MariposaNews

n. 2 Summer 2010

SUMMER ISSUE OF THE NEWSLETTER OF PHA EUROPE,
EUROPEAN PULMONARY HYPERTENSION ASSOCIATION

- **Austria**
- **Belgium**
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- **Turkey**

Dear friends,

I am delighted to introduce the Summer issue of PHA Europe's official journal, MARIPOSA. The first part of our newsletter contains reports on recent activities of the national PH associations in Europe. I would like to thank them for sharing their achievements and providing precious news for MARIPOSA. Many European associations have also sent reports on initiatives taken as part of the "Blue kisses" campaign, officially launched by PHA UK in May. This is the first time ever that PH associations worldwide join together in an international campaign to raise awareness on PH. I am grateful to our friends from PHA UK for their leadership and practical support. Collecting the "Blue kisses" will go on until October 2010. In our next newsletter, due in the autumn, we will be reporting on the results and, I hope, on the official entry in the Guinness Book of Records!

Representatives of a number of European PH associations, including myself, Ümit Atli (PHA Europe Vice President) and Hall Skåra (President PHA Norway) have participated to, and spoke at, the 9th International PH Conference organized by the USA PH patient association in June. Nearly 1,300 persons from 20 nations attended this event which brought together patients, families, caregivers and medical professionals for a weekend of education and networking. I would like to thank Christine Dickler from PHA for her report and our members for their interesting comments.

Other speaking opportunities for European PH leaders include the International Nurse Workshop in Berlin (May), which I attended and the conference Focus on PH: 15 years on in Bologna (June), where Pisana Ferrari (PHA Europe Vice President) was asked to put forward the patient perspective. The newsletter contains brief reports on these events.

While I write Pisana Ferrari and Luisa Sciacca della Scala (PHA Europe Secretary) are preparing to leave for Stockholm, where PHA Europe has a booth at the European Society of Cardiology's (ESC) Annual Congress. The Congress will provide an excellent opportunity for distributing material and providing information about PHA Europe as well as for networking with the medical professionals and the industry. Pisana and Luisa will also be meeting the President of the Swedish PH association.

We are now finalising the arrangements for our Annual General Assembly which will be held in Barcelona from the 18th to the 20th of September, during the Annual Congress of European Society of Respiratory Medicine's (ERS). We are very gratified by the exceptional turnout: 40 confirmed delegates from 19 European countries. The General Assembly has a very interesting programme and we will hold our first corporate meeting with representatives of pharmaceutical industries.

Other important upcoming events include the ESC Course on Pulmonary Hypertension in Sophia Antipolis (France) from the 16th to the 17th of October, where I have been asked to speak about "Patient Expectations".

The last part of MARIPOSA includes news on recent EU legislation, in particular the recently approved Directive on Organ Donation and Transplant.

Last but not least, we are delighted to welcome as members of PHA Europe the national associations of Netherlands, Norway and Slovakia and look forward to meeting the Presidents of these associations in Barcelona.

Warmest regards

Gerald Fischer
President PHA Europe

Contents

PHA EUROPE

WHAT IS PULMONARY ARTERIAL HYPERTENSION?

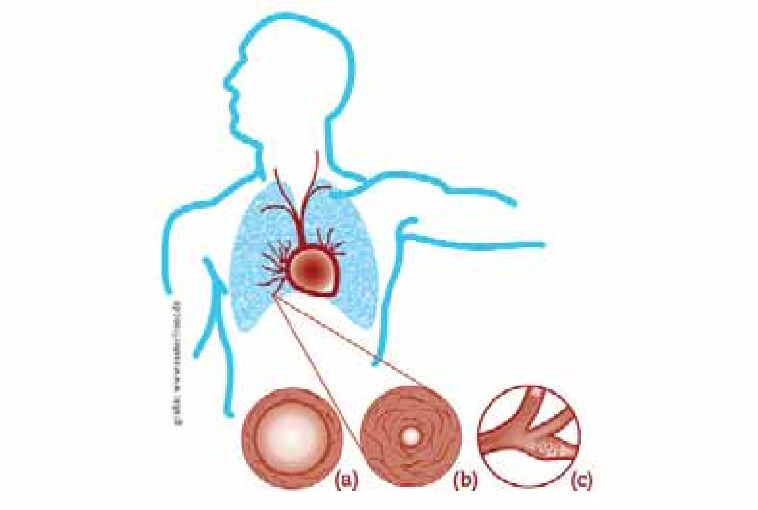
In patients with Pulmonary Arterial Hypertension characteristic changes occur within the pulmonary circulation, which include thickening of the linings and obstruction of the small pulmonary blood vessels. They are both structurally and functionally abnormal. In severe cases up to 80% of these very small blood vessels are rendered non-functional. As a result the pressure in the pulmonary circulation rises well above normal and this places strain on the right side of the heart. This strain can cause the heart to enlarge and the patient may develop heart failure.

This is a disease that can affect all ages and is more commonly seen in females. Pulmonary Arterial Hypertension has an estimated prevalence of about 50 per million population.

TREATMENT OF PULMONARY ARTERIAL HYPERTENSION

Over the past decade a number of evolving therapies that either use complex delivery systems such as 24-hour intravenous or subcutaneous drug infusion, drug inhalation and more recently with the advent of oral medication, have transformed the outlook for PAH-patients. PAH is a condition that can be rapidly progressive and needs careful, ongoing expert care and management.

The disease can be insidious in its onset, with unexplained breathlessness and tiredness as its two main symptoms. If undiagnosed and/or inappropriately treated the life expectancy for these patients is estimated to be around 2-3 years. For those patients who fail to respond to medical therapies double lung, or in some cases, heart and lung transplantation may be appropriate.



a. Cross section of normal pulmonary artery

b. Reduced opening of pulmonary vessels due to cell proliferation and remodelling in advanced Pulmonary Arterial Hypertension

c. Longitudinal section with pathological changes within the vessels proliferation, deposition of blood clots, thickening) causing difficulties for the heart to pump blood through the lungs

THE FUTURE FOR PULMONARY ARTERIAL HYPERTENSION

While a cure for this aggressive and life threatening disease is still some way off, there is much to be optimistic about. There are an everincreasing number of therapies available for the effective treatment for Pulmonary Arterial Hypertension, which improves the quality and length of life. The aim for the present should be to ensure that all patients with Pulmonary Arterial Hypertension have access to centres of excellence in the diagnosis, management and ongoing treatment of this disease.

AUSTRIA

PHA Austria newsletter

Since the beginning of 2010 we have a newsletter for our patients. The third issue is now out. *PH-Newsletter* is printed and distributed through the post and can also be downloaded from the PHA Austria web site. The newsletter contains reports about association events and activities, patient stories, interviews with PH specialists, etc.

Patient meeting

A patient meeting was recently held in Innsbruck (see photos). I attended on behalf of our association.

Eva Grassmugg from PHA Austria at the patient meeting

From Vienna to Amsterdam by bicycle for PH

Maleen with Franz Fegelin (2nd from right), Uwe Foitl and the famous Austrian professional cyclist Gerhard Zadrobilek (3rd from left)

On 27 July Mr Franz Fegelin, an Austrian athlete, left Vienna on his bicycle on a trip that will take him across Germany and to Amsterdam where he is expected to arrive at the beginning of August (see photos).
Mr Fegelin's mother passed away from PH some time ago (Amsterdam was her home town) and he is doing this trip to raise awareness on the disease. Mr Fegelin will be going through Krems an der Donau (Austria), Plattling, Kitzingen and Siegen (German) and Enschede (Netherlands).

Further details at:
http://tvthek.orf.at/programs/70018-Wien-heute/episodes/1529093-Wien-heute/1530167-Pedalritter-im-Kampf-gegen-Lungenhochdruck

Private museum opening

A private museum held its official opening in July with a reception where the Bishop of Vienna and the Governor of Austria were present. On this occasion we organized a few exhibits for a "silent" auction and raised about € 5.000 for PH.

Eva Grassmugg, Selbsthilfegruppe Lungenhochdruck

www.lungenhochdruck.at

BELGIUM - HTAP BELGIQUE

HTAP President at Erasme University seminar on PH

During the month of June I had the opportunity of meeting fifteen young cardiologists from Italy during a Seminar organized by Erasme University on PH. The doctors were particularly interested in hearing about and understanding how prostacyclin treatment works (Remodulin and Flolan), its side effects and impact on patient's day to day life.

Remodulin in Belgium

Negotiations are now going on at government and industry level about reimbursement for Remodulin in Belgium. At present it looks as though in future the treatment will not be made available to "new" patients. This would be disastrous... We are very concerned and will be monitoring future developments closely.

Rosie Matthysen, HTAP Belgique

htapbelgique@hotmail.com

BULGARIA

PH Patient seminar

Todor Mangarov, President of the Bulgarian PH Association, at the PH patient seminar

A seminar for patients with Primary Pulmonary Hypertension was held on 29 May 2010 as a parallel workshop of the First National Conference for Rare Diseases and Orphan Drugs. The guest speaker was Dr. Tsvetomira Chorbadzhiyska, a specialist in cardiology. The meeting's aim was to exchange experiences and information between the participants on how to deal with their problems in times of economic crisis and to discuss proposals for actions related to funding for treatment and support for patients.

Website and Facebook page

PHA Bulgaria now has a web site: www.apph-bg.org/

We are also on Facebook.

Todor Mangarov, National Association of PPH

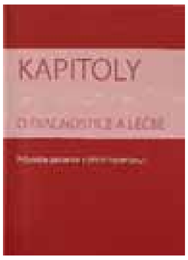
www.apph-bg.org

CZECH REPUBLIC

Katerina Nováková, President of the Czech PH association (3rd from right) and Yveta Makovnikova, President of PHA Slovakia (2nd from right)

Annual General Assembly

On the 29 and 30th of May we held our Annual General Assembly. The 2-day event was organized in a hotel in Seč, a very nice village in the countryside about two hours from Prague. About 50 persons attended, most of whom were patients. On the first day the programme included a presentation about 2010 activities, about future projects for 2011 and the approval of our financial report. This year we invited Pisana Ferrari, Vice President of PHA Europe, to tell us about her association's activities in Italy and about what other countries in Europe are doing. She was also asked to be the "godmother" of a new patient booklet which was printed recently and distributed at the meeting. The programme also included some workshops covering different aspects of life with Pulmonary Hypertension. There was a workshop about treatment with oral drugs and one about 24 hour infusion treatment. In the evening we all enjoyed dinner together and had time for socializing. We had organized some activities for our guests: some played bowling, others took personality tests and a few benefitted from a wonderful facial massage done by one of our members. On the second day we had the great pleasure of having as our guest Yveta Makovnikova, President of the newly set up PH Association in Slovakia.



New Patient booklet presented at the General Assembly

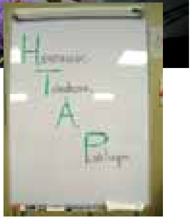
Katerina Nováková, Sdružení Pacientů s Plicní Hypertenzí

www.plicni-hypertenze.cz

FRANCE

Family week-end, Chédigny, 8-9th of May

Our yearly family week-end took place between the 7th and 9th of last May. Like last year, Céline (our Vice-President, and mother of Paul, who very sadly passed last January at the age of 9) chose to organize it at "Hotel La Saulaie", as the team there had really done a wonderful job to welcome our group last year. The families with the children that were already there last year came back, and two "new" families took part. The very positive observation is that families made friends during previous weekends, and they stay in touch very regularly. We are more than happy about this, as one of our main objectives is that patients and families make new connections and thus feel less isolated. Families with sick children from 1 year old up to 16 years old were present, parents, brothers and sisters, and also some grand parents. Two cardio-pediatricians, Prof. Damien Bonnet with his family and Dr. Mailyne Levy, participated and led interactive sessions with children and with parents. Some other professionals, including a psychologist and a nurse, also came. The week-end was a great success and we plan to organize it next year in another part of France, where other families could come more easily.



Children at the Family weekend in May

205 km "ultra marathon"

Every year since 2005, Marie-Andrée, a patient from Toulouse, organizes with her energetic team of volunteers an "ultra marathon", a 205 km run between Toulouse (south west part of France) and Port la Nouvelle (on the Mediterranean sea). One runner actually runs the whole race, and it takes two days. But some other volunteers (patients, family members and friends, supporters of the association, some medical professionals…) run or cycle with him. This event requires a lot of organization in the 6 months preceding it, and a lot of help from people there. But the atmosphere during the event, the motivation of the racers and of all the volunteers, the enthusiasm of the patients, who are "tutored" each by a runner, is full of very positive energy. The images that stay afterwards are very encouraging for patients who realize that it is a solidarity moment, and, on top of that, the media also like it, so it is an occasion for us to raise awareness about PH.

Running for PH in Lyon and Sète

Two other races were organized in Lyon and in Sète. In Lyon, it was the 4th "Lyon a pleins poumons", where Sylvain (our President), his family and friends from his former Athletes' club invited everyone to spend a couple of hours together, running a few kilometers in Parc Gerland. There was a race for children, and one for adults, and a possibility also to walk. Once again, Sylvain can be very satisfied about his success, as there were more people than last year. In Sète (near Montpellier), Xavier, a young patients' dad, organized "Sète en baskets", with a run during the day and a concert by Michel Fugain (a very famous French singer since the 70's) with 700 persons.

These events are very pleasant and allow us to talk to the media. But it is not so easy to attract their attention, because it is not so much in the French culture to organize such events and to talk about one's problems, or even to raise money for research, for instance.

It is also necessary to have competent and numerous teams in the places where you want to organize such big events, and it is not always possible.

That is why we are thinking about how to make our "ultra-marathon" last, while some of the most active volunteers might not want to go on for long and while our "special runner" is getting older (he is over 60!). If they are not replaced or reinforced, it will not be possible to go on.

HTAP France's new website

Mélanie Gallant Dewawrin, HTAP France

News from European PH patient associations

HUNGARY

General Assembly and membership

Patients mingling at the Trófea Grill (above)

Eszter Csabuda, President of the Hungarian Association (left, 1st from left)

PHA Hungary held its General Meeting on the 25th of May in a very nice restaurant in Budapest, the *Trófea Grill* (see photos). This meeting provided a great opportunity to network and exchange information in a pleasant and informal context.

The number of the members of the Hungarian Association is steadily increasing and is now over 30.

"Szivünk Napja" (Day of the Heart)

Photos from the 2009 "Szivünk Napja" ("Heart day")

Dr. Karlokai being interviewed at the 2009 "Heart day" (below on left)

Last year in September our association participated in an event called "Szivünk Napja" (Day of the Heart), organized by the National Association of Cardiologists in the city park of Budapest. Mr. Karlocai MD, from one of the Hungarian PH Centres, and Vice President of the Association, made a presentation on PH and gave an interview to the local media. We had a booth and our members, wearing blue and purple T-shirts with the association logo, handed out brochures and gave information to visitors (see photos). We will be participating again this year and the Vice President of the Association will make a presentation on prevention of the disease.

New website

PHA Hungary is working on a new website. The PHA Europe newsletter, *Mariposa News*, has been posted on the current website at: www.isacahu.com/tudoer2/

Eszter Csabuda, Tudoer Egylet Hungary

www.tudoer.hu

IRELAND

PHA Ireland

The Pulmonary Hypertension Association of Ireland was established in late 2003 (www.centreforlunghealth.com). The patient association is the first and and only charitable association of its kind in Ireland.

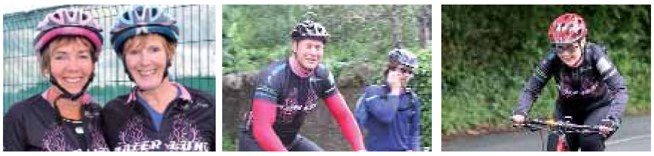
The association serves primarily as an educational resource, providing up-to-date literature and advice for those diagnosed with Pulmonary Hypertension and their carers. It also aims to advance awareness and education amongst members of the medical and allied health professionals as well as the general public through the provision of Annual Association meetings. The President of Ireland, Ms. Mary McAleese became Patron of the Association in 2004.

Annual Association meeting

At the forthcoming PHA Ireland meeting, scheduled for November of this year, we expect the attendence to be even greater as knowledge and awareness of the disease has grown.

PH awareness week

Preparation for the National Pulmonary Hypertension Awareness Week is underway at present and is scheduled for the 16th to the 22nd of August 2010. This year will be be joining in with the worldwide "Blue Lips" campaign and hope to help in breaking the Guinness world record while raising



Photos from a charity cycle held in 2009 the profile of Pulmonary Hypertension. We are fortunate to have the support of patients, relatives, friends and staff who continue to assist the association through fundraising and organising events in local their communities.

Support groups

In the coming year we hope to establish Support Groups in response to increasing needs for those with Pulmonary Hypertension and their caregivers, in order to create a resource that will provide information, emotional support and hope to all involved.

Both interest and membership of the Association continues to grow and we hope that active participation from patients and families will contribute to its ongoing success.

Diane Moran, PHA Ireland

www.centreforlunghealth.com

ISRAEL

“Blue Kisses Campaign” in Tel-Aviv

PHA-Israel joined the international initiative organized by PHA-UK: “Pucker-Up for PH”.

"Wall of Blue Kisses" in Tel Aviv in July

The aim is to increase PH awareness by collecting Blue Kisses and breaking the Guinness Book of Records for blue lip prints on a piece of paper.

Israel’s first event was held on July 6th on a busy boulevard in Tel Aviv. Celebrities and hundreds of passers-by were invited to apply blue lipstick and give blue kisses, which were then pinned onto a *Wall of Kisses*. This generated a great deal of interest, particularly from the young people who were eager to help and find out more about PH.

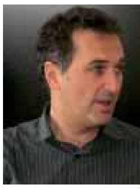
People who had read about the event came from other cities to participate and some have volunteered to help the association in the future. Some people who had “donated” kisses came back later with their friends. Lots of school children, on holiday, were particularly excited about having their “blue lips” photo placed on the Facebook site set up for the duration of the campaign, something they’ll no doubt show their families and friends, enlarging the circle that we can reach out to. The atmosphere was one of fun and enjoyment.

Another event was held two days later during a high school graduation fun event with hundreds of young people donating “blue kisses” to the *Wall of Kisses*.

Over 500 kisses were collected during these events but more importantly many people were made aware of PH. The event was sponsored by Neopharm Israel, representatives of Actelion in Israel.

Meeting Dr. Olivier Sitbon

Dr. Sitbon, a distinguished PH specialist from the Antoine Beclère Hospital, Clamart. France, visited Israel in June and kindly accepted an invitation to meet members of the Israeli PHA (patients and families). The meeting was held in the house of a PH patient, as an informal open forum for questions from the participants. The questions were mostly on new treatments, new drugs, pregnancy with PH, transplantation, and other question that concern living with PH.



Prof. Olivier Sitbon, from the Antoine Beclère PH Center in Clamart (France) at the Israeli patient meeting

Dr. Sitbon gave clear and informative answers which were then translated to Hebrew. After the meeting with Dr. Sitbon the General Assembly of the Israeli PHA was held, for the purpose of the annual elections for the board. The atmosphere was very pleasant and all the participants enjoyed the opportunity to meet other patients and family members.

The meeting was sponsored by GSK.

Iris Tal, PH Israel

www.phisrael.org.il

ITALY – AIPI

New website

AIPI's website has recently undergone major restyling and will be online shortly. The graphics on the home page are more bright and colourful and the website will have new features such as a photogallery, a section for merchandising items, and for uploading videos. There will also be a section in English. Some of the contents is also being updated.

AIPI on national TV

On the 26th of April Italian state TV (RAI 2) showed a brief documentary filmed at the Bologna S. Orsola-Malpighi Hospital in Bologna. Some of the doctors from the PH team, including Prof. Nazzareno Galiè and Dr. Massimiliano Palazzini, were interviewed for the film, and they described in great detail the diagnostic tools (including RHC) and all the treatments available for PH. There was also an interview with a patient who was being visited and who explained the disease and its symptoms.

The organizers had also asked to have some input from the patient associations so I went to Bologna and was interviewed very briefly about the support provided by AIPI to patients and their families.

The program the film was done for - Medicina 33 - is quite popular so it provided an excellent opportunity to spread awareness on the disease and its implications for patients. The film will be downloadable from our new website shortly.

Prof. Nazzareno Galiè (top)
Pisana Ferrari (above)

Dr. Alessandra Manes performing a Right Heart Cath (right)

Summer issue of AIPI newsletter

The summer issue of AIPI*news* has recently been posted to members and can be downloaded from the AIPI website. It contains reports of the recent GSK event in Bologna and of the European Conference on Rare Diseases (see also page 17) as well as of the Patient Meeting in the Czech Republic where I was very kindly invited to speak (see also page 17). Members' contributions include recipes, reading suggestions, fashion tips and a number of patient stories. These stories are very popular with our readers. We have an average of three to four in every issue and have published over 60 over the last few years. We are now thinking of putting them all together in a publication which could go to print early next year. In 2011 we will have celebrations for our ten years of activity and this could be a good opportunity.

Blue Kiss Campaign

Along with a number of other European patient associations AIPI is also taking part in the Blue Kisses Campaign. It was not possible for us organize a Blue Kiss event over the summer months as most people are away on holidays but about 15 volunteers are busy collecting blue lip prints from their family members, friends or colleagues at work.

Our youngest volunteer is Maria Simionato, a 12 year old patient from Mestre, near Venice (see photo). Maria has already collected over 100 lip prints and has asked for a second kit! We will be collecting the lip prints at the end of the summer and are very happy to contribute to this important international campaign!

Maria Simionato, 12 years old, is our youngest "kiss-collecting" volunteer. She has collected over 100 lip prints! Here she is with her parents Riccardo and Michela

Pisana Ferrari, AIPI Italy

www.aipiitalia.org

ITALY – AMIP

left: the AMIP group in front of the Certosa di Pavia

right: Maria Pia Proia, former AMIP President, (1st from left) with Prof. Stefano Ghio (2nd from left) and two other guests

AMIP's tenth aniversary and annual patients' meeting

Pavia, May 14-15-16th

On Friday morning we left Rome under a rain storm, but when we reached Pavia in the afternoon a pale sun was waiting for us. Many friends had already arrived in the hotel and one of the first things we did was to watch the dvd with the interviews on PH that Sky TV broadcast last winter. Greetings and chatting went on till dinner time, when around the tables it was easy and pleasant to renew old friendships and form new ones.

On Saturday morning, at breakfast, I explained that AMIP is taking part to Pucker Up 4 PH campaing (launched by PHA-UK) and everybody was given a Blue Lips entry form. Then we all went to San Matteo Hospital where the Conference was being held.

The Conference was a huge success: more than 100 people attended and the whole team of doctors (cardiologist, pulmonologist, reumatologist, the expert on HIV, the cardiac surgeons and so on). Some of the nurses were present too. Prof. Ghio, the head of Pavia's PH Expert Centre, talked about the importance of being able to provide a multidisciplinary approach to the PH patients. The doctors explained the illness, the treatements, etc. Every session was followed by a debate and the patients had the opportunity to "ask all the questions they had never dared to ask". At one o'clock a nice lunch was served near the Aula Magna that hosted the Conference. In the afternoon the Conference went on with other interesting sessions and debates. All the patients were very happy, some of them weren't members of AMIP yet and they joined our association on this occasion. This is also important for us because it gives us more power when we go to the Authorities to speak on their behalf.

On Sunday morning those patients who were coming from outside the Region and that had stayed the night were offered from AMIP a Tour to the famous "Certosa di Pavia", a beautiful historical Abbey full of art and atmosphere. At Midday everybody left, the trip to Rome was long but we were really happy. What did I like best during the 3 days of the meeting? The laughs, the friendship, the songs! PH patients lack breath, but they were happy and they were able to make a lot of noise!

Football match

For the second time the town of Ciampino, not far from Rome, helped us to organize a football match: the members of their community against a team of TV show men. It is really moving to see how so many Ciampino citizens have adopted AMIP as "their" charity! They were able to fundraise almost 5.000 euros that will contribute to pay for the new ECHO machinery that we offered the Policlinico of Rome Specialized Centre. Other fundraising events have been held during springtime with the same purpose: social dinners, raffles, etc.

Media

AMIP is having a very good response with the Pucker Up 4 PH campaing launched from our PHA UK friends. Our members are cooperating very well, sending the press releases that we suggested to the local press. This resulted in several articles about PH and interviews on the radio. The fact that there is no fundraising connected with the campaign facilitates it, on the other hand we value the resulting visibility very much.

Luisa Sciacca della Scala, AMIP Italy

NETHERLANDS

Kinderdag - PH Children's day

PHA Netherlands held a very successful *Kinderdag* (PH children's Day) on 26 May in a studio at the Mediapark in Hilversum (see photo). The event featured jodoka Dennis van der Geest. He opened the day with a brief speech about the importance of good health and AIR (our theme of the day) during his sport career. After that he let balloons up in the air with wishes from the children for their future. There was also a talk show with the famous actor Sebastiaan Labrie. He talked to the children about what it is like to have PH or to have a relative with PH. A pulmonologist from the VUmc in Amsterdam, Dr. A. Vonk-Noordegraaf, the mountaineer Ronald Naar and an F16 pilot also took part in the talk show. They all spoke about what AIR means to them.

The pop group *Djumbo* (3 Dutch girls, see photo) came to sing for the children. There was a oxygen lounge to relax, and a *stormbaan* (enormous pillow filled with air where the children can jump and play on). There was also an ergometer. Sebastiaan Labrie and some parents had a spin on this bicycle (see photo). Whilst they were on the bike the output of oxygen was gradually turned down so that they could feel what it is like to have PH. We ended the day with pasta and ice cream for everyone. The entire event was filmed by 3 professional cameramen and all the families who attended received after a few weeks a nice DVD of the day. 34 children and 31 parents attended.

New website for kids

The association has also recently launched a new website specially designed for children with PH (see photo).

The website is bright, colourful and very attractive. It is very user-friendly and provides useful information targeted to young patients on the disease, diagnostic procedures, such as ECG and right heart catheter, and treatment options. It contains a section with tips for every day life and on how to relax when stressed or fearful. There is also a forum where the young patients can chat and exchange information: www.ikhebph.nl/

Many young patients are happy that they can give the name of the website to their friends so that these can read for themselves about PH. Children don't like to always have to explain the difficulties related to their disease.

New brochure

PH nurses Sylvia Oudakker (Erasmus mc, Rotterdam) and Iris van der Mark (VUmc, Amsterdam) wrote a new brochure with all the information one can possibly need when using Remodulin. On September the 10th PHA Netherlands will be holding a day meeting for this group of PH patients in Utrecht.

Maaike Atres, Stichting PHA Nederland

www.pha-nl.nl

NORWAY

Increasing membership

In Norway we are struggling to get in contact with all the PH patients. Through our web pages, we have found some, but there are probably many more patients that are not aware of the existence of our organization.

We plan to make brochures that can be distributed to hospitals and doctor's offices to inform about PHA Norway.

Hall Skåra, PHA Norway

www.pha-no.com

PORTUGAL

Mini marathon in Lisbon

On the 10th of April the Portuguese Society for Respiratory Medicine organized a mini marathon for persons suffering from cardiac and respiratory diseases. This event was held within the context of the Society's Annual Congress in the presence of the Portuguese Prime Minister José Socrates and ex Olympic athlete Rosa Mota. The marathon consisted in a 2.000 metre walk and its objective was to stress the importance of physical exercise and its contribution to patients' general well being. Our little group of PHers was made up of myself, Ana Pinto, Miguel e Ana Boavida. We spent a wonderful afternoon, we were cheered on by the Prime Minister and Rosa Mota gave out autographs to all of us.

Maria João Saraiva,
Associação Portuguesa de Hipertensão Pulmonar

www.aphp-hp.org

SLOVAKIA

PH association set up

The Slovakian PH association was founded on the 5th of March 2010 and registered with the Ministry of Interior. The first General Assembly took place on the 30th of April and was attended by 37 patients, family members, professionals, representatives of pharmaceutical companies and friends. The president of the Czech Patient Association, Katerina Novakova, was also invited. At that time there were 31 registered members and now we have 33 members. Elections for the Board of Members took place during the General Assembly. It was a great honour for me to be elected as President. Dr. Milan Luknár, a doctor and an expert in Pulmonary Hypertension, was elected Vice President. .

Mrs.Yveta Makovnikova, Chairman of the Slovakian PH Association (above center)

Activities of last few months

In the last few months we have been quite active and these are some of the initiatives taken:

- setting up of a our web site;
- participation in the *Czech Society of Cardiology Congress* which was held from the 16th to 19th of May 2010;
- participation in the patients meeting of the Czech PH association in Seč on 29th and 30th of May 2010;
- article about founding the association published in the *Slovakian Cardiology Journal*.

We have also begun working on a rehabilitation program and plan to hold a two-day educational meeting, reconditioning for patients in the early autumn.
At the European level, we have applied for registration in PHA Europe and will take part in the European meeting in Barcelona in September.

Future plans

These include:

- search for new partners;
- fundraising activities for the association;
- search for sponsors and financial assistance;
- contact the Ministry of Health, obtain support for the association;
- work on increasing membership;
- create a program to familiarize professionals, patients and the general public with the diagnosis and treatment of PH;
- issue a brochure on PH for patients and leaflets to distribute in hospitals etc.;
- promote the active participation of all patients in the association;
- shoot a video of the activities of the association and show it on television;
- publish articles in magazines and on the internet;
- create our own magazine;
- register on Facebook;
- continue to cooperate with the Czech association, while we are considering to organize a joint meeting of patients from both countries;
- expand cooperation with associations from other countries.

Yveta Makovnikova,
Zdruzenie Pacientov s Plúcnou Hypertenziou

www.hypertenziapluc.szm.com

News from European PH patient associations

SPAIN

Respiratory Medicine Congress

The Spanish PH association was present at the Summer Congress of the Spanish Society of Pulmonology and Thoracic Surgery (SEPAR) which was held in La Coruna (Galicia) between the 24th and the 28th of June. We had our own booth (see photo) and were able to distribute the Association's educational material and give out information on PH. It was also a great opportunity to make ourselves known.

Irene Delgado, President of the Spanish PH Association

Annual General Assembly

This year's Annual General Assembly was held from the 11th to the 13th of June in Marina d'Or (Castellon). The meeting brought together patients from all over Spain to talk about PH and share experiences and information about day to day life with the disease. Marina d'Or is on the seaside and patients were able to also enjoy the lovely weather and wonderful beach (see photos).

Irene Delgado, Associacion Nacional Hipertension Pulmonar

Photos from the meeting in Marina d'Or

www.hipertensionpulmonar.es

SWEDEN

Recent news

The Swedish PH group now has its own web site: pah-sverige.se! We also have a Facebook group, where we can meet and plan/inform about future happenings. In autum meetings in Linköping and Malmö will take place.

The Swedish PH group has recently connected with the larger Heart-and-Lung group in Sweden.

Kirsten Dahl with her son Linus who sadly passed away from PH last year

Kirsten Dahl, PAH i Sverige

pah-sverige.se

SWITZERLAND - Schweitzer PH-Verein

Bruno Bosshard speaking at SPHV patient meeting

Patient meeting

Zurich, 27 February 2010

On Saturday 27 February 2010 a PH patient meeting took place at the University Hospital of Zurich. Over 50 persons attended. The event was organized by Mrs. Ulla Treder of the University Hospital. She also led through the interesting daily schedule.

Professor Dr. R. Speich presented the PH team. It was nice to meet the co-workers who do their work in the background. Professor Dr. R. Speich explained to us the possible interactions and side effects of the different medicines. Professor Dr. Grünig and Mrs. N. Elken were scheduled to speak about a study on “PH and Rehabilitation” but were unable to attend for health reasons. Professor Dr. R. Speich took over their task and presented the results of this study. The investigations carried out up to now show a very big improvement in the condition of patients. No medicine could achieve such an increase in distance walked (>100m) as the one obtained through the special training done in the context of the study. It must be emphasized that this is not just a basic training. Every patient has a training program adjusted to his particular situation and condition. During the training investigations are carried out and patients are monitored with echo stress test. For safety reasons the training must take place within the context of a 3-week rehabilitation program in the Rehabilitationsklinik Heidelberg Königstuhl, which is very experienced with Pulmonary Hypertension patients. Experience has shown that “moderate” is a very individual term and the line between “effort” and “excessive effort” is extremely fine. The person concerned must be supervised by a specialist in Pulmonary Hypertension during the entire training. The program is applicable for patients that have been stable for at least two months in PH-specific therapy.

International Rare Diseases Day

Basel, 28 February 2010

Local events for the International Rare Disease Day took place for the first time this year in Switzerland in the cities of Basel and Zurich. As Swiss PH association (SPHV) we had a stand in Basel to advertise ourselves. The meeting was well organized and there were also several other associations or self-help groups who took part. As we all know, with Rare Diseases the diagnosis is difficult and often drugs are missing. More than 30 million people in Europe suffer from one of the approximately 7000 admitted rare diseases. 2010 was the second Rare Disease Day and this initiative has had a significant impact in raising awareness on this important issue.

Therese Oesch, President of the Swiss PH Association (SPHV) - Breathing as effort

“In the hot summer of 2003 I suddenly had trouble making any effort and I did not know what was wrong with me”, says Therese Oesch, President of the Swiss PH association SPHV. She suffers from Pulmonary Arterial Hypertension.

Fortunately, four weeks after a first, wrong, medical diagnosis, Terese Oesch saw a TV show where her exact symptoms were described. “From there on I knew what I had...”, “now I am living slower and I am able to plan just one day after the other”. As President of the Swiss Patient association Terese Oesch has decided to speak out with all her forces about this disease on all possible occasions so that it becomes better known and so that concerned persons get a correct diagnosis as soon as possible and benefit from a more favorable prognosis.

News from European PH patient associations

8th PH patient meeting - Olten, 29 May 2010

Over 60 persons took part in this meeting. This year two fascinating topics were part of the program:

- Patient education
  Most persons suffering from a chronic disease will at some point in their lives ask themselves: “What can I do for myself...?”. In the last few years the concept of “informed patient” has come up over and over again: “What is to be meant by that? And what not? Does it cost energy, to be an expert and independant patient?”. Together with the social psychologist Cristina Galfetti, who is affected by a chronical illness herself, we debated these issues. We also spoke about how a psychologist can help with the handling of a chronic illness.
- Relaxed and free breathing at pH
  Breathing is an expression of the individual health, the personal life story and the current mental state. The respiration must be able to react on physical as well as emotional aspects. It is the vital exchange between inside and outside. A healthy breathing movement keeps the physical and mental equilibrium of people. Eva Lea Glatt explained during her report how this complex, holistic process works, described by different exercises and gave valuable hints for a free and healthy breathing movement. During the following lunch the opportunity was offered for an informal exchange of experience and opinion with other concerned persons.

Oxygen filling stations in Europe

In Europe at some places refilling tanks with pure oxygen have been set up, so that oxygen-requiring patients are able to refuel their portable equipment. With this possibility they can extend their radius of action. A part of these offers are so called “oxygen filling stations”, the other possibilities are pharmacies, manufacturer, medical practices, hospitals etc. On our web page these filling stations are evident on a map. Please inform us, if you know other oxygen filling stations or CO_2 filling possibilities in Europe.

Bruno Bosshard, SPHV

www.lungenhochdruck.ch

TURKEY

Regional offices

A corresponding office was set up in Istanbul in May. PH Turkey plans to set up a regional office in Izmir shortly.

9th International Conference on PH

PHA’s 9th International Pulmonary Hypertension Conference took place in Garden Grove, California, from the 25th to the 27th June and Ümit Atli, President of Ph Turkey, was invited to make an presentation at the Leaders Meeting about “Patient Education”. See also page19.

Patient meeting

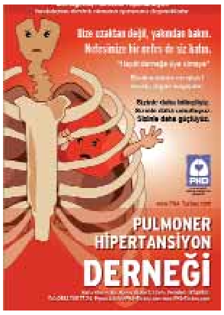
PH Turkey held a PH patient meeting on the 13 th of July in Istanbul with a special guest speaker, Dr. Metin Aytekin, who lives in Cleveland-USA and who was received an award from PHA for his PhD studies on Pulmonary Hypertension in 2008.

General Assembly in September

PH Turkey will hold its Annaul General Assembly in September in Ankara. One of the items on the agenda is the elections of the New Board for the next two years.

Raising awareness

- Two brochures on “PH - awareness” have recently been printed and have been distributed to the hospitals in Istanbul, Izmir and Ankara.
- PH Turkey will take part in the 26th National Turkish Cardiology Congress being held between 21-24 October 2010, in Istanbul.



Documentary short film on PH

PH Turkey plans to prepare a documentary film about PH, diagnosis, treatments and the daily life of PH patients in Turkey. The film will feature an interview with Prof. Dr. Hossein A. Ghofrani, MD from the Pulmoner Hypertonie Clinic in Giessen (Germany) which has recently been made for the film. An interview with Prof. Dr. Walter Klepetko and the team in the AKH General Hospital of Vienna will follow in August.

Ümit Atli, Pulmoner Hipertansiyon Dernegi

www.pha-turkey.com

UNITED KINGDOM

Help Us Kiss Goodbye To A Lack Of Awareness About Pulmonary Arterial Hypertension

PuckerUp4PH, the global campaign to raise awareness of Pulmonary Arterial Hypertension (PAH) whilst seeking to break a Guinness World Record for the largest collection of blue lip prints, created and led by the UK's Pulmonary Hypertension Association, is quickly gaining a following around the world.

29 PAH patient support organisations/groups are working together using the simple, but memorable symbol of blue lips to attract attention and create opportunities to talk to people around them about PAH. PHA UK research discovered that only 3% of the UK population had heard of PAH and it is believed there is similar public ignorance about the condition across the World, which has inspired a growing number of people who live with PAH to do what they can to help overcome this lack of awareness. From the simplest of gestures such as a support group leader in Canada encouraging the curious postman delivering her PuckerUp4PH Kits to put on blue lipstick and kiss one of our official entry forms to a joint Zumba/Blue Lips world record attempt in Australia, the PuckerUp4PH team have been delighted by the enthusiasm and creativity the campaign has inspired so far.

We've seen Kissing Walls in Israel, kiss collecting and PAH education activity at hospitals, workplaces, shopping centres and kids camps in Puerto Rico, a Kissing Booth staged at the recent PHA Conference in the USA gathered 400 prints, stars from a series of top London theatre shows have lent their lips to the initiative and we know of Blue Lipped banquets, fashion parades and football matches taking place across Italy! Visit www.puckerup4ph.com website and log on to the latest news section for photographs and details of events we know of.

Since the campaign commenced the PuckerUp4PH campaign website has received several thousand visits, 70% of which are new visitors finding about more about the campaign and PAH which is great news!

Please Help Us to Help Others

We need over 40,000 lips prints to set a new Guinness World RecordT, which is quite a task so we need as many people as possible to help. We hope by reading this article, it will inspire you to want to get involved. All efforts no matter how small will make a difference. Please visit www.puckerup4ph.com/worldrecord-aipi.php to download entry forms, PAH information leaflets, posters and more that have been translated and customised specifically for AIPI members!

Even if you only download one form for yourself and pass the link on to all your family, friends and colleagues asking them to do the same, you could start a chain of events that makes a huge contribution to the campaign. Every blue kiss collected is another chance to raise vital awareness and put PAH on the map!

Paul Pennington, PHA UK

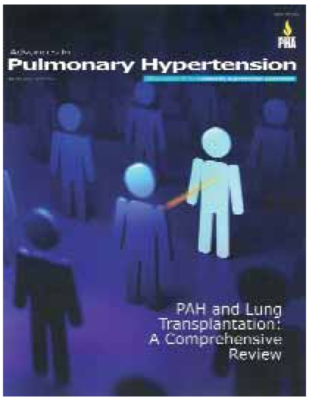
Summer issue of newsletter

The summer edition of Emphasis, the PHA UK newsletter, is now out and can be downloaded from the PHA UK website. A large portion of the newsletter contains information about the Blue Kisses campaign and various activities being carried out in the UK and around the world (see map). There is also an interesting article about the issue of treprostinil (Remodulin) no longer being made available to "new" patients either in the UK or Northern Ireland. We have also received news of possible future difficulties in Belgium (see page…). PHA UK has written to the pharmaceutical company producing Remodulin and both the letter and the reply have been published in the newsletter (page 3). Supply will be maintained for those already established on therapy for as long as they require treatment. For further details see:
http://www.phassociation.uk.com/downloads/emphasis_summer_2010.pdf

USA

Advances in Pulmonary Hypertension

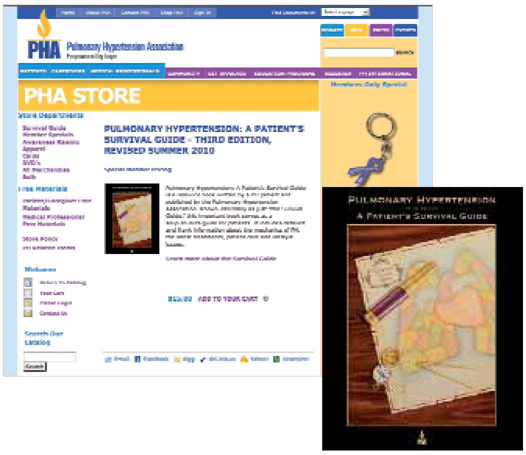
The latest edition of PHA's Official Journal is about PAH and lung transplantation. The magazine contains a very comprehensive review of all the various issues involved: getting listed for transplant, how the organ allocation system works, surgery techniques, post transplant patient management, survival and quality of life, etc. As the editor points out PAH and transplant have been closely linked since the early 1980's when the first transplant (heart-lung) was performed on a patient with PAH. At that time there were no other options for patients. Over the past 15 years enormous progress has been made with respect to medications but transplant remains a very good option for patients who do not respond effectively to treatment.



Anyone can subscribe for free to Advances in Pulmonary Hypertension by contacting medical@phassociation.org. There is also a link to back issues online at www.PHAOnlineUniv.org/Journal

PHA's new Survival Guide

The new edition of PHA's Patient's Survival Guide is now available.This important book includes useful information about the mechanics of PH, the latest treatments, patient care and lifestyle issues such as what to eat when you have PH, working, exercising and travelling, dealing with emergencies, doctors, colds and flu. The survival guide also includes a chapter on paperwork and legal matters involved in the management of PH.



The Survival Guide was written by Gail Boyer Hayes, a PH patient, and is updated twice a year by a team of patient and medical writers under the leadership of Dr. Ron Oudiz, who is currently serving as medical editor.

Order your copy from the PHA store at:
www.phassociation.org/Page.aspx?pid=192&nccsm=21&__nccscid=12&__nccsct=Survival+Guides&__nccspID=897).

www.phassociation.org

Next PHAE newsletter

The Winter issue of the PHA Europe newsletter is due out around end of November/early December. The first part of the new Mariposa will contain a report on the PHA Europe Annual Assembly being held in Barcelona September 18-20. We would like to do a section on comments from the participants and would be grateful for your precious input. If you have any photos taken during this event please send them as well and we will publish them.

We will also have the usual section on reports from the national PH associations and hope to receive your contributions about recent activities, and if possible, any photos you may have. You may send your contributions in your own language and we can provide for translation.

We would also very much welcome any suggestions for future editions of the newsletter. For example, do you think it would be interesting/useful to have some patient stories? Or articles written by our members on PH related issues? Are there any items that are not currently covered or that you would like to read more about? Another point on which we would appreciate your help is the distribution of Mariposa and building up of a mailing list. We are planning have the newsletter printed as well as in PDF format. The PDF can be e mailed. The printed version can be posted either directly from Milan to your mailing list or sent to you for further distribution. Please advise. Many thanks in advance!

Berlin

7 May 2010

On the 7 th of May I was asked to speak on behalf of PHA Europe at an International Nurse workshop organized by BAYER. It was the first time I was invited to such an event. The workshop was held in the Swisshotel in the Berlin city center. I must say that I was very impressed by the excellent organization: simultaneous translation cabins for 5 languages, a huge stage, monitors in front of speakers to see one's presentation and all kinds of microphones, etc. About 180 PH Nurses from all over the world attended (including Saudi Arabia, Korea and all of Europe). The workshop started with a speech from a very nice Belgian PH doctor, Prof. Jean Luc Vachiéry, then it was me about the role of Patient Associations and PH in relation to PH Nurses and it continued with speeches about psychiatric training in the interaction with the patient and his relatives. Unfortunately I had to leave after the first day but the programme for the second day was also very interesting. During lunch I had the opportunity of making a number of useful contacts including nurses from Sweden & Denmark.

Gerald Fischer, PHA Europe President, Austria

Kracow

13-15 May 2010

It was a great pleasure and unique privilege for me to participate in the 3 day European Conference On Rare Diseases (ECRD 2010) in Krakow. This event gathered over 600 participants from 43 countries, a third of which from Central and Eastern Europe, and many from outside of Europe as well: US, Canada, Israel, Tunisia and Argentina. The Conference, entitled "From Policies to Effective Services for Patients", provided the occasion to raise some of the main issues facing rare disease patients in Europe. Discussions centred mainly on four of these: National Plans for Rare Diseases, Centres of Expertise and European Reference Networks, Research and Treatments, Information and Specialised Services. There were 25 different sessions organized covering 8 themes, involving 73 speakers and 37 chairpersons. The programme included presentations, debates, workshops, satellite workshops, a poster session. For some of the sessions there was simultaneous translation in several languages. Of particular interest were the discussions on improving access to orphan drugs for patients in Europe and on the EU directive on cross-border care (see also page 20) and its impact on future patient mobility. There was a welcome reception and time off to give the opportunity to participants to network and meet informally. I made many new interesting and useful contacts and met old friends from the Eurordis meeting in Athens last year. I had brought several copies of our first Mariposa News and personally handed them out to Mr. Terkel Anderson, President of Eurordis, from Denmark, who speaks beautiful Italian and who appeared very interested in our "PH European umbrella"', to Mrs Domenica Taruscio, leader of the EUROPLAN project and Director of the Italian Rare Disease government centre and others. Many people were interested in PH. It would have been very useful to have more copies and more material for distribution. Information is never enough!

For full report see: http://www.eurordis.org/content/european-conference-rare-diseases-%E2%80%93-ecrd-2010-krakow

Marzia Predieri, AIPI Italy

Bologna

24-26 June 2010

It was a great honour for me to be asked to present the Patient Organization's perspective on behalf of PHA Europe at the event organized by GSK in Bologna June 24 to 26. The meeting, entitled, "Focus on PH, 15 years on", wished to commemorate another landmark meeting on prostacyclin (Flolan) held in Bologna in 1995. About 300 persons from 22 countries were present. During the 3 days, distinguished researchers and PH specialist physicians went through the great advances made in the diagnosis and treatment of Pulmonary Hypertension, from the basic science and first pioneer trials to the new treatment strategies, and explored possible ways to further improve outcomes in patients. There were presentations on the new treatment pathways currently being tested as well as on ways to optimise available resources. The program was very interesting as it included not only presentations but also interactive sessions, workshops and debates. One of the highlights of the meeting was the presentation from Prof. Andrzej Szczeklik, who was part of the team that discovered prostacyclin. In his brilliant speech he told us about the excitement of this finding and how he and one of his close colleagues first injected themselves with prostacyclin to see how it worked…! Another very interesting debate was about the value of transplant. Prof. Walter Klepteko (Austria), a world renowned lung transplant surgeon, questioned the idea that transplant be used only when all else has failed and suggested that it be considered more upfront as a treatment option thus allowing for better recovery. I would like to end by thanking again the Board members of PHA Europe for their precious input and suggestions for my presentation.

Pisana Ferrari, Vice President PHA Europe

European PH leaders at PHA USA Conference

The crowd mingles at the pre-conference Patient and Caregiver Meet & Greet

Fifty PH Association leaders from all over the world attended the First International Leaders Summit organized within the context of the 9th International PH Conference of PHA USA (Garden Grove, California).

European leaders present include Gerald Fischer (President of PHA Europe and PH Association Austria), Ümit Atli (Vice President PHA Europe and President PH Association Turkey), Hall Skåra (President PH Association Norway), and Joni Berg (President PH Association Israel).

We are delighted to publish a report on the conference kindly sent to us by Christine Dickler, Associate Director of International Services, PHA USA as well as comments from some of our European friends present: Gerald Fischer, Diane Moran (PHA Ireland), Hall Skåra and Ümit Atli.

Nearly 1,300 registrants from 20 nations "rode the wave to a cure" at PHA's 9th International Pulmonary Hypertension Conference and Scientific Sessions, PHA's largest Conference ever. PH patients, families, caregivers, international PH association leaders and guests and PH treating medical professionals gathered for a weekend of education, networking, inspiration and renewed hope for a cure.

The International PH Conference has a long tradition of drawing leaders from all corners of the globe. This year, PHA enriched the Conference experience for our fellow association leaders by adding additional programming to further the global fight for a cure. The First International Leaders' Summit, in which 35 association leaders from throughout the world participated, offered presentations made by Hall Skåra (Norway) and Ümit Atli (Turkey) on developing patient education programs, Paula Menezes (Brazil) and Debbie Castro (USA) on engaging volunteers and grassroots power, Valerie McLaughlin, MD (USA) on developing medical education, Gerald Fischer (Austria) and Rino Aldrighetti (USA) on fundraising, and Emma Bonanomi (USA) on raising awareness of PH. Leaders from Japan, Israel, Mexico, Iran, Venezuela, Canada, Ireland, and Australia also contributed experiences and ideas in a series of relevant and engaging conversations.

Throughout the rest of the weekend, everyone had the chance to meet new friends and reconnect with those they'd met at past conferences. Nearly 40 Medically-Led Sessions offered exclusive information about aspects of living with and treating PH, Patient & Family-Led Sessions connected long-term survivors and other active members of the PH community with those looking to learn more about living with PH, caring for loved ones with PH, and just returning to normal. Support group meetings and children's activities rounded out the schedule to keep people having fun and learning lots.

Medical professionals enjoyed the 9th Scientific Sessions, which centered on Inflammation and PH. Seventy research abstracts presented cutting-edge developments and inquiries, and the popular Research Room collected samples to further the work of ten research teams from various institutions around the nation.

Visit www.PHAssociation.org/Conference to watch recordings of and download handouts from the education sessions, find your friends in the photo gallery, and learn more about this year's programming. Coming this fall, many of the videos and slide presentations from Conference will begin appearing on the PHA website, launching new educational value for PH patients, caregivers and medical professionals. Keep your eyes out for news of PHA's 10th event, which will be held in Orlando, Florida June 22-24, 2012!

Christine Dickler, PHA Associate Director of International Services

A family at Conference lends their lips to save lives and take part in PHA UK's 2010 campaign

Gerald Fischer (left) and Joni Berg of PHA Israel (right) with PHA Board Chair Laura D'Anna at the Faces of PH International Reception

I was not so sure about travelling 20.000 KM for only three days to attend the PHA conference in LA. Now I know that I would do it again anytime! I was more than impressed by the size and the quality of the meeting. The Hyatt at Disneyland is a huge hotel with three towers and even the plastic keys for the rooms were branded with PHA. To be among thousands of participants (doctors, members of the association, international leaders and patients) gave me the confidence that soon we will reach our goal: Finding a cure for PH. The *motto* of the Conference was "Riding the wave to a cure" and with all the different sessions, meetings, speeches and lectures I really hope that we will continue to ride this wave as perfect as in LA. Congratulations and a big thanks to Rino and his whole team!

Gerald Fischer, President PHA Europe

From left: Deirdre Clerkin and Diane Moran

Deirdre and I travelled to the USA for the conference, and for me it was the best to date! A truly wonderful mix of patients, families and healthcare providers. It is quite an emotional experience and definitely pulls at the heart strings; sessions such as "Patient Journeys" and "Keynote Address" were particularly powerful. Lunch and dinner were semi-formal, with around twelve per table and this really helped in encouraging attendees to mingle. Overall the conference is well structured with a large scientific input and sessions aimed at all ages of patients, yet it still maintained a "friendly" feel. I am sure it is quite unique that patients and health care providers mingle so informally! Two physicians even participated in the fashion show! I attended some support group meetings that covered a variety of topics, these meetings had patients as their leaders and actively encouraged participants to speak up and share, these patients offered a unique insight into the every day stresses that living with PH brings and their coping strategies. The event is two years in the making and the dedication and hard work of the committee is unbeliveable.The overall theme of the conference was one of "empowerment" and "hope": this is truly an inspiring message to bring home.

Diane Moran, PHA Ireland

Hall Skåra with his family

This was my first international PH conference in the States. It was very inspirational experience, and I hope I will get a chance to attend it again in the future. The 1250 participants were like one big family as we were all joined together by the disease. It also felt great to participate in the medical experiments, and through my blood donation I felt like I contributed to the efforts to find a cure for PH. The sessions were truly informative and the highlights for me were learning more about stem cell research and listening to the stories of the long time survivors. It was also great to meet with the other international leaders and I am very much looking forward to future collaboration within the European PH community.

Hall Skåra, President PH Association Norway

From left Ümit Atli and Rino Aldrighetti (President PHA USA)

The conference was a big event having deep roots. In particular, I found the scientific education session and the patient workshops very beneficial. It was a big motivation for me to be with such a large patient group. One the one side I admired the organization and what they have achieved during these years, but on the other side I was worried about the organization in Turkey. There is no point in comparing, I realize this, but I still did! The conditions we face are so different and we have to fight with very poor and limited resources...

Ümit Atli, President PHA Turkey

Update on PH treatments and research on PH drugs

In this section of the newsletter we will be reporting on ongoing research on PH treatments, both on approved drugs and new substances being tested. There have been no significant news since our last Mariposa. We expect to have more information for the Winter edition, due out end November/beginning of December.

If any of our members have any input please send to p.ferrari@phaeurope.org

Organ donation and transplantation

On the 19th of May 2010 the European Parliament voted in favour of the EU Directive of the on standards of quality and safety of human organs intended for transplantation. The Directive has received political backing from EU member states and will enter into force later on in 2010. It is due to be published shortly in the Official Journal of the EU and a detailed report will follow in our next issue. The aim of this directive is to standardize standards of quality and safety of organs throughout Europe, expand the pool of organs available and prevent illegal practices of procurement.

John Dalli, the European Commissioner for Health and Consumer Policy, declared that this vote "is a major step forward for the over 50.000 European patients waiting for an organ transplant. Organ transplant is a life saving operation and often the only available treatment for end stage organ failure. Common standards across Europe will ensure the highest level of quality and safety of organs while ensuring that all donations must be voluntary and unpaid. This is the key to ensure that European citizens that need an organ transplant can benefit from the best possible quality and safety conditions. This is a concrete example of how EU legislation can work to save lives and foster solidarity in Europe. I look forward to swift implementation of this text by the Member States" (Source: *EU press release*).

One of the most important measures that the Member States will be required to take to implement the EU directive is the setting up of a National Authority responsible for maintaining quality and safety standards for organs intended for transplantation. These authorities will:

- approve procurement organisations and transplant centres;
- set up reporting and organ traceability systems for serious adverse reactions;
- collect data on the outcome of transplants through continuous monitoring of performance, thus leading to learning and improvement;
- supervise organ swaps with other member states and third countries.

Under the directive all organ donations must be voluntary and unpaid, while living donors may receive compensation "provided it is strictly limited to making good the expenses and loss of income related to the donation". Member States must ban any advertising of the need for - or the availability of - human organs where the aim is financial gain.

The European Commission has issued a very interesting document analyzing the issue of transplant in Europe called: "Questions and answers".

http://europa.eu/rapid/pressReleasesAction.do?reference=PRES/10/167&format=HTML&aged=0&language=EN&guiLanguage=en

One interesting point the Commission makes in this document is that there is already considerable cooperation in Europe. There are areas already covered by international agreements where the interchange of organs accounts for up to 20% of total organ transplants. This exchange is carried out with recognised quality and safety standards. Eurotransplant is the largest organ exchange organization. It includes Austria, Belgium, Croatia, Germany, Luxembourg, the Netherlands and Slovenia as members. Eurotransplant also exchanges with other national and international organizations. Scandiatransplant is a Nordic exchange organization and covers Denmark, Finland, Iceland, Norway and Sweden.

Full text of which can be seen at:
http/ec.europa.eu/health/ph_threats/human_substance/oc_organs/oc_organs_en.htm

As explained in the last issue of Mariposa (page 20) the EU also approved (in 2009) an Action Plan on organ donation and transplantation. The Commission explain that the directive and the Action Plan are mutually reinforcing. While the directive lays down binding measures for the Member States, the Action Plan has a broader scope, covering also the availability of organs and efficiency of transplantation systems. The Action Plan will, inter alia, promote a number of initiatives aimed at increasing organ donation. The availability of organs varies greatly between the Member States. Spain has the highest rate of donation with 33.8 organs donated per million inhabitants. The lowest rate in Europe is 1 per million.

Patient rights in cross-border healthcare

On the 8th of June the Council in charge of Employment, Social Policy, Health and Consumer Affairs agreed on the text of a Draft Directive concerning the application of patients' rights in cross-border healthcare. This directive would allow patients to seek medical treatment outside their main country of residence (within the EU) and be reimbursed by their country "of affiliation". The draft directive supplements the rights that patients already have at the EU level through the legislation on the coordination of social security schemes (regulation 883/04).

A first draft was first proposed by the Commission in 2008 but run into controversy as some Members States claimed that legislation in this field ran counter to the principle of "subsidiarity" (of the role of the EU in health matters). One of the main problems was defining which Member State should pay in the case of pensioners living in one country and going back to their country of origin for medical treatment (eg. German pensioners in Spain going back to Germany for treatment).

The text now approved is a compromise solution which takes into account this and other important issues such as the definition of "country of affiliation". After the legal-linguistic revision of the draft directive, the Council will adopt its position at first reading and forward it to the European Parliament for its second reading.

Patient representatives on European Committee of Experts in Rare Diseases

The Official Journal of the European Union published on the 28th of July the list of experts and their alternates who be part of the European Union Committee of Experts on Rare Diseases (EUCERD) (see Mariposa News Spring 2010 issue, page 19).These include representatives of: the European rare disease information and reference portal Orphanet, the European Rare Disease Organization (EURORDIS), academic and research institutes throughout Europe, and pharmaceutical companies having shown a commitment to developing rare disease products, such as Genzyme, Celgene, Orphan Europe, and Baxter. The four representatives from EURORDIS are Dorica Dan, Torben Grønnebæ, Yann Le Cam, Christel Nourissier.

Another 27 members, one from each of the EU Member States, are to be appointed by the Member State, along with a representative of the European Centre for Disease Prevention and Control (ECDC) to be appointed by the ECDC.

For complete list of experts see:
http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2010:204:0002:0005:EN:PDF
Source: *Orphanews 4/8/2010*

Medicinal products containing genetically modified cells

The European Medicines Agency has recently published a Draft EU Guideline on the quality, non-clinical and clinical aspects of medicinal products containing genetically modified cells. The full text can be viewed at:
http://www.ema.europa.eu/docs/en_GB/document_library/Scientific_guideline/2010/06/WC500093309.pdf

This guideline defines scientific principles and provides guidance for the development and evaluation of medicinal products containing genetically modified cells intended for use in humans. Its focus is on the quality, safety and efficacy requirements. The text is open for public consultation until 30 November 2010.

The template for submitting comments can be downloaded from the EMA website and sent by e mail to: gtwpsecretariat@ema.europa.eu
Source: *Orphanews 4/8/2010*

Communicating safety-related issues for human medicines

A new policy on Communicating safety-related issues on medicines for human use was published by the European Medicines Agency (EMA) on the 9th of July 2010. The full text of this document can be viewed at:
http://www.ema.europa.eu/docs/en_GB/document_library/Other/2010/07/WC500094757.pdf

The new policy describes the various communication tools that are used. This includes the criteria for communicating on specific issues, the preparation and publication of communication material (including roles and responsibilities), the timing of the publication, how the EMA works with the EU Regulatory Network and how it shares communications material with other regulatory authorities both in Europe and beyond.

www.ema.europe.eu
Source: *European Medicines Agency (EMA)*

EU funds for health

On 20 July 2010, the European Commission formally published calls for proposals worth almost €6.4 billion under the *Seventh Framework Programme* (FP7). The budget in 2011 is up 12% in comparison to 2010 (€5.7 billion) and 30% in comparison to 2009 (€4.9 billion). The package, the biggest ever, covers a vast range of scientific disciplines, public policy areas and commercial sectors. This funding will advance scientific boundaries, increase European competitiveness and help solve societal challenges such as climate change, energy and food security, health and an ageing population. For example, health gets €682 million. Improving the health of European citizens and increasing the innovative capacity and competiveness of the European health sector, are at the core of the 2011 calls. Translating research into new technologies, products and services is at the heart of the package. In health research alone, around €206 million - one-third of the overall budget for 2011 - will be spent on investigator-driven clinical trials to get new medicines on the market quicker. The call will also tackle lifestyle-related health issues such as diabetes/obesity, cardiovascular disease, brain-related diseases and social determinants of health.

For more information:
http://cordis.europa.eu/fp7/dc/index.cfm?fuseaction=UserSite.FP7CallsPage#Health
Source: *Marta Czerniawska, Senior Consultant, Interel European Affairs*

New drug against rejection in transplant patients

On 22 July 2010 the Committee for Medicinal Products for Human Use (CHMP) adopted a positive opinion recommending the granting of a marketing authorisation for the medicinal product Myclausen, 500 mg, film-coated tablets intended for the prophylaxis of acute transplant rejection in patients receiving allogeneic renal, cardiac or hepatic transplants in combination with ciclosporin and corticosteroids. The active substance of Myclausen is mycophenolate mofetil, an immunosuppressive agents (L04AA06). Myclausen is a generic of Cell Cept, which has been authorised in the EU since 14 February 1996. Cell Cept is also widely prescribed for patients having undergone lung transplant.

See also:
http://www.ema.europa.eu/docs/en_GB/document_library/Summary_of_opinion_-_Initial_authorisation/human/001218/WC500095009.pdf

Upcoming events for 2010

28 August - 1 September, Stockolm, Sweden

■ ESC ANNUAL CONGRESS

The European Society of Cardiology Annual Congress is currently the largest cardiovascular medicine meeting in the world. It covers all disciplines, from basic research to clinical practice.. Over 30.000 persons attended the 2009 ESC meeting in Barcelona. As in past years there are a number of sessions dedicated to Pulmonary Hypertension. PHA Europe will be present as an exibitor with a booth and will be represented by Mrs Pisana Ferrari, Vice President of PHA Europe, and Mrs Luisa Sciacca della Scala, Secretary of PHA Europe and President of AMIP, Italian PH Patient Association.

18-22 September, Barcelona, Spain

■ ERS ANNUAL CONGRESS AND PHA EUROPE GENERAL ASSEMBLY

PHA Europe will be present with an exibitor booth also at the European Society for Respiratory Medicine's Annual Congress in Barcelona. This Congress is the world's broadest respiratory gathering. It involves not only leading experts in respiratory medicine, but also in other areas, covering the entire spectrum of research and practice in respiratory medicine. Over 18.000 persons attended the 2009 edition in Vienna. As in past years there will be a number of sessions dedicated to Pulmonary Hypertension. PHA Europe will be holding its 2010 General Assembly within the context of the ERS Congress (see below). The three day program includes presentations from national associations, sessions for sharing best practices and defining future strategies, updates on PH treatments and research from top medical experts and a meeting with representatives of the industry. There is also a social program and delegates will have to opportunity to visit Barcelona and spend an evening in town. Fourty delegates from 19 countries will be present. PHA Europe also has a booth at the ERS.

15-16 October, Sophia Antipolis, France

■ ESC EDUCATIONAL COURSE: PULMONARY HYPERTENSION - REGISTRIES, TRIALS AND ANNUAL G5 MEETING

This course will address the importance of screening and proper diagnostic algorithms, will explore the relationship between treatment and survival outcomes, provide guidance on better treatment adherence and review the newest tools for evaluation of treatment through the ESC Guidelines. The target audience are cardiologists, pulmonologists and other specialists involved in Pulmonary Arterial Hypertension care. The Faculty includes some of the most prominent PH specialist physicians in Europe and the world.

On Saturday the 16th Session 3 is dedicated to the Annual G5 meeting (patients, regulatory agencies, physicians, nurses, industry) and the topic is "How to proceed and overcome difficulties".PHA Europe President Gerald Fischer has been asked to speak about "The expectation of the patients". There will be a presentation on "The role of the nurses in patients information and education" (speaker yet to be defined). Representatives of the industry will present their perspective (Actelion, Pfizer, GSK, Bayer, Eli Lilly, Lung RX). The point of view of the regulatory authorities will be given by A. El-Gazayerly (EMA, European Medicines Agency, EU) and S. Brar (FDA, Food and Drugs Administration, US). Prof. G.Simonneau will conclude the session with "The Vision of the physicians".

NEXT YEAR

2011 AT A GLANCE
Summary of main events

- Rare Disease Day 2011 - 28 February
- ESC 2011: Congress of the European Society of Cardiology - Paris, 27-31 August
- ERS 2011: Congress of the European Society of Respiratory Medicine - Amsterdam, 24-28 September
- ESC Educational course on PH and Annual G5 meeting (date to be defined, probably in the Fall)

The European Conference on Rare Diseases is held every two years and the next event is planned for 2012 in Brussels (date to be defined). PHA USA's International Conference is also biannual and the 10th edition will be held in Orlando, Florida, June 22-24, 2012.

European Patient Forum July newsletter


Issue 4 (31): 14 July, 2010

Dear EPF Members and Allies,

The European Patient Forum (EPF)'s July newsletter can be viewed at: www.eu-patient.eu/Documents/Publications/EPFMailing/2010/04_EPF_Internal_Mailing_2010_July.pdf

This is an extremely interesting issue, it contains details and comments on the recently adopted Directive on organ donation and transplant, the political agreement reached on cross-border health care, the FP health research upcoming calls and much more.

The EurActiv network

EurActiv is an independent media portal fully dedicated to EU affairs. The EurActiv network produces content in Belgium, Bulgaria, the Czech Republic, France, Germany, Hungary, Poland, Romania, Slovakia, Spain and Turkey. Based on independency and close mutual co-operation, the Network delivers localised EU policy information in 11 languages, reaching readers across Europe. EurActiv's coverage of EU affairs concentrates on policy positions by EU actors trying to influence policies already in the pre-legislative phase, before a Commission proposal. By providing links to the full text of these positions, EurActiv brings more visibility to the processes of influencing EU policies.

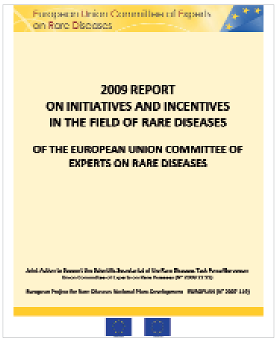
www.euractiv.com

Orphanet Annual Report 2009

Orphanet, the reference portal for rare diseases and orphan drugs with partnerships in 38 pan-European countries, has recently published online its Annual Activity report for 2009, describing the diverse activities of the network. The report can be downloaded at: www.orpha.net/orphacom/cahiers/docs/GB/ActivityReport2009.pdf

This document is also available in Spanish and French.

www.orphanet.org


European Union Committee of Experts on Rare Diseases

2009 REPORT
ON INITIATIVES AND INCENTIVES
IN THE FIELD OF RARE DISEASES

OF THE EUROPEAN UNION COMMITTEE OF
EXPERTS ON RARE DISEASES

European Public Health Alliance (EPHA)

EPHA is an international non-profit association registered in Belgium. Its membership is composed of non-profit organisations working on all aspects of public health. EPHA's mission is to promote and protect the health of people living in Europe and to advocate for greater participation of citizens in health-related policy making at the European level. Around 100 local, national, regional and European non-governmental (NGOs) and non-profit organisations are members of the European Public Health Alliance (EPHA).

http://www.epha.org/

EU institutions:

European Parliament: www.europarl.europa.eu/
European Parliament Legislative Observatory: www.europarl.europa.eu/oeil/
European Council: www.consilium.europa.eu/showPage.aspx?id=&lang=en
European Commission: http://ec.europa.eu/
Economic and Social Committee: www.eesc.europa.eu/

PHA EUROPE

Aims of PHA Europe

Pulmonary Hypertension causes breathlessness and is a rare, progressive and currently incurable lung disorder. PHA EUROPE, European Pulmonary Hypertension Association, was founded in 2003 and is registered in Vienna, Austria, as an international non profit organisation. PHA EUROPE is an umbrella organization bringing together Pulmonary Hypertension patient associations across Europe. The primary objective of PHA EUROPE is to establish a narrow cooperation between the members and the European institutions, international organizations and public institutions worldwide and work towards achieving the best possible standards of care for all European Pulmonary Hypertension patients.

Members of PHA Europe

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