 Euros (~£3500) to PHA Ireland for Annual Conference and World PH Day activities</p> <p>Donation of £20,000* towards International Scientific and Families weekend * £10,000 from Actelion UK</p> <p>Donation of £6,200 towards filming of interviews at ECTRIMS 2017 Congress</p>
<p style="text-align: center; color: red; font-weight: bold;">US</p>	<p><i>For New Jersey</i> Penn State THON</p> <p>Scleroderma Foundation</p> <p>National MS Society</p>	<p>Company Sponsorship - \$ 2,500 US for Pediatric Cancer</p> <p>Donation \$ 1,000.00 US to support the 2017 Stepping Out -Ventnor Walk</p> <p>City to shore bike ride \$ 3,000.00 US for employee donations</p>



<p style="text-align: center; color: red; font-weight: bold; font-size: 2em;">US</p>	<p><b><i>For San Francisco</i></b>  American Heart Association</p> <p>American Lung Association of the Southeast and KY</p> <p>BAPS Charities, Inc.</p> <p>Blue Lips Foundation</p>	<p>\$5,000: Pittsburgh Heart Ball</p> <p>\$5,000: Fight For Air Climb Atlanta</p> <p>\$3,000: 2017 Derby Eve Gala</p> <p>\$1,500: BAPS Charities Health Fair</p> <p>\$5,000: Blue Lips Foundation Gala</p> <p>\$10,000: Fore The Heart Open</p> <p>\$5,000: Halloween At The</p>

	Camp del Corazon	<p>Hangar</p> <p>\$5,000: Heart to Heart Educational Symposium for Children and Families Affected by CHD</p>
<p>US</p>	<p>Cincinnati Children's Hospital</p> <p>DeWitt</p> <p>International Scleroderma Network</p> <p>Minneapolis Heart Institute Foundation</p> <p>NORD (National Organization for Rare Disorders)</p> <p>Project Scleroderma</p>	<p>\$10,000: 27th International Patient Symposium on Adult Congenital Heart Disease</p> <p>\$1,500: DeWitt Take a Breath for PH and Get Moving for MS</p> <p>\$15,000: 2018 Scleroderma and PAH Awareness, Education and Support</p> <p>\$2,500: Women,s Event: Hope, Health &amp; Humor</p> <p>\$25,000: 2017 Rare Impact Awards</p> <p>\$75,000: Dear Scleroderma Web Series, GRASP Project</p>

	Pulmonary Hypertension Association	<p>Documentary, and Video Series for Patient APP</p> <p>\$10,000: The Woodlands BBQ Festival</p> <p>\$6,000: Driving Fore a Cure Golf Tournament</p>
US		<p>\$1,000: Desert Divas And Dudes Walk For PH</p> <p>\$1,500: 5th Annual Steps for Stripes O2 breathe Fun Walk</p> <p>\$1,300: Zebra Wine PHest III</p> <p>\$5,000: North Texas CrawPHish Boil</p> <p>\$1,000: Sarah Smiles PHun-Raiser for PH</p> <p>\$2,500: GA PHA Fun Walk for a Cure</p>

	St. Vincent Hospital Foundation Inc.	<p>\$20,000: Rochester (MN) PHA Gala</p> <p>\$104,000: 2017 National O2 Breathe Sponsorship</p> <p>\$15,000: Love It! Soiree</p>
<p>US</p>	<p>T Cell Leukemia Lymphoma Foundation</p> <p>UPHill Journeys</p>	<p>\$8,000: TCLLF 2017 Seattle T-Cell Lymphoma Patient Education Forum</p> <p>\$8,000: TCLLF 2017 San Francisco T-Cell Lymphoma Patient Education Forum</p> <p>\$8,000: TCLLF 2017 Hawaii T-Cell Lymphoma Patient Education Forum</p> <p>\$8,000: TCLLF 2017 Alaska T-Cell Lymphoma Patient Education Forum</p> <p>\$1,100: 11th Annual "Swinging Fore a Cure" Golf Tournament</p>

	<p>Vera Moulton Wall Center at Stanford (The Board of Trustees of the Leeland Stanford University)</p> <p>American Heart Association</p> <p>Bike PHifty, Inc.</p> <p>Echo Hill Outdoor School Heart Camp 2017</p>	<p>\$25,000: 17th Annual Race Against PH</p> <p>\$5,000: Washtenaw County Heart Ball</p> <p>\$2,700: Bike PHifty 2017</p> <p>\$5,000: Heart Camp 2017</p>
<p style="text-align: center; color: red; font-weight: bold;">US</p>	<p>Have a Ball Foundation</p> <p>LSU Health New Orleans Foundation</p> <p>National Comprehensive Cancer Network (NCCN)</p> <p>Scleroderma Foundation</p> <p>UCSF Benioff Children's Hospital San Francisco</p>	<p>\$5,000: 13th Annual "Have a Ball" Golf Tournament</p> <p>\$1,000: Mudbug March to Stomp Out Pulmonary Hypertension</p> <p>\$5,000: 2018 NCCN Patient Advocacy Pavilion</p> <p>\$395,000: 2017 Patient Support And Advocacy Grant</p> <p>\$5,000: Phamily Camp for Pediatric Pulmonary Hypertension at the Painted Turtle</p>

	Westchester Medical Center Foundation phaware global association	\$2,000: Girls' Night Out \$10,000: breathless on Broadway
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