

PHA EUROPE

PULMONARY HYPERTENSION ASSOCIATION

NEWSLETTER

June 2005 Number 1

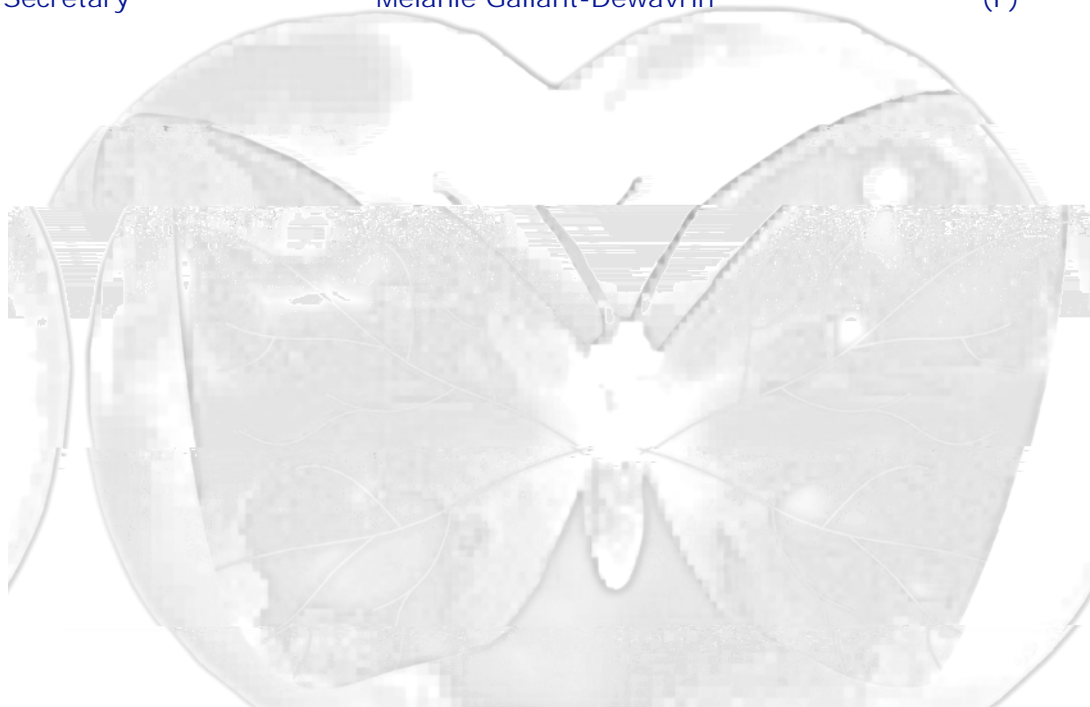


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Executive Committee

President	Leo Kwakkenbos	(NL)
Vice-President	Bruno Kopp	(D)
Vice-President	Kay Yeowart	(UK)
Treasurer	Steve Waller	(UK)
Secretary	Mélanie Gallant-Dewavrin	(F)



Newsletter Submissions

Do you have an article, announcement, quote, photo or tribute you want to see in the Newsletter? It will be printed as space permits!

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CLOSING DATE: September 15th, 2005



Message from Pisana

It was a great honour for me to be elected first President of PHA Europe, and I am very happy to write about this experience for the first number of the PHA Europe Newsletter.

When our group first got together in Vienna in September 2003 during the European Respiratory Society's Annual Congress, on the initiative of the German and Dutch patient Associations, it was generally felt that the creation of a Europe-wide association could be very significant in furthering the interests of PH patients. It took some time for the project to get off the ground and this happened at the beginning of 2004 with the adoption of a Constitution and elections for the first President and Executive Committee.

During our meetings in Brussels and in the months that followed we all had the opportunity to get to know each other better, share information about activities at national level, and begin to work on common projects. Contacts between us were kept on a regular basis via e-mail and phone calls.

In June 2004 some of us attended the bi-annual conference on Pulmonary Hypertension organized by the American Pulmonary Hypertension Association (PHA) in Miami, USA. Melanie Gallant Dewavrin (President of HTAP France), Iain Armstrong (Chairman of PHA UK) and myself as President of PHA Europe, were invited to speak at an international session attended by over 600 people. It was a unique opportunity for PHA Europe to "present" itself and its members, and to meet with PHA's President and colleagues as well as representatives of patient associations from other countries (Mexico, Canada, etc.).

In September 2004 a PHA Europe delegation was present with its own stand at the European Society for Cardiology's Annual Congress in Munich, Germany, attended by almost 20,000 medical professionals, and representatives of industry from all over Europe. The same month members of PHA Europe attended the European Respiratory Society's Annual Congress in Glasgow, Scotland, where we also had our own stand. ERS Conference attendees were about 15,000.

Both these congresses and other meetings I and other members attended gave us the opportunity to meet up with doctors and other medical professionals as well as representatives of industry and other interested parties from all over Europe and indeed the world to make our views and needs known. It was also a very useful occasion for us to better understand in what directions our future projects should point.

PHA Europe is still "in its infancy", so to speak.... One year is too short a time to really achieve anything of major significance. However, I hope I have in some way contributed to laying the foundations of our organization! I think we all understand that there are objective difficulties in putting together a European association and the project is an ambitious one.

I would like to thank each and every one of you for your cooperation and support and enthusiasm. I am sure PHA Europe is now ready to become a "mature" organization in the capable hands of our colleague and friend Leo Kwakkenbos. I wish Leo all the best and am sure he will be a great President!

Pisana Deciani



A New Challenge

First of all I want to thank you all for the confidence you gave me through voting for me being new the president of PHA Europe.

PHAE is a young association.

It is always very hard to find the rhythm in the start up phase; especially when we all represent different cultures. Nevertheless Pisana Deciani did a great job and I want to thank her for that.

Each of us is also extremely occupied with the national PH support associations.

This activity is, for many of us, even one next to a normal job!

We have had the opportunity to learn more about each other as well as the individual difficulties.

I know from each of you that you all are highly motivated to make a success of PHAE.

The role of PHA Europe is extremely important. The added value of PHAE lies in complementing the national activities. As we all know the support to patients has reached different levels in each country so priorities may vary.

Some of the objectives as stated in the PHAE presentation were:

- ✓ Support other countries in starting up patient organisations
- ✓ Promote a better quality of life for patients
- ✓ Advance the education and awareness of the general public about PH
- ✓ Ensure availability of all drug therapies associated with the treatment of PH

What we have experienced in the past months is that Luc and Rosie had difficulties in supporting other European countries. The reason being the failure of a mutually accepted strategy. Important is to define a joint vision and strategy for the future for all objectives.

On June 11th 2005 the Executive Committee has scheduled a meeting in Amsterdam. The agenda will be sent to each of you and the minutes as well. Main objective is to prepare this strategy.

In September we plan a meeting of the General Assembly where the EC can present what has been discussed and come to final conclusions how to deal with the above.

As mentioned before, it is obvious that PHAE needs to come up with clear and visible projects to show PHA Europe's vision.

The specialist doctors I spoke during the Seville Symposium urge us to give this a high priority.

Such projects may be:

- ✓ DVD for increasing awareness to patients/family
- ✓ European Leaflet for professionals
- ✓ European Survival Guide
- ✓ European Patient Survey

The EC will discuss and prepare these projects and any other project any of you proposes.

The final decision will be made during the General Assembly meeting.

I sincerely hope we can optimize our corporation which leads to a mature European association.

Leo Kwakkenbos



4th Scientific Symposium at Seville

It was the first time that a representative of a PH Association was invited to speak on a scientific symposium. A chance to present the patient's perspective to 700-800 physicians is a great opportunity.

So it wasn't difficult to make a positive decision.

Friday morning 0900 hrs there was a presentation review planned with the 3 other speakers in my session.

At 13 and 15 hrs I had an interview, one about PHAE and one about my private situation.

The presentation and the interviews will be part of the CD-rom made of this Symposium.

Saturday during the first session I gave my presentation.

The presentation was about the patient's perspective. What do patient feel, think and experience due to this disease.

The slide covered the following topics:

- ✓ Diagnosis process
- ✓ Living with PH
- ✓ Patients and Information
- ✓ Role of the national Ph association
- ✓ PHA Europe mission
- ✓ Role of PHA Europe
- ✓ PHA Europe organisation
- ✓ Awareness



The conclusions were:

- ✓ Improve communication and understanding
- ✓ Care for the patient with sensitivity
- ✓ Involve patients in their care and provide them with appropriate information
- ✓ Recognise importance in communicating and sharing knowledge with non-specialist centres
- ✓ More specialist centres with multidisciplinary PH teams
- ✓ Raise awareness to increase early diagnostics

PH Medical Centres advise patients and non-specialist doctors of PH Support Associations



I asked the audience two questions for which they could vote electronically.

1. Are you informed about the roles/ activities of your national PH association?
39 % answered YES
61 % answered NO
2. Do you provide your patients with information on the national PH association?
43 % answered YES
57 % answered NO

As you can see there is some work to do for both the national PH association as well as the specialized doctors.

Afterwards there were very nice reactions from various people.

Many doctors confirmed that this way of presenting the general problems of patients is very clarifying.

This symposium was also an excellent opportunity to network.

I spoke with various specialists from Europe and United States and Canada



PHA Europe received a check of € 15.000 as an unrestricted grant for future projects from Jean-Paul Clozel, CEO, Member of the Board and Founder of Actelion.

Leo Kwakkenbos



From our doctors

Dr. Ruggero Piperno is the Director of the Psychiatric and Psycoterapeutic Departement in Ospedale Nuovo Regina Elena in Rome – Italy -. These last five years he put his vast experience about serious and chronic diseases at the service of the PH patients of Rome, leading their self-aid group meetings that gather every months.

MOMENTS OF TRUTH

In everyone's life, there exist moments of truth. They can be called "defining moments" that stand out as a dividing line between a "before" and an "after". They are generally caused by events that change our lives.

At times, these defining moments are pleasant, as when we fall in love, or when our child is born, but at other times, these moments are painful, as when, for example, we are told sad news.

A sense of excessive fatigue, of being tired out, of feeling somewhat out of breath when accomplishing common, every day activities are the first warning signs of pulmonary hypertension; since these warnings are fairly generic we or whoever is close to us do not immediately understand what is happening.

Even the physicians, at least in the beginning, may be unsure of what causes this, as it is not easy to immediately diagnose a rare disease, and fortunately, pulmonary hypertension is a rare disease. However, its very rarity can boomerang for those who suffer from it.

The big pharmaceutical companies, which are the main players when it comes to pharmaceutical research, are rarely interested in funding specific research efforts, unless they can reap substantial revenue profits from it. As a result, the drugs that are nonetheless produced and sold are very costly, and the specialized clinics are few. This situation often forces patients to be subject to stressing transfers, precisely when they are feeling at their worst. Additionally, most physicians are unprepared to face the specific clinical conditions, which may come up at any given moment.

All of this is of no little importance, since when we are ill, we need to be able to count on people who can help us. It is imperative that we are able to refer to a permanent information center, which is available to us, even when we do not need it. Since knowing that that we can avail ourselves of experts in case we need help is by itself reassuring. It is also reassuring to know that help is around the corner, and not five or six hundred kilometers away. This is all the more important when we are not feeling well, and do not know what is happening to us.

Finding out that we have an illness is in itself always painful. However, it can also put an end to wondering about what is wrong with us, and paradoxically, knowing our illness can trigger resources and strengths within ourselves which we did not know we had.

A "moment of truth" is a very significant moment. It is a time when our character, our personality, our strengths and weaknesses are suddenly exposed, when the personalities, inner resources and limitations of those close to us are also revealed: our children, our parents and our spouses. It is a moment when suddenly we confront our fears: the fear of death, of suffering, the fear of the unknown, of being alone, of no longer being able to be self-sufficient.

However, during such defining moments, we can also discover new strength within ourselves, a time when we discover who we are, and form new bonds with others.



These bonds can often allow us to be less afraid, and they may enable us to overcome taboos, loneliness, and overlook the more formal or unessential aspects in life.

It happens that the person who is suffering must comfort those who are close to him or her. This is a strange but a frequent paradox.

Nevertheless, the individual who becomes ill with a serious disease must feel a sense of aggression, especially from the people who are closest, since the worst looming threat that we may be faced with is that our loved ones will leave us, abandon us, irrespective of whether it is by free will, necessity or fate. Also, it is not uncommon that the person who is well may think: "How do you dare to be ill! How do you dare to do this to me!" These thoughts are nevertheless a sign of a close relationship, and of the mutual love that exist between people who, for whatever reason, cannot face the threat of a separation. And, pulmonary hypertension "favors", so to speak, men and women who are known to like to be looked after, and who therefore do not tolerate any abandonment, even if it is due to illness.

Is it then possible to be able to share with others one's own problems? Of course it is possible, however, we often need to establish new and more meaningful bonds with people. As a result of this belief, psychologists and psychiatrists have been encouraging, for quite some time, the strengthening of such processes, by organizing group meetings, where people can find an outlet for their emotions, and allow themselves to communicate their feelings, and relate to people in similar situations. By establishing such meetings where communication is not limited to expressing oneself, but where the patient and the family can also get updates on the patient's condition, and on the state of the disease, the medical community helps to prevent misunderstandings, and to minimize any anxiety of both the patient and his family. The establishment of such support mechanisms is critical in promoting self-help, information, and is bound to lead to the elimination of any misunderstandings, doubts and all other negative feelings.

However, the dangers do not solely arise from the lack of interaction with ourselves or with our family members. The interaction and the rapport with our physicians are essential too. These professionals whom we need to idealize when we are ill, often do not respond to us in kind.

And perhaps the physicians themselves, even when they are top specialists, are often unprepared to have a more personal relationship with the patient, and to see the patient not only as a sick body, but also as a suffering individual who is often anxious and afraid. As a result, the patient often does not feel accepted, or supported. He or she feels as a non-person, but is unwilling to manifest these feelings, because he or she is unable to blame the physician whom they view as necessary to their survival. This situation is akin to the mother-child relationship. While for the patient, his or her physician is a unique person, for the physician, however, the patient is one among many. Even though this should be like this, it does not mean that the rapport between the physician and the patient ought to be impersonal.



There are ways and ways to communicate unpleasant news, and surely, doing it in a hurry, standing in a corridor, perhaps even in front of other people, is certainly not the best way. Similarly, it is not the best way to withhold the truth from the patient.

It is not unlikely that, when devoid of information regarding their condition, patients feel compelled to anxiously observe the physician's expression, gestures, or even any whispered exchanges with other physicians, or with the nursing staff, in order to grasp any news or information regarding their condition.

Additionally, the quality of the interaction with the drug providers and with the medical bureaucracy is just as essential. This is all the more fundamental in view on the high cost of such drugs.

Unfortunately, in dealing with these organizations, we find ourselves, more often than not, to be a number, a case, a national burden who puts the nation or the insurance company to the test and to unjustified expenses, in a word, we feel undesirable citizens.

All this cannot but increase the sense of humiliation, guilt, and anger of those who are ill. If life goes like this, and life does happen like this, the individual will feel powerless to change the unpleasant circumstances he or she is in.

Thus, all the factors I have previously described, have contributed to the creation of patient associations. These associations can do a great deal to encourage and promote the respect for the dignity of the individual, especially for the suffering individual, and to ensure that his or her rights are respected, and that he or she receives the support they most need when confronted with difficult situations. Without the existence of these patient associations, it would be very difficult for an individual alone to achieve this, and to feel part of the community, not as a burden or a victim, but as a rightful person on equal terms with the community.

I am therefore very pleased in my role as a person and a professional who is mindful to all that can affect the well being of patients, to have been given the opportunity to contribute to the growth of this movement and of this association.

National associations need the participation and support of as many people as possible: patients, as well family members, and the medical staff. Each and all can contribute to make them a continuous starting as well as an ending point to better the patient's quality of life, and to improve the attitude of all those who provide health care, whether they are administrators, politicians, or physicians and nursing staff.

Dr. Ruggero Piperno

Interviews...

The publication of this interview has been kindly allowed by the German National Association. Similar interview to European PH experts will be published in the following numbers of the European newsletter.



Dr. Ghofrani



Bruno Kopp

An interview with Dr. Ghofrani

Dr. Ghofrani was the first to be awarded with the Price of the Rene Baumgart –Foundation for his research in the field of Pulmonary Hypertension. The Rene Baumgart-Foundation was founded by the German PH association PH e.V. to support research and increase awareness for PH in Germany. On October 28th 2004 the data of the Phase III study about “Sildenafil for the treatment of Pulmonary Hypertension” (SUPER-1) were published at CHEST in Seattle. Dr. Ardeschir Ghofrani from the University Hospital in Giessen presented these data for the first time to the public.

Bruno Kopp, President of PH e.V. Germany interviewed Dr. Ghofrani in Giessen:

Kopp: The data of the PHASE III Study “Sildenafil for the treatment of Pulmonary Hypertension”, everybody has been waiting for, have been published now. Did they meet your expectations?

Dr. Ghofrani: The results have exceeded all our expectations. As you certainly know, new therapies for the treatment of PH have been studied and developed for a long time in Giessen (Heads: Prof. W. Seeger and Prof. F. Grimminger). From our own studies and from numerous published studies - both experimental and clinical - on the application of Sildenafil for PH, we already knew that it is in fact an effective and safe therapy. But in regard to the prospected approval procedures, the data of PHASE III Study have been expected with bated breath, of course.

Kopp: What's your interpretation of these data?

Dr. Ghofrani: This study included 278 patients with PAH. During the survey of 12 weeks three different doses of Sildenafil (20 mg/40 mg/80 mg) were given three times daily and compared to placebo. The primary outcome of the study, as a measure of effectiveness of the medication, was the improvement of the nearly 40% of patients was in the functional NYHA class II (almost 60 % were in class NYHA III). So far patients of this group (less affected by the disease) have been excluded from most of the previous studies with other medications. The reason for this is that significant changes (towards improvement or worsening) during a relatively short observation period in such trials are not to be expected in this patient sub-collective. Taking into account this consideration, an increase of 50 meters in walking distance as seen in the current study.



(within the group taking 80 mg Sildenafil) is very remarkable. Simultaneously the increase of exercise tolerance within all groups, treated with Sildenafil, was accompanied by the improvement of other important parameters such as the reduction of pulmonary arterial pressure, pulmonary vascular resistance, and the increase in cardiac output as well as an improvement of the functional NYHA class. Considering the high effectiveness as well as the excellent tolerability of this oral medication, Sildenafil is a major step forward in the development of new therapies for this severe disease.

Kopp: In the meantime you can find out on the homepage of the company www.pfizer.com that Sildenafil as a treatment for PH has been submitted for approval at the FDA in the USA and the EMEA in Europe. What's the formal procedure and how long will it probably take?

Dr. Ghofrani: I think it's very important that the submission for approval has been made very shortly after termination of the study, as we urgently need new, safe, and effective medications for the treatment of PH. I'm sorry to say that at the moment nobody can predict how long the approval procedure will take. However, there is some evidence that approval for the US may be given in the summer of the year 2005 and for Europe in the first quartile of 2006. I hope that the experts of the FDA and the EMEA recognize the urgent need to help our patients with this effective treatment.

Kopp: The medicaments for PH have been approved only for restricted indications in Germany. After submission for approval of Sildenafil have the chances increased that insurance companies will accept refunding of the expenses for a compassionate treatment of the numerous PH-patients receiving "off-label" Sildenafil in case there is no approved therapy applicable?

Dr. Ghofrani: Many insurance companies have already been more liberal in refunding, recognising the positive data about Sildenafil for the various origins of PH. I really appreciate this and want to refer to different personal positive experiences with some representatives of insurance companies and their medical experts for whom the well being and the fate of our patients are most important. In absence of alternatives, Sildenafil has already been refunded in many cases. I hope that in regard of the results of the actual PHASE III study and its submission to the FDA and the EMEA, the willingness to refund the highly effective and well tolerated therapy will even increase.

Kopp: Thank you very much for the interview, Dr. Ghofrani. I wish you all the best and much success for the year 2005.

Bruno Kopp



From Austria...



Health Award of the city of Vienna presented by the Councilwoman for Health, Dr. Elisabeth Pittermann

Moving People to Take Action!

The year got off to a busy start for us with the organization of the once again immensely successful symposium for general practitioners and pediatricians in the Palace Wilhelminenberg to promote the early diagnosis of pulmonary hypertension.

We are incredibly proud of the fact that we were able to implement our project "Initiative Against Pulmonary Hypertension". The goal of this campaign is to raise money for research on this rare disease. By purchasing a memorial paving stone in Vienna's Prater Park with a personalized engraving for just € 25.00, we wish to give people the feeling of having immortalized themselves for posterity while at the same time having lent a

helping hand to an important cause! The City of Vienna granted us the use of the prominent square close to the Riesenrad, where the paving stones are to be laid in May 2006. A large construction company is producing the paving stones with brass plates where the name of the donor can be engraved with a personal saying. Bank Austria-Creditanstalt was an indispensable partner in making this Austrian-wide campaign a reality. Without their support, it could never have been done. As our main sponsor, the Bank Austria-Creditanstalt has financed our project with € 280,000.00. Our goal is to sell 20,000 paving stones. Donation payment forms are available at every bank branch. We expect to raise € 500,000.00 and attract the attention of the media. With this in mind, we held a large press conference with our Austrian superstar Rainhard Fendrich. In August we are organizing a kick-off-event, followed in October by a prime time, half-hour television show on ORF, and coverage of our milestone campaign by the Austrian Broadcasting Service during the Christmas season. We are also quite pleased that the German television broadcasting service ARD has also expressed interest in our campaign.

Beginning in fall, McDonald's Austria has also agreed to advertise for our project on their paper placemats.

In May 2006, once all of the paving stones have been placed at the "Platz der Meilensteine" (Milestone Square), we have organized a benefit gala concert in Vienna's Prater Park with

AUSTRIA 3, the most popular pop group in Austria, which we expect to be attended by 20,000 "milestone owners".



We currently financially support 3 research projects:

- Study in the gene sector (University Hospital Vienna – Univ. Prof. Dr. Irene Lang)
- Study VIP (Vaso Intestinales Peptid - University Hospital Vienna)
- Study on animal testing – Combination therapy Tracleer/Viagra, Tracleer/Cialis (University Hospital Innsbruck – Univ. Prof. Dr. Ralf Geiger)

We hope that our “Initiative Against Pulmonary Hypertension” will set a “milestone” for other self help groups in Europe and would be happy to share our positive, as well as our negative experiences, once we have completed our campaign and thus offer you all our support.

We are also extremely happy that we have once again been provided with a stand at the ESC Convention in Stockholm, and we invite you to come and present “PHA Europe” together. We look forward to sharing more information with you in Stockholm about the progress of our project!



Milestone Square 2005



Milestone Square 2006

Love Karin & Gerry



PH Awareness Week 4 - 10th April 2005 – PHAntastic!

A big thank you to all those who helped to make the first PH awareness week a big success. The week was chosen many months ago and awaited with much anticipation. Concerns did grow steadily during the lead up to the week however, as one important potential media diversion after another followed. We found ourselves competing for coverage with a Royal Wedding, the Pope's death and a general election announcement. Fortunately apart from the cancellation of some TV coverage, it all proceeded very smoothly and the publicity received well-exceeded expectations.

Many members, their families and friends held events locally to raise awareness in their neighbourhood. These events were very diverse and also raised funds for the Association, which has been greatly appreciated. Patients also very kindly shared their experiences and stories with others, during media interviews conducted to a wide variety of papers, magazines and radio stations. The importance of patient involvement cannot be over stressed, they really do make a huge difference, their courage and fortitude is a huge inspiration to many.

The radio broadcasts reached well over 2 million people and were played on 35 different stations. The BBC West Midlands interview also consisted of a phone in from the general public, raising some very interesting questions and all emphasised the very important key messages to aid patients to a brighter future. (Many of the broadcasts can be listened to via the audio section on the website).

On Tuesday 5th April the Helpline took 126 calls from a huge variety of people, including those with possible symptoms of PH, already diagnosed PH patients, concerned family members, nurses and newspapers wanting more information and over 200 information packs were distributed. By the end of the week a phenomenal 433 calls were received and the phone line continues to be exceptionally busy. The website has also been extremely popular with double the amount of visitors visiting than usual.

Various national and local newspaper articles reached an audience of over 25 million readers with articles still to appear in numerous magazines including Woman Own. There will be an ongoing campaign with various media outlets to continue the awareness work, as many are still interested in publishing articles.

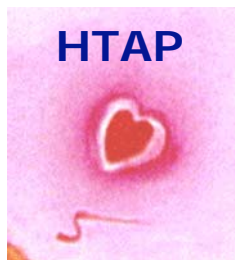
Over 500 key medical professionals were sent the latest informative medical brochure from PHA-UK, thus raising the profile for the disease and hopefully assisting earlier diagnosis and access to specialist care.

An estimated 27,579,127 people have now heard of PH due to the awareness week and the monetary value of the media coverage taking into consideration the content of each piece totals an estimated £162,847. Amazing!

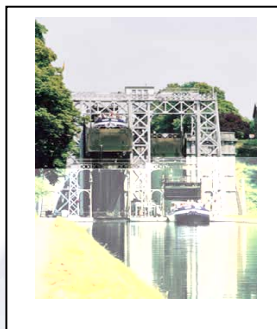
Many more activities are planned by the Association to help raise PH awareness over the coming year including an asthma nurse education programme, PHA-UK stand and staff attendance at medical conferences, more mailings to medical professionals, political lobbying and ongoing media work. We look forward to an exciting and productive time. The meaning of growing awareness cannot be underestimated, more doctors are considering PH as a diagnosis and the public are learning about the disease. We are committed to improving the lives of those affected by PH – if you would like to help please phone the Helpline, we hope to hear from you soon!

Kay Yeowart

More from National Associations...



From Belgium...



... Spending a nice day, visiting the "Ascenseurs Hydrauliques du Centre", UNESCO classified as World Patrimony. With all comfort for the patients and with all they need to live a...day light heartedly, with their families and friends.

Sharing a simple but tasty convivial meal in an historical and bucolic environment.

Strolling along the towpaths, in the middle of the spring countryside, across the Hydraulic Lifts, which are unique in the world.

Going on by cable car to visit a nearby modern dam. And finishing that unique day with a good cup of coffee, a delicious piece of pie and...some wonderful Belgian chocolates...

We have always believed, at HTAP Belgium, that enjoyment and participation in a pleasant and joyful event is one of the fundamental rights of the patients. This is an activity which maintains PH Patients fit for everyday life. It is a convivial moment, that brings optimism, discovery, sharing. Everybody needs it, especially in difficult times. Do you know that for somebody this was one of the rare days when they enjoyed themselves, forgetting their heavy and painful routine? And each time we reach our goal, we are very proud!

Organizing such an activity is not easy. You must think about hundreds of things regarding the patients' comfort, security...and satisfaction!! But we have courageous and generous people who worked hard to make everything perfect! Thank you Michel, Thank you Léon ! Thanks to all the ones who made possible this Celebration of Life.

All our respect and gratitude goes to Electrabel SA whose sponsoring is always present in such a discreet and efficient way.

Rosie and Luc

HTAP Belgique asbl

2005 Annual Touristic Day for PH Patients

Among others, one of our principal aims is:
« La réinsertion des Patients dans la Vie de tous les jours »

PH patients getting back into everyday life

More from National Associations...



From Italy...

AMIP 5th Anniversary

On May 28th, 2005 AMIP celebrated the 5th anniversary of its foundation. We were 192 people: doctors, patients, family and friends and we gathered in the countryside not far from Rome, in a well know Horse Centre. We had organized a lunch, a raffle and, to make thing more interesting, rides in horse-carriages. No scientific meeting this time, just fun!

Some of our friends already knew each other, but most were meeting for the first time. What we appreciated most was the atmosphere of friendship and sharing that caught everybody.

Among us there was a friend that recently successfully underwent a double lung transplant. He's so happy now that there's no way to keep him still: to be with us he had caught a plane in the morning, rented a car... and back! There was also a lady just recovered from a TEAP surgery operation. She was telling us: "Imagine that a month ago I couldn't speak with my relatives on the phone for lack of breath... and now I can send them a photo of myself going around in a carriage!!".

There were also some people that lost their dear-ones because of PH. The parents of one of our friends, a young woman that is no more with us, wanted to join us in awarding the doctors of Rome Specialized Centre for their work, done with competence and humanity. What fills us with joy is that they smiled with the others, ready to go on fighting the battle against this rare disease, hoping in a final success, just like all the others.



Maria Pia & Luisa

The current members of PHA Europe



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