

# Hellenic Pulmonary Hypertension

*H.P.H. is a non-profit organization representing Greek patients with Pulmonary Hypertension*



## Mission statement

Hellenic Pulmonary Hypertension – H.P.H is a non-profit association established in 2013 with the aim of providing its members with accurate and timely information about developments regarding pulmonary hypertension (PH). The reason for the establishment of a Hellenic national association was to help towards the positive reinforcement and enrichment of the work of international PH associations, as much as towards the much-needed coordination of Greek patients with PH.

Our association was established with the initiative of Greek patients with PH, for it was deemed necessary to create an organization that represents patients with the rare disease of PH, protects their legitimate rights, and seeks to ensure the betterment of living conditions for them and their families. The association's mission is to work towards the solution of the problems patients are facing with everyday activities. Notwithstanding progress in recent years, problems are still many and serious. Our continuous and increased efforts vis-à-vis government institutions are even more necessary for the protection of patients' rights in a time of economic crisis.

The holding of events, fairs, conferences, sport activities and information campaigns advances awareness about PH, bolsters the sentiments of solidarity and communion, and improves the social, psychological and economic conditions of patients and their families.

## What is Pulmonary Hypertension?

<b>Description</b>	PH is a rapidly progressive, deadly disease, affecting the lungs and heart. It comes in 5 types.
<b>Symptoms</b>	Often non-specific, with the most common of them including breathlessness, fatigue, and blue lips.
<b>Prognosis</b>	One in two patients die within two years if not treated. Survival and life quality can be significantly improved with early diagnosis and treatment.
<b>Patients</b>	It is estimated that there are more than 25 million patients globally.
<b>Treatment</b>	Currently, there is no cure for 4 of 5 PH types. Lung or lung-heart transplantation is the only curative treatment, for those eligible.



*Time matters greatly for patients with PH. As symptoms are non-specific and common in many diseases, diagnosis may take up to two years. PH is a rapidly progressive disease and valuable time lost in its progression cannot be regained. Early diagnosis and treatment can significantly improve survival rates and living conditions.*



*Our vision is to see this disease termed as 'non-deadly'*

HPH family, facing such a serious disease, has often to deal with losses. Tough losses that are never easy to handle. Members of our family that leave us early. The most unfair losses are those happening from ignorance—either the doctor's or the patient's. This is something that needs to change.

A major concern of our association is the more frequent and energetic advice and guidance, not just to patients but also to the medical community, on matters pertaining to the disease. Among our highest priorities is to encourage deeper expertise of PH specialists, as well as to achieve collaboration with international specialist centers to secure access for Greek patients.

HPH's imperative goal is the establishment of a specialist center for children with PH. Towards this aim, we have already launched the process of planning an intensive care unit for children with PH at the city of Thessaloniki.

It is very difficult to carry on after a loss. But quitting is not an option, because our vision to see this disease termed as non-deadly takes us forward.



Hellenic  
Pulmonary  
Hypertension

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PHA Europe is the umbrella organization for 33 patient associations from 29 countries that work together to enhance awareness and understanding of PH.

## With the support of PHA Europe

H.P.H. is a member of the European family of pulmonary hypertension association, which was founded in 2003 in Vienna, Austria. PHA Europe works together with national patient associations to enhance awareness of PH across Europe, promote optimal standards of care for people living with the disease, ensure the availability of all approved treatments, and encourage research for new medicines and therapies.



# The Work of H.P.H.

## *Our goals and accomplishments through our projects*

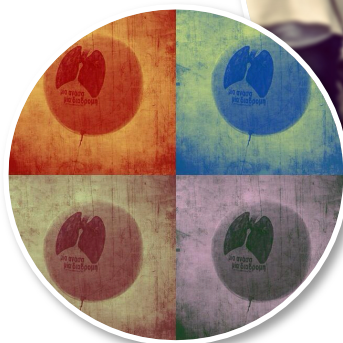
*In the two years since the founding of our association, HPH has successfully established a series of activities with the aim of making them customary practice. Our goal is to instill a sense of power and solidarity to our members, and develop a similar mentality of concern and consideration for rare diseases in our society.*

### *Cycling*

Every year around May 5, in honour of World Pulmonary Hypertension Day, we ride our bikes in the city of Athens. The aim of our cycling event is to raise public awareness through a sport that draws the attention of people in the streets and combines physical and mental health. Cycling is a sport of the open road and nature; a sport for everyone; a sport of strong hearts! Our objective is to hold a cycling ride on a yearly basis in order to make it a habit both for our members and patients and for the athletes, volunteers and other participants that join us.

### *Women in action*

We have established a day dedicated exclusively to women, to be celebrated every year on the last Sunday of November—PH awareness month. Given that PH shows a preference for women, hitting them twice as commonly as men and usually at ages between 25 and 35, we decided to bring all womens' positive energy together. On that day, we take power from mothers, sisters, wives, daughters and friends, and spend a night together showing our solidarity to each other. On this day we look at women's heart not as a diseased organ but as a symbol of love and endurance.



*Under the slogan “One Breath, One Ride”, our cyclists filled the streets of Athens*

### *Educative program*

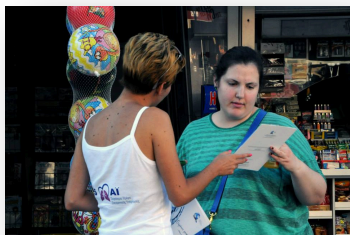
We have launched a pioneering initiative at Greek preschools and schools, which was congratulated by teachers, tutors and counselors for laying the basis for conscious, informed and responsible adults. “*I Learn about Rarity and I Live with it*” is an interactive program of education on rare diseases aiming at increasing familiarity with rare diseases, building social conscience, as well as achieving understanding and early recognition of the symptoms. HPH representatives visit nurseries and schools, and in simple and playful ways talk with children about rare diseases, taking PH as an example.

### *Life marathons*

The pulmonary artery pressure of a classic marathon runner, after an average of four hours of running, is not greater than 30 mm Hg. A PH patient is running a double marathon every day, as the pressure in his pulmonary artery is greater than 60 mm Hg. With this strong symbolism in mind, athletes and volunteers representing HPH participate every year in the Athens Classic Marathon and Half Marathon. Our objective is to make our rare disease known to the broader public, including athletes and spectators from all over the world that attend the event.

### Information campaigns

Each year we organize a series of information campaigns in central places in various Greek cities, distributing information leaflets and factsheets along with PH-logoed souvenirs like ribbons, hats, badges, flags and balloons. The aims of this effort are to strengthen patient's voice, highlight the importance of recognizing symptoms and achieving early diagnosis, and make our rare disease visible everywhere.



### Honouring Rare Disease Day

To celebrate World Rare Disease Day—an annual observance held on the last day of February—HPH joins forces with the European Organization for Rare Diseases (EURORDIS) and organizes various activities to raise awareness for rare diseases and stand for better access to treatment for Greek patients.



### Organizing and participating in conferences

Our contribution in organizing medical seminars and conferences in Athens and Thessaloniki brought as a result the recognition of the importance of patient's voice in the medical community, as well as the get-together of specialists from different disciplines and departments. Medical specialists have been willing to participate in our activities and support our efforts to foster better collaboration between patient and doctor.

### Pongo the mascot

HPH has created a mascot—*Pongo* the rare purple elephant—that accompanies us in all our activities and is also the hero of our educative program. Pongo draws the attention of our little and big friends on every appearance, sending a message of optimism, courage and solidarity. Thus, our rarity becomes a symbol of strength and hopefulness, and two of the most common symptoms of PH—breathlessness & skin bruises—become the story of Pongo's life.



### Purple ribbon

HPH has designed and produced a unique ribbon especially for pulmonary hypertension, symbolizing PH awareness. It is purple in colour with illustrations of puzzle pieces in shades of purple. Our goal is to make PH visible and recognizable, and familiarize the public, as much as the medical community with our rare disease. Thus, we ask everybody to wear it on his chest and explain what it stands for.



## Review of Actions

*The goals of Hellenic Pulmonary Hypertension are the assertion and protection of patient's rights, the improvement of patients' standards of living, the establishment of customary activities, the active participation in various community events, and the organization of activities that strengthen the spirit of solidarity between patients, carers, families and health professionals.*

### *The birth of our association*

In January 2013 our association was officially established with the aim of representing all Greek patients with the rare disease of Pulmonary Hypertension. The intention behind this initiative was the formation of an association to defend the rights of Greek patients and provide support and solidarity to patients and their families. We started amid a dire economic crisis with a single aim: ensure optimal standards of healthcare for people living with the disease.



### *Pedalling for PH*

We ran our first event on the occasion of World PH Day. On Sunday 28 April, 2013, members and friends of our nascent association took their bicycles for a different ride. In the morning, we held the first press conference for pulmonary



*The panel of our first press conference*

hypertension in the presence of *Dr. Ioannis Lekakis*, Professor of Cardiology at Medical School of University of Athens, *Mr. Panagiotis Kariofyllis*, cardiologist at Onassis Cardiac Surgery Center, and *Ms. Ioanna Alissandrato*, President of HPH.

The bike ride started at 11.00 a.m. from Hagia Sophia square at Psychiko, and ended at the Olympic Velodrome of Athens, where we also held our first conference. Our bike ride was the first patient-driven event in Greece, receiving highly positive and encouraging comments from medical newspapers, websites and radio shows in Greece, as well as in Europe through PH Europe.



*Participants and supporters of our first bicycle ride*

We were highly honoured by the presence of Under-Secretary of Health *Marios Salmas*, President of the Medical Association of Athens and Mayor of Maroussi *George Patoulis*, Associate Professor in Medical School of Athens *Stylianos Orfanos*, and cardiologist *Panagiotis Kariofyllis*. At our side for our first event were also the Hellenic Cycling Federation, numerous cycling associations, as well as many bicycle fans and volunteers!



### Information campaign around Athens

In the summer of 2013, our association organized a series of information events in various municipalities in the northern suburbs of Athens, with the aim of raising awareness about PH, as much as all rare diseases, and strengthening the voice of Greek patients with rare diseases. The members of our association distributed information leaflets, HPH-logoed pin, budes and hats to everybody interested.

The Mayors of all the municipalities we visited — Maroussi, Chalandri, Psychiko, Kifissia and Dionysos — supported our information campaign and honoured us with their presence.



*HPH with the Mayor of Chalandri*

The results of our information campaign were impressive, as we found four new patients, one of them diagnosed with PH but without medical treatment. This remarkable result was not only rewarding for the efforts we put, but also pointed out the urgent need for accurate and credible information to the Greek public, as much as to the medical community.

### Our first appearance on TV

At the end of June 2013, *Newsit Channel* hosted the President of HPH Ioanna Alissandratou to speak about our rare disease at the health show “Disabled’s people voice”, which is presented by journalist Vangelis Sarris.

The show was devoted to rare diseases and mainly to the voice of the patient. The other guests of the show were Mr. Sotiris Sakellariou, patient with achondroplasia, and Mr. Thanasis Anahourlis, President of the Association of athletes with kidney disease.



*HPH President on Newsit Channel*

### European distinction for HPH

In September 2013, HPH took part for the first time in the PHA Europe’s General Annual Meeting (GAM) in Barcelona, Spain. There, we received a warm welcome from the rest members of our big family and we had the opportunity to unite our voices for patients with pulmonary hypertension. In recognition of the efforts, achievements and rapid development of our nascent association, PHA Europe awarded us third place for Best Campaign for World PH Day.

The 2013 GAM marked PHA Europe’s tenth anniversary and had the highest turnout with 65 representatives from 27 countries. We were given the opportunity to exchange ideas, share experiences and discuss ways to improve the quality of life of all European patients.

The acknowledgement of the huge efforts we made during the first few months since the establishment of our association filled our members as much with pride as with a sense of responsibility to keep trying for the best.





*The three winners for best World PH Day campaign! From left to right: Natalia Maeva from Bulgaria, Agnieszka Bartosiewicz from Poland, and Ioanna Alissandrato from Greece.*

### Special Magazine for Rarity

In October 2013, HPH took another initiative to integrate all rare diseases, publishing the first issue of a magazine written for and from patients with rare diseases. “Communicating Rarity” has been an effort to share information about rare diseases based on patients’ experiences with the ultimate goal to reach out and foster solidarity among all “rare” patients.

Our major concern has been to eradicate the symptom of isolation that is caused by the rarity of our diseases, and create a “strong chain” with thousands “rare links” that, notwithstanding the differences between our diseases, have one very important thing in common: the need for better medical care, treatment and standards of living.

The newsletter belongs to all “rare” patients who can use this space to talk about the major issues that trouble them, share their experiences, exchange information, and seek workable solutions for our “rare” community.



### Opening up to northern Greece

HPH participated in the 6<sup>th</sup> Rare Diseases Conference held by the Greek Alliance for Rare Diseases (Π.Ε.Σ.ΠΑ.) in Thessaloniki on 11 & 12 October, 2013 and entitled “Rare Diseases in Northern Greece”, thus giving us the opportunity to reach out to patients with PH that leave far away from Athens. The conference was organized in cooperation with the Athens Medical Society in the framework of continuing education of health professionals with the objective of creating a series of educational programs for promoting better and wider training on rare diseases.

### Another distinction for HPH from Greek patients

On 8 & 9 November, HPH attended the 2<sup>nd</sup> Panhellenic patients’ conference entitled “Patients in Power 2013” and organized under the auspices of the Greek Ministry of Health. With patients’ initiative as the message of the day, the conference was attended by 449 participants mainly representing patients’ associations from all over Greece. The conference provided an excellent opportunity for everybody to meet and discuss common problems and suggestions for solving them, as well as to urge for a more efficient and equitable health system, and appeal for patients’ participation in planning, implementation and evaluation of health policies.



HPH was honoured to receive a distinction award in recognition of the good practices with respect to raising awareness, providing information, and protecting the rights of patients with PH.

### Women in action

In November 2013, on the occasion of PH awareness month, HPH organized for the first time a charity music event with fabulous live music from composer *Antonis Gounaris* and the delicious food menu of restaurant “57” in Glyfada. We were also glad to host the actor *Thanassis Tsaltampasis*, who supported fulheartedly our initiative and continues to stand by us.

Given that PH shows a “preference” in young women, our idea was to hold a charity event exclusively for women; women that are involved in any way in our lives—the mother, the sister, the wife, the patient. The aim of this effort was to foster solidarity among women patients and draw from womens’ heart all the positive energy, strength and love.



*A ladies night out for the patients with PH*

### Official recognition of PH

Following the repeated appeals and interventions of HPH, the rare disease of pulmonary hypertension was officially recognized by Ministerial decree—as published in the Official Government Gazette/*ΦΕΚ* 2906/18-11-13—and it was included in the list of the 43 diseases for which the status of disability is awarded for an indefinite period (for Class III and above). As a result, insured patients are not required any longer to go through reexamination at the Disability Certification Centres.

### “All about my Health: Rare but not alone.”

HPH was hosted along with other “rare” associations in «All about my Health», the most popular TV health show in Greece, with Mr. Michalis Kefalogiannis at Mega Channel, that was broadcasted on Saturday 21 December 2013. This particular show was devoted to rare diseases and «rare» patients that in total rise up to 800.000 people.

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**ΥΓΕΙΑ**  
μου

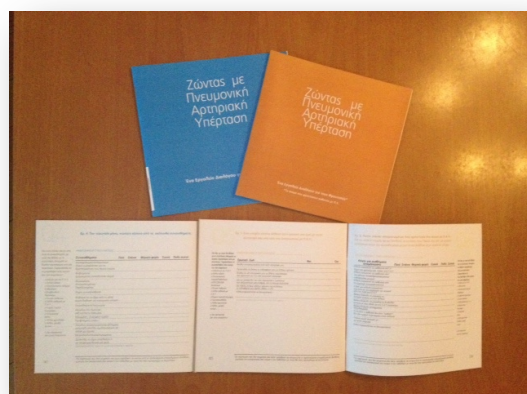


*“Rare” patients in Greece are about 8% of the population*

### Patient and Carer Dialogue Tools

Given that PH is a personal condition and its symptoms vary in each individual, the *Dialogue Tools* is one of the most important means at a patient’s disposal to keep track of the development of the disease and his feelings. Findings from the International Patient and Carer Survey highlight not only the physical but also the often-overlooked emotional and social impact of PH on the lives of patients and their carers. In response to these findings, PHA Europe, in conjunction with a steering committee of PH experts and patient organization representatives, developed the *Patient and Carer Dialogue Tools* and made them available to local patient organizations across Europe. In practice, these tools work like a diary to help both the patient and the doctor to keep record of the development of the disease and to encourage focused discussions about these issues in consultations.

The purpose of the Dialogue Tools is, through a series of simple questions, to help patient and carers to gather symptoms, thoughts and feelings in a structured way to help having more productive consultations with the doctor. These Dialogue Tools have been translated in various languages and national associations were asked to make the most out of them.



*The Greek version of the Patient and Carer Dialogue Tools*

HPH did not just have the Dialogue Tools translated, but also promoted its use and created a shorter version making it more accessible and practical, with PHA Europe bestowing us the best practice award. HPH organized a variety of activities aimed at increasing the knowledge and understanding of the Dialogue Tools. A press conference was held at the PH unit of Attikon Hospital on 19 December 2013, in which PH specialists *Apostolos Armaganidis* and *Stylianos Orfanos* together with HPH President *Ioanna Alysandratou* sought to demonstrate their value and educate health journalists on the importance of the tools.

In March 2014, HPH participated in a roundtable meeting to provide a practical overview and demonstrate how the tools can be used and filled in, but also to encourage their regular use and remind healthcare professionals about the importance of using them with patients and carers alike. The single-page version of the Dialogue Tools was hailed as a great idea and was adopted by PHA Europe.

### *I Learn about Rarity and I Live with it*

With the aim of supporting and contributing to the work of international organizations for rare diseases, such as the European Rare Diseases Organisation (Eurordis), Rare Connect, and the U.S. National Organization for Rare Disorders, and on the occasion of World Rare Disease Day, HPH decided to create the educational program «I Learn about Rarity and I Live with it».

Rare diseases are often neglected when discussing about diversity in society. Moreover, preconceptions are usually developed in children and adolescents, while children with some form of rare disease may be found in a school class or the neighbourhood. HPH seeks through its education program to touch on these sensitive issues and introduce rarity to the citizens of tomorrow.

The aim of the program is to sensitize children and teenagers on rarity and diversity in society and life. The program is orientated to children of preschool and school age, as it involves stories and fables about rare words, flowers and animals, as well as simple and playful ways to think and reflect on rarity and diversity. The ultimate goal of the program has been to sensitize the Greek society, laying strong foundations for future generations that are free from biases and phobias, understand the meaning and origin of diversity and are ready to accept and welcome it.

*The poster of HPH's education program*





### *Celebrating World Rare Disease Day*

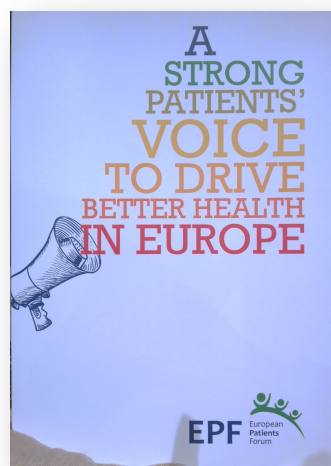
February 28 has been designated since 2008 as World Rare Disease Day with various events taking place all around the world. HPH held an event in the central square of Kifissia—a northern suburb of Athens—with the aim of raising awareness about rare diseases. Colourful balloons, smiling faces, and optimistic messages from our members and volunteers sent away the clouds on that raining day and spread the message of solidarity to all “rare” patients of the world. HPH members gathered in the busiest shopping street of Kifissia distributing information leaflets, balloons and badges to passengers who showed a keen interest in our cause and lend us their support.



*HPH celebrates Rare Disease Day in Kifissia*

### *Participating in EPF's conference*

The European Patients Forum (EPF) organized a conference about cross-border healthcare from 7 to 9 April 2014 in Athens, with representatives from Greece, Cyprus, Italy and Malta. EPF's objectives were to build knowledge about the EU directive and patients' rights enshrined within this legislation. HPH participated in the conference, expressing its views on the aspects of the EU Directive that are particularly important for Greek patients, as well as its concerns about its implementation in the Greek context. HPH underlined the importance of creating a network that will increase cooperation between patient organizations and that will check and evaluate implementation in Greece.



### *Creating our own website*

In the spring of 2014, HPH managed to create its own website, thus having the ability to share information about developments in the field, advertise its activities, and build better relationships with its members. Visitors of HPH website can find information about patient's rights and all the details of and changes in European and Greek legislation, as well as news about scientific research on PH. They can also look at our website to find reviews and photos from past events. Visitors can subscribe to our newsletter to receive all news to their email address. Our web address can be found at [www.hellenicpulmonaryhypertension.gr](http://www.hellenicpulmonaryhypertension.gr)






### One breath, one ride for WPHD

HPH organized a bicycle ride for a second consecutive year to celebrate 2014 World PH Day. This was the first among a series of events we held with the aim of showing solidarity to patients around the world and raising awareness about the rare disease of pulmonary hypertension. On Sunday 27 April, we gathered at the historic centre of Athens for a “different” ride in the streets around the Acropolis. Despite the raining morning, the turnout was impressive. Our cyclists started from Ermou street at 9.30 a.m. and finished at Thissio, where our volunteers waited for them with purple balloons on their hands. For the first time we created a television commercial spot to advertise the day and the cause of our event with the assistance of the artist Nikos Ignatiadis who composed the musical score.

The Greek media reported on the event with enthusiasm and favourable comments. *Iatronet.gr*, *onmed.gr* and *To Vima*, among others, communicated our event and published the following statement from HPH President Ioanna Alissandrato: “It is especially important to us to see the appeal of the event and the support of our fellows, members and friends. The life of patients with Pulmonary Hypertension is very difficult and every breath we take is valuable. Watching people coming in to lend us a breath and show us their support, with their participation to the bicycle ride, is very rewarding and fills us with courage and optimism to face the future; a future that hopefully involves deep breaths for all of us.”

ΠΑΓΚΟΣΜΙΑ ΗΜΕΡΑ ΓΙΑ ΤΗΝ ΠΝΕΥΜΟΝΙΚΗ ΑΡΤΗΡΙΑΚΗ ΥΠΕΡΤΑΣΗ  
27.04.14





**μία ανάσα  
μία διαδρομή**  
για τους ασθενείς με ΠΑΥ

Σας περιμένουμε όλους την Κυριακή 27 Απριλίου 2014, για μία βόλτα με ποδήλατο υπέρ των ασθενών με Πνευμονική Αρτηριακή Υπέρταση.

Σημείο εκκίνησης το παρκάκι στην οδό Ερμού και Ασωμάτων στις 9.30!

Στο τέλος της διαδρομής, στην οδό Αποστόλου Παύλου και Ηρακλειδών, σας περιμένουμε με ή χαρις ποδήλατα, να δείξουμε όλοι την υποστήριξη μας στους ασθενείς με Πνευμονική Αρτηριακή Υπέρταση

Διοργανωτής:    
PHA EUROPE

με την ενεργή συμμετοχή της  
Ελληνικής Εταιρείας Βρογχολογίας

50th  
World Pulmonary  
Hypertension Day

Ελληνική Εταιρεία  
Βρογχολογίας  
Εταιρεία για την  
Μέτρηση του Νωτός

ACTELION

HPH family at Thissio for WPHD 2014



### Working lunch with Health Minister

On Wednesday 30 April, following an initiative of HPH, PH specialists, health professionals, and patient representatives met with Health Minister



Health Minister Georgiadis with Ms Alissandratou

Adonis Georgiadis to discuss and seek solutions to the major problems in the health care system for patients with rare diseases. Mr. Georgiadis committed to turn things around and help us implement a patient registry program, which is very important in maintaining data, observing the course of the disease and assessing clinical outcomes.

### Running in Athens Half-Marathon

On Sunday 4 May, HPH was represented in the Athens Half-Marathon by runners Nikos Skourias, Nontas Xenos, Nikos Mandalopoulos and Panagiotis Agiannidis, as well as by Vangelis Thrasylvoulou who participated in the 3 km race. They all gave their breath to our cause, and made us very proud for running on behalf of patients with PH.



### Presentation of good practices and activities

HPH along with four other patient associations (Hellenic Cystic Fibrosis Association, Panhellenic Association of Individuals with Attention Deficit Hyperactivity Disorder, Hellenic Retina Society, and Greek Guide Dogs Centre) coorganized an event at Impact Hub Athens, a local network of collaboration that hosts various activities. The aim of the event was twofold: firstly, the bonding of the community of rare diseases, and secondly, the presentation of each association's program with emphasis on those practices that proved fruitful and can be imitated by the rest of the associations.

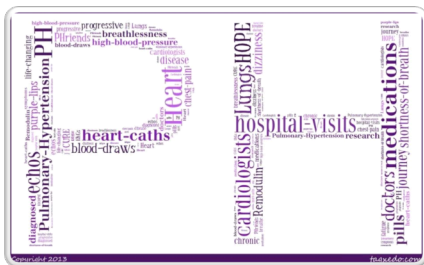


HPH opened the event presenting its program for 2014, as well as three of its good practices: the annual bicycle ride; the education program on rare diseases; and the creation of the unique purple ribbon. For each of our good practices, we presented the idea behind it, the reason for carrying it out, the benefits for the association, as well as the obstacles we faced.



### Intervention at the European Parliament

In May 2014, HPH issued an official statement to the Greek Members of the European Parliament about the problems patients with pulmonary hypertension and other rare diseases encounter in Greece. Our association requested the facilitation of transplantation procedure, the control of implementation of Directive 2011/24/EU on patients' rights in cross-border healthcare, and the interconnection and specialized medical education of the medical community across Europe.



### PH excluded from prescription ceilings

In September 2014, following HPH's successful intervention at the Greek Ministry of Health and the Greek National Health Service Organization (EOΠΥΥ), PH was excluded from the prescription limit imposed on all public doctors. HPH issued a detailed letter of statement to all organizations involved, explaining the important reasons for the exclusion of PH from the prescription ceilings imposed on both clinical and private doctors. This was a huge success for our association and a big relief for PH patients.



### “Communicating Rarity” inserts Volta

Our special magazine for rare patients «Communicating Rarity», wishing to strengthen the network of rare disease associations through the public discussion of issues of concern of local, national and global origin and interest, initiated a cooperation with *Volta Magazine*, which has a circulation of 20,000 copies in the northern and southern suburbs of Athens. «Communicating Rarity» will be freely distributed as a pullout insert with the printed edition of Volta. Thus, we contribute towards the aim of strengthening and bringing together all “rare” associations, as well as individual patients, for a brighter future for the community of rare diseases and the integration of rarity into mainstream social and everyday life.



### *Taking steps to improve patients' daily lives*

With the aim of advancing Greek patients' right to better quality of life, HPH came to agreements with a number of private companies to facilitate everyday life of patients with the rare disease of pulmonary hypertension.

HPH agreed with a private company that specializes in infusion solutions to deliver medicines at home for patients prescribed with *Flolan*, *Remodulin* and *Veletri*. Thus, HPH made sure that PH patients are provided with the CADD®-Solis ambulatory infusion pump and all its expendables without prepayment from the patient, but with direct payment from the insurance company; a service that contributes much to patient's convenience.

HPH came to an agreement with a private company that specializes in medical supplies and tools to provide oxygen at home for patients with PH, as well as to offer discounts for the supply of medical equipment and items necessary for healthy daily living that are not covered by public insurance companies.

### *Participating at the Patients' Conference*

HPH participated at the 3<sup>rd</sup> Panhellenic Patients' Conference «*Patients in power*», that was held under the auspices of the Greek Ministry of Health on 7 & 8 November 2014 at Divani Caravel Hotel, Athens, and was about Healthcare Strategy. In her presentation, HPH President Ioanna Alissandratou drew attention to the numerous problems that patients with rare diseases encounter in their daily lives and recommended a series of measures to tackle them.

*“It is unacceptable to see our lives sacrificed on the alter of bureucracy and to have to make continuous interventions to achieve the obvious”*

### HPH's supporters

HPH is supported by the majority of Greek PH specialists and PH units in Greek hospitals. The aim of our collaboration with private companies is to facilitate and improve the daily activities of patients with PH, and make things easier for them and their families.

HPH's collaboration with pharmaceutical companies is of outmost importance in order to promote specialized research and information about PH to the medical community as much as to the patients.



*HPH's president at the panel of the Patients in Power Conference*



### *The Marathon of our lives*

Athens Classic Marathon is not just a sporting event of worldwide importance, with thousands of athletes participating and millions of people watching. Nor is it just a tough race of 42.195 meters. More than anything else, Athens Classic Marathon showcases the strength of human will, and this is something we can identify with. The participation of our athletes in the 32<sup>nd</sup> Athens Marathon for the cause of strengthening our voice, raising awareness about PH and making our rare disease visible to a wide audience made us proud and filled us with optimism and hopefulness. Our marathon runners are thereby the bearers of the message of hope in the fight against the rare disease of pulmonary hypertension.



*HPH flag at finish point at Panathenaic Stadium*



*Our marathon runners showing their medals and HPH posters*

### *Women in action, together again*

For a second consecutive year, HPH organized an event exclusively for women. On Sunday November 30th, we gathered at the restaurant “Kimolia” in Drossia, to hang out, discuss with each other, meet new members, and be entertained with the live music performance of the one and only Paschalis. The event opened with an incredible choreography prepared exclusively for PH by the dance team of Dionysis Dimitrakopoulos. Our second ladies’ night out had an impressive turnout by women that left their homes and families on a Sunday morning to wear the purple ribbon on their chests and join us to show their support to our cause. Once again this year we were very happy and proud for all the love, support and positive energy we felt all around us.



*Paschalis sings for us in our second ladies' night out*

### Thessaloniki Information Campaign

In May 2014 we gathered at the famous Aristotelous Square to inform the public of Thessaloniki about the rare disease of pulmonary hypertension. Our campaign in Thessaloniki was one of the most successful, as the people of northern Greece were enthusiastic and warm giving us confidence, hope and strength to carry on.



### HPH's good luck charm

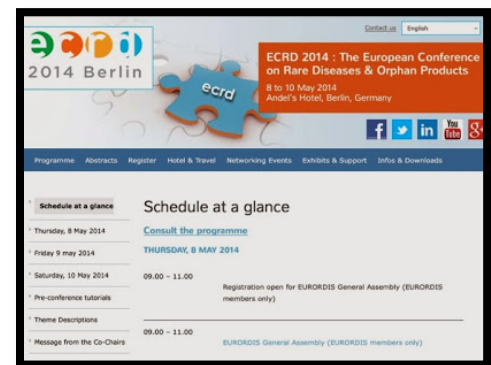


HPH had a silver jewellery designed exclusively for us in the shape of lips. This little piece of charm jewellery is the symbol of our hope for finding a cure for PH. The shape of lips is a direct reference to the common

symptom of blue lips. The idea behind creating the charm jewellery is to have another recognizable item for our rare disease. Our objective is to turn the symptoms of PH into symbols of awareness and hope, and make our rare disease visible and recognizable.

### Attending conferences

Within its two years of existence, HPH has managed to attend and actively participate in most conferences about PH, both in Greece and abroad, and follow closely all developments in the field of rare diseases. Putting our voice at conferences is very important for making our rare disease visible and highlighting the importance of listening to the patient.





## #selfieforPH: Hold your breath for PH

In October 2014 HPH initiated a campaign of awareness in tune with the spirit of our time; a time when social media and selfies are extremely fashionable, but they can also be used for a higher cause. Wishing to reach out to the global community and promote awareness about PH to a wider audience, we depicted the typical symptom of breathlessness and turned it into a symbol of solidarity. We called everybody to take a selfie while holding his breath in every way he liked, and then share it in all social media as a way to show his support to patients with PH. The selfie campaign started from Greece, but soon spread around the world. PHA Europe officially adopted it, while reports of our campaign appeared in many international media, describing our initiative with enthusiastic comments. The aim of the campaign to make our rare disease visible and recognizable has been met with huge success!



*Our initiative was spread around the world with people of all ages taking selfies, thus showing their support to PH patients. A big thanks to everybody!*





### *Pongo comes to the world*

Once upon a time, a rare purple elephant was born, and his name was Pongo! The idea of having a mascot came through our interaction with children and teens during our educative program. The beautiful story of Pongo touched all our hearts, and the little purple elephant was soon loved by our little and big friends! Pongo is unique because his colour is different: he is not grey like all elephants, but purple, because he has a very small nostril that makes breathing difficult, and as a result of his huge efforts to breathe Pongo turned purple. Two common symptoms of PH — shortness of breath and skin bruises — are behind the beautiful story of Pongo. The first acquaintance of Pongo with the Greek public took place at *The Mall of Athens* in December 2014, where our little hero became a huge attraction and helped us to inform an incredible number of people and distribute more than 8,000 leaflets. Having a mascot during our information campaign was proven a fantastic way to attract people's attention and make PH visible.





### *Voluntarism is the source of our strength*

Volunteers are the backbone of our association. Without their assistance, we would have not achieved any of our goals. Their role in our work is of utmost importance, because all of our activities depend solely on voluntarism. Wishing to express our gratitude to these people, HPH established the *Volunteer of the Year* award. The award goes to the volunteer that, without hesitation or reservation, every hour of the day is ready to help and stand by us. The aim of this award is the recognition of their assistance and contribution to our tough work.



*A picture of HPH's loyal volunteers!*

### *Our association grows up*

The effective exercise of Greek patients' rights, the unrestricted supply of medicine, the betterment of living conditions for them and their families, and the increase of awareness about pulmonary hypertension have been the fundamental objectives of our association since day one.

Two years later, HPH has grown older and bigger, and with it responsibilities and expectations have grown too. As the demands grow, our members and volunteers can no longer carry the entire burden alone. We need higher involvement from more people and better burden-sharing. Our work is exhausting and it can even be disheartening, while most of the times the obstacles are momentous. Yet, it is also the most rewarding of all. Our vision to see PH termed as "non-deadly" is what carries us on and helps us overcome all difficulties.

### *EURORDIS Photo contest*



*HPH submitted these two pictures for the Eurordis photo contest which has the aim to communicate visually the many diverse facets of living with a rare disease.*




*HPH family with its new member, Pongo*


# Our work continues


## *HPH's goals and vision for a better future*


- Greek patients' access to international transplantation centers is of urgent necessity and our highest priority, as it is now considered as the only chance of permanent treatment of pulmonary hypertension.
- Reinforcement of economically disadvantaged patients ranks high among our priorities.
- Recruitment of volunteers with various specializations and qualifications—like lawyers and psychologists—is of high importance to help us improve patients' lives and implement our objectives.
- Active participation in international events and conferences relating to Rare Diseases and Pulmonary Hypertension will help us to grasp a better knowledge and understanding of the issues of our concern, including scientific research and developments in medication and treatments, as well as the effective exercise of patients' rights.
- Better coordination and optimization of the project “Care and Treatment at Home” with the creation of Care and Treatment Crews for patients with PH in cooperation with local authorities and the relevant government organizations.
- Offering a shelter for patients living away from Athens at HPH's head office, thus providing them with the opportunity to get access to PH specialist units of Athens, has been a major practice for HPH since its beginning. The goal is to make arrangements to be able to host more patients.


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