

PHA Europe's  
“Breathtaking” campaign  
RDD 2011

EURORDIS  
*Pisana Ferrari*  
*Paris, 30 June 2011*

# Pulmonary Arterial Hypertension

- A rare, incurable and progressive lung/heart condition with very poor prognosis which ultimately leads to right heart failure.
- Still relatively unknown and being diagnosed and treated very late with dramatic effects on prognosis.
- Differences in access to approved drugs across Europe.
- Differences in access to surgery and problem of long waiting lists for transplant across Europe.

# PHA Europe

- European federation, set up in 2003, registered in Vienna (members are PH patient associations, currently from 20 countries).
- The aim is to be the link between the members, the EU institutions, NGO's and public institutions and further the cause of PH patients in Europe.
- Key objective is to help patients set up associations in countries which have none ("White spots" program).
- Activities include website, Facebook page, monthly reports, quarterly newsletter, Annual Assembly.
- PHA Europe represents the members at key European scientific events (ESC, ERS, etc.).

# Campaign objectives

- To show the true impact of PH on the life of persons affected.
- To raise awareness about the importance of early diagnosis and treatment.

# Campaign concept

- “Blue lips” are one of the clinical signs of PH.
- Original idea: PHA UK, for blue lip print collection campaign 2009-2011, which entered World Book of records Feb 2011 (55,000 kisses collected worldwide).
- In the aftermath of this success PHA Europe built on the idea of the blue lips for its “Breathtaking” campaign.
- Powerful imagery was developed incorporating the blue lips concept with a blue hand around the neck, symbolizing the extreme breathlessness that goes with PH.

# The campaign

**VANSKELIGHETER MED  
Å GA OPP TRAPPENE?  
TRØTT? ANDPUSTEN?**

KAN DET VÆRE AT DETTE ER SYMPTOMER PÅ  
SYKDOM SOM TAR PUSTEN FRA DEG OG SOM D

"Noen gang følt deg  
Se for deg aldri  
tilbake... og mi  
og mer over  
andpustethet  
ikke kan leve et

Hvis du opp  
andpustethet, s  
utmattelse m  
legen fo

LAKTEN PÅ HELBEREDISE FOR  
**PULMONAL  
HYPERTENSJON**

PHA EUROPE

For mer informasjon, bes  
[www.pha-no.com](http://www.pha-no.com) eller  
[www.phaeurope.org](http://www.phaeurope.org)

Under beskyttelse av



**DIFFICULTY CLIMBING  
THE STAIRS? TIRED?  
BREATHLESS?**

COULD BE THE SYMPTOMS OF  
A BREATHTAKING DISEASE THAT KILLS...

"Ever felt out of breath?  
Imagine never getting it back...  
and losing more over time.  
Unexpected breathlessness  
means I can't live  
a normal life!"

If you are experiencing  
unexpected breathlessness,  
weakness or fatigue please  
visit your doctor for  
accurate diagnosis.

PHA EUROPE

CURE FOR  
**PULMO  
NARY  
HYPER  
TENSION**

For more information visit:  
[www.phaeurope.org](http://www.phaeurope.org)

Under the Patronage of  
**EURORDIS**  
Rare Diseases Europe

Bayer HealthCare  
is proud to support the 'breath-taking' campaign.



**OBTÍŽE PŘI VÝSTUPU  
PO SCHODECH?  
ÚNAVA? DUŠNOST?**

MOHOU TO BÝT PŘÍZNAKY DECHŔEROUCÍHO  
ONEMOCNĚNÍ, KTERÉ ZABÍJÍ

„Cítíte se stále udýchaní?  
Představte si, že to nikdy  
neustoupí... a časem se to  
bude zhoršovat. Nečekaná  
dušnost znamená, že nemohu  
žít normálním životem.“

Pokud zažíváte nečekanou dušnost,  
slabost nebo únavu, navštivte svého  
lékaře, aby stanovil přesnou diagnózu.

PHA EUROPE

INFOLINKY: 800 333 340 (VFN) / 800 888 068 (IKEM)

Přejezte-li si další informace, navštivte:  
[www.plicni-hypertenze.cz](http://www.plicni-hypertenze.cz) nebo [www.phaeurope.org](http://www.phaeurope.org)

Pod záštitou: **EURORDIS**  
Rare Diseases Europe

Bayer HealthCare



# Preparing for the Campaign

- Concept and draft materials sent to national member associations who were asked if they wished to take part (nov 2010).
- 7 member associations volunteered and submitted projects and budget, 3 held minor activities.
- Revision of PH materials by key medical opinion leader and translation into 11 European languages.
- Finalisation of all materials (posters, flyers, press releases, blue lips lollipops, other gadgets etc.).

# Campaign organization

- Launch events held in Brussels and Vienna on Rare Disease Day 2011 in the main train/metro station of these cities
- National events were organized in Bulgaria, Germany, Hungary, Norway, Poland, Portugal, Spain
- Some awareness raising activity in Czech Republic, Italy and Slovakia
- Follow up with Facebook “Send a blue kiss” application, videos on Youtube, other events



# Events at national level

National patient associations were entirely responsible for:

- Printing and distribution of materials.
- Rental of spaces: advert, LCD screens, train and metro stations, public areas.
- Organization of events: sports, music etc.
- Media coverage: press conferences, interviews for press TV, radio.
- Follow up activities.
- Report on funding received from PHA Europe

# Campaign results


- Extensive dissemination of information and excellent media coverage across Europe.
- Increased visibility for the federation (with institutions, medical, industry, etc.).
- Enthusiastic involvement of national associations.
- Empowerment of the national associations (even the small associations can do a lot!).
- Building up of community spirit.
- Created a successful precedent for further common action.

# Campaign key factors

- Official support of RDD org and patronage of Eurordis.
- Funding for all activity.
- Full time campaign coordinator.
- Participation of many member associations.
- Good communications agency for PR and logo and materials design/translation.
- Prestigious international medical opinion leader for revision of texts.
- Endorsement of national medical PH experts.

# Budget and costs

Expensive campaign BUT it is possible to:

- Find more than one sponsor.
- Tap personal resources/contacts for better prices or even pro bono: logo design, graphic layout of materials.
- Enquire about specific advantages for charities: free or cheap advertising space on journals, billboards, printing and distribution.
- Enquire about free public areas for events.
-  Plan well ahead of time!

# A few examples from the PHAE awareness campaign

Poland, posters  
in 12 cities



Norway, top league basketball  
team playing with blue lipstick



Austria, press conference with  
popstars and politicians



Spain, posters  
in metro stations



Bulgaria, concert



Hungary,  
press conference

# A few examples from the PHAE awareness campaign



Ads in Metro journal, Portugal



Blue lip lollipops



Gare Centrale, Brussels



"Branded" bus, Austria



Hungary, miming the Breathing message

# A few examples from the PHAE awareness campaign



Poland, distributing materials



Poland, large outdoors ads



PHA Norway President on popular TV talk show



Bruchsal train station,  
Germany

PHA Portugal President  
on national TV



For more details of the campaign please  
visit the PHA EUROPE website at

[www.phaeurope.org](http://www.phaeurope.org)

