Pain Alliance Europe

JUNE 1, ISSUE 1/2013

NEXT ISSUES:

- 1st September
- 1st December

INSIDE THIS ISSUE:

PAE General Assembly	2
SIP Meetings	3
Pain Pathway Recommendations Project	4
News from members	5
Conferences impressions	7
Future	10

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Welcome word

Dear Readers,

As president of Pain Alliance Europe, I would like to wish you a pleasant reading of this first seasonal newsletter of PAE.

In this news letter we would like to inform all of you, chronic pain patient association, pain patient, healthcare provider, policy maker, politician and all others about the activities done by PAE during the past quarter, with the latest information we received from our members and with all the other things which might be of interest for you, the reader.

November 2012, Aachen

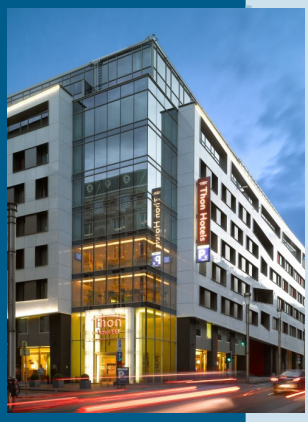
We would welcome your input and reactions because we need your feedback in order to provide the best possible advocacy for the chronic pain patients across Europe.

Enjoy reading this first newsletter and let us know your thoughts.

Joop van Griensven

President PAE

PAE General Assembly, 15 May



The meeting took place in Thon Hotel EU, Brussels

On Wednesday, the 15th of May, PAE held its Annual General Assembly Meeting in Brussels, in combination with the SIP (Societal Impact of Pain) Focus Groups (14th, 15th of May) and the 7th European Patients' Rights Day (16th May).

20 people attended the meeting - members, guests and supporters.

The meeting was chaired by Mr Joop van Griensven and followed closely the agenda:

AGENDA

1. Opening (9:00)
2. Approval of last meeting minutes
3. Elections (for members and for Board Members)
4. Annual reports
5. Changes in statues (official language, office address, founding members, other material errors)
6. AOB (projects, info)
7. Closing (12:00)

The most important ideas, actions and developments deriving from this meeting will be further discussed.

We once again benefited from Grunenthal's support for holding this meeting in the top-notch Thon Hotel in Brussels.

Everyone had a chance to enjoy a good reception and dinner on Tuesday evening in the Thon Hotel, together with the other participants of the SIP Focus Groups.

New members

The Polish Myeloma Patient Help Association - PMPHA

-Ordinary member-

"The main mission of the organization is to advocate for the cause of the patients, at national and European levels; access to new therapies for multiple myeloma patients, integration of the patients in the community, providing adequate information."

Roman Sadzuga, President

ACT Healthy, Cyprus

-Associate member-

"Our laboratory was created for the scientific study of various phenomena that may lead or maintain human suffering. A special interest is in the examination and creation of new prevention and intervention programs."

Dr. Maria Karekla

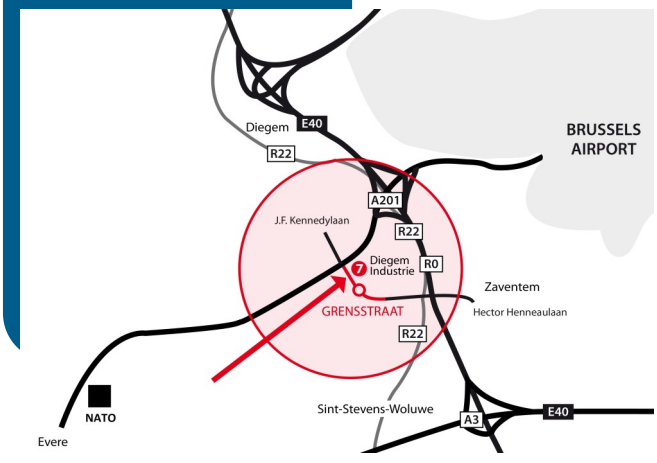
Liga Reumatoloxica Galega

-Associate member-

"We represent the group of people with rheumatic diseases with the government, the institutions and the society, in order to sensitize the public authorities and the general public about the importance of rheumatism, and to promote research on the causes of these diseases and new treatments."

Ana Vazquez Lojo, President

PAE new office and secretariat services



As of January the 1st, PAE concluded an agreement with Glocal Solutions for office space, office assistance, administration and basic association management services, in order to be professionally represented and assisted in reaching its goals.

The new PAE office is located in Grensstraat 7, between the NATO building and Brussels Airport. PAE has access to a board room for its meetings and all PAE members are entitled to "client prices" for the other meeting facilities of the building (auditoriums, council rooms etc).

Glocal Solutions is a Management Consulting, Project and Association Management company founded in 1993. For more information, visit: www.glocal-solutions.com

The appointed person to carry out PAE's administration and association management services is Georgiana Huiban. She is a 23-old Graduate in International Management and originally from Romania, but living in Bruxelles for almost a year. She is proficient in English, knows French, Spanish, Italian and studying Dutch. Contact her at info@pae-eu.eu.

SIP Focus Group 1

Pain as Quality Indicator for chronic, non-malignant pain management

Venue: Renaissance Hotel, Brussels

Key Result from the SIP 2013 Focus Group 1, which took place in Brussels on 14 May, is a working document on "*Recommendations on the European Implementation of Quality Indicators in Chronic Non-Malignant Pain Management*".

The document was discussed by all Focus Group participants and will serve as basis for future working sessions on the proposed European set of indicators to measure the quality of pain services and management outcomes.

Read here the: SIP 2013 Recommendations Working Document.

The objective was to agree upon a comprehensive, but "European-reduced" set/selection of indicators for pain management of chronic non-malignant pain.

All the Participants were experts in the field of using and/or implementing pain indicators such as health care professionals and representatives of health authorities or insurances.

SIP Meetings, 14-15 May, Brussels

The "Societal Impact of Pain" (SIP) is an international platform created in 2010 as a joint initiative of EFIC and the pharmaceutical Grünenthal GmbH and aims for:

- raising awareness of the relevance of the impact that pain has on our societies, health and economic systems

- exchanging information and sharing best-practices across all member states of the European Union

- developing and fostering European-wide policy strategies & activities for an improved pain care in Europe (Pain Policy).

The platform provides opportunities for discussion for health care professionals, pain advocacy groups, politicians, insurances, representatives of health authorities, regulators and budget holders.

In contrast to the past three symposia, the SIP 2013 Focus Groups concentrated on two concrete policy topics, which are following closely one of the seven policy dimensions of the SIP Road Map for Action.

187 international and national patient advocacy groups, scientifc organisations and health authorities have shown their support to this initiative.

PAE launched its brochure at the SIP Meeting . Every participant of the SIP Focus Groups received a copy of this in their conference bags. It was also posted on the SIP website, under the section "Endorsers News"

SIP Focus Group 2

Chronic Pain in the Working Population

During Focus Group 2 (15 May, European Parliament) the "SIP Proposal for Action: Using European Best Practices for the Reintegration of Chronic Pain Patients into the Workforce" was discussed.

The Proposal for Action is based upon key success factors from five national best practice projects from different EU countries. Amongst others, the group calls upon European governments to consider:

1. Strong, early involvement of stakeholders to ensure a holistic and collaborative approach towards the successful implementation of future projects.
2. Development of guidelines for healthcare professionals
3. Development and implementation of chronic pain patient education programmes and chronic pain patient activity/work programmes
4. Continuous monitoring/ governance and evaluation systems and risk-management procedures to ensure consistent, quality outcomes.

Read here the final:

SIP 2013 Proposal for Action.

Pain Pathway Recommendations Project

Patients (Pain Alliance Europe, PAE), Citizens (Active Citizenship Network, ACN) and Industry (Grünenthal GmbH, GRT) will work together in a multi-stakeholder project to:

- become a strong European Pain Patient advocacy group by developing concrete proposals for the improvement of pain management;
- encourage active participation of citizens in European and national public policy-making and the cooperation among patient organizations, necessary to get heard by the policy makers.

The project will run until December 2014 and consists of 3 steps: writing the report based on questionnaires, developing the recommendations and publishing the "Pain Pathway Recommendations.

Impressions

When we started the project Pain Patient Pathway Recommendations November 2012, we were not aware what impact it would have for our members regarding their input.
For the patients associations it was relatively easy to retrieve patient information on the patients rights.

More difficult was it to retrieve this information from the the different countries ministries. So far, we succeeded only in 10 of the 18 involved countries. Discouraging was it to find out that some countries simply refused to cooperate. This is indirectly a confirmation that these countries don't respect patient rights at all, or at least have no intention of improving the situation for patients - if it are chronic pain patients or others.

However this was something which did not really came as a surprise for the patient associations as we were informed on that by our members. We only hoped that the situation would be improved by now.

More disappointing was it to find out the lack of willingness of professionals operating for the benefit of chronic pain patients to fill out the questionnaires. The excuses they provide for that did not show much respect for the chronic pain patients in general. In our opinion, everyone who is involved in the chain of treatment in a professional way has a roll to make sure that the patient rights are respected.

That counts for the treating physician but also for the manager of the hospital, the nurses involved in the treatment, the specialists involved in research, the GP's, the Psychologists and all others. An excuse as " we understand the need of it but we think that the medical professionals should organize that" is the best example of not excepting thier own responsibility in this. It doesn't respect the patient as an individual who should be treated whit respect and dignity.

One of the things which these first results clearly show is that regarding awareness for chronic pain patients rights, a lot has to be done. Not only for the patients, but even more towards the healthcare professionals and the policy makers. It is not only in one or two countries but it is across Europe. An European approach to this would be logical and I'm sure Pain Alliance Europe would support and or initiate such a champagne. We also would push for better education for the health care professionals because if nothing is done in this area we are still facing these problems in twenty years from now.

We are going to continue with this project and try to get as much information as possible and present a final report somewhere in October 2013.

I would hope that my remarks of now should be withdrawn then because everyone did participate.

Greetings,
Joop van Griensven
President Pain Alliance Europe.

News from members

Pain Alliance Europe currently has 28 members from 14 European countries, which makes it a true European Organisation. However, the goal is to grow more—Bulgaria, Croatia, Czech Republic, Estonia, Greece, Latvia, Lithuania, Luxembourg, Hungary, Malta, Portugal, Slovenia, Slovakia—are not represented in our Alliance. Help us grow this association to new heights, so we would be a truly unified voice of all the chronic pain patients across Europe.

This section focuses on the news and activites provided by the PAE members, As an alliance, it is important to know each other, to learn one from another, to coordinate our national efforts and to spread the best practices to the other members. Short facts will be further presented,

We will thus be able to see the different national approaches to our common goal of:

Improving the quality of life of people living with chronic pain in Europe

Fibromyalgia Association of Sweden

► Our association has changed its name, from : "Sveriges Fibromyalgiförbund" to "Fibromyalgiförbundet".
► We are currently working on a new brochure: "Young with Fibromyalgia", aimed at school nurses, and teachers.
► We recently attended the school nurses' annual, national congress, and also a congress on general practice, two good opportunities for increasing the awareness, and knowledge, of fibromyalgia among these target groups.

► We have also attended a Nordic meeting with the national fibromyalgia associations in our neighboring countries, Denmark, and Norway.
►We have contacted the government, and asked for a personal meeting to discuss the situation for those suffering from fibromyalgia, and what improvements we would like to see in the management of fibromyalgia patients. We have also sent a letter to The Swedish National Board of Health and Welfare regarding the same issue.
► On the 12th of May, International Fibromyalgia Awareness Day, we had an event called "March for Fibromyalgia". Local marches were arranged in 14 cities where we have local associations. Hopefully this will be a recurring event on the 12th of May.

Sent by: Johanna Spetz

Foundation Pijn Platform Nederland

The way we inform people who are interested in our work is by take up messages in our journal/paper.
This paper we send to about 25.000 addresses all over in the Netherlands. The peoples who received our information are patients as well as professionals.
Furtheron we cooperate with different patient-organizations in the Netherlands for many years already.
Our main goal is to make pain-care better for patients.
We get a lot of reactions on the journal, have discussions about this, make announcements of congresses which could be relevant for patients and professionals too.
In the moment we have two large project by the name "Zicht op Pijn"" . This projects are providing materials from out of the patients point of view to inform about what you may expect from health professionals in regard to pain, whishes and expectations of patients, and give them tools to make better decisions.
Look for more information: www.pijnplatform.nl/PijnPeriodieken/pijnperiodiek.html.

Sent by: Hilda Wieberneit-Tolman

EURAG Austria

The Alliance started a signature campaign on their new website, with the motto: "Together we are strong", everyone who signs this campaign (also possible per "click" on the website) shows that they support the concerns of the Alliance:
- Recognize chronic pain al a disease on its own.
- Ensure a rapid diagnosis and effective treatment.
- Improve communication between patients and doctors.
- Strengthen personal responsibility and competence of the patients.

These aims are supported by the newly formed "Schmerzplattform Österreich" (Austrian Pain Platform) – an alliance of doctors, patients and caretakers – who recently wrote an "open letter" to the Health Minister in order to ensure that chronic pain will be given sufficient recognition in the ongoing Healthcare reform. For more information and to sign the campaign, please visit the website of Allianz Chronischer Schmerz Österreich

www.schmerz-allianz.at

Sent by: Erika Folkes

Allianz Chronischer Schmerz Österreich

REDEFMSCSQM Spain

We get in touch with you to inform you about some of our activities, both of which are due in a short time:

1. Forum "Ask an Expert" - World Day for Fibromyalgia and Chronic Fatigue Syndrome, June 25, from 18.00 to 20.00h via the web: www.sergas.es

Objectives:

§ To provide the general public access to current information about the disease.

§ Clarify doubts to patients, families and the general public about the management of the disease.

2. Development of best practice questionnaire

Because of the teachings at the Council of Patients, created by the Galician Health Service (SERGAS), patients actively participate in the creation of a Commission against Chronic Pain through proposals and workshops for patients organized by the Galician School of Patients.

Nowadays, in Galicia, Administration, Health Professionals and Patients Organizations are working together to prepare a standard procedure for attention to Chronic Pain Patients. For this purpose they created a support group that works together on the elaboration of these proceedings and also on the preparation of courses and workshops for Health Care Professionals on the attention to Chronic Pain of Primary Health.

There is also another group that is putting together the contents of a Chronic Pain workshop for patients.

The methodology consists of various personal meetings, emails, and the creation a an interactive work webpage.

Sent by: Marisol Morales Cañás

FAKS Denmark

We have recently discovered that we are excluded from receiving any state subsidies from the pool of lottery in Denmark. This pool has the purpose to cover running costs, which disease fighting associations can apply for.

The reason for exclusion is due to the simple fact, that chronic pain is not considered a disease but a symptom by The Ministery of Health in Denmark.

Actually, we applied for the very same subsidies two years ago and received the following answer from The Danish Ministery of Health - " chronic pain cannot be categorized as a disease but is a condition due to many different causes. Pain is a symptom in relation to diagnosis".

We look upon this with great seriousness, and we see it as a fundamental problem concerning how not only people in general but even governmental officials from the Ministery of Health view chronic pain.

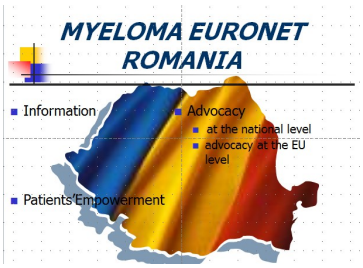
People do not distinguish chronic from acute pain, and if no objective, somatic reason can be identified, it is not considered real. This is a prevailing paradigme.

The situation also concerns how we pain associations financially get by. There exists a great deal of polemic and negative press on the topic of patient associations receiving money from the pharmaceutical industry. No matter how open and regular patient associations are about taking money from the industry, it often comes with great negativity and the notion of being biased, and this undermines trust.

Sent by: Lars Bye Møller

FAKS

Myeloma Euronet Romania



On 2 April 2013, Viorica Cursaru was invited to make a presentation during the conference organized by Tarus Media and Medica Academica at Pulmann Hotel in Bucharest about Cost of Treatments versus Quality of Services. The conference was attended by patients organizations, officials from the Ministry of Health and National House of Health, Pharma Companies and media. In her presentation, Viorica Cursaru was very critical about the quality of services rendered to the patients in the Romanian hospitals , the lack of any information about pain management , HTA and most importantly, the very high costs of the medication and treatments which are not reimbursed by the national authorities.

Sent by Viorica Cursaru

EURORDIS MEMBERSHIP MEETING, DUBROVNIK, 30 MAY - 1 JUNE

In May, I received a fellowship to attend the Eurordis Membership Meeting which took place in Dubrovnik between 30 May - 1 June 2013. Eurordis is one of the largest European Organizations and represents the interests of all national organizations for rare diseases in Europe, including rare cancers. Multiple myeloma is a rare cancer and therefore I joined Eurordis in 2007.

Eurordis Conference was extremely important because, aside from several other workshops planned to take place during the conference such as Learning from Each Other, Social Media Best Practices and Launching of a RareConnet project, the main theme of the conference evolved around National Plans across Europe, Funding of the National Plans and not in the least important, National Registries and Data Protection EU Regulation and its implication for Registries.

Most of the speakers re-emphasized the need to enlarge the centers of expertise across Europe and to promote the improvement of health services. It was stated that European member states must ensure better access to treatment and special services for all citizens and most importantly, create the policy framework to secure the rights of the patients to be well treated in their own countries. A particular focus was placed on prevention and early diagnosis and the need for a multidisciplinary approach for diagnosis and treatment, on Quality of Life as well as on patients' empowerment. It was particularly emphasized that throughout all these years the patients have propelled the process for the recognition of patients' rights.

The Conference was very inspiring. It triggered some thoughts which need to be shared.

► Coordinated actions of the patients always trigger the attention of decision makers, be it at EU level or national level

► Information on EU and national legal procedures represent powerful instruments for the patients and patients' organization in pursuing with and securing their rights

► Networking with other European Organization, Researchers and Academics, Pharma and Official Institution will ensure the accomplishment of the proposed goals and objectives

► EU patients' organizations have to thoroughly assess where they are and what they wish to become and, most importantly , define very clearly their actions and goals required to attain the proposed strategies

Last but not least important, EU patients 'organizations must employ proper mechanism to measure performance.

Viorica Cursaru

PAE Treasurer

EUPATI 2013 CONFERENCE—A VISION FOR 2020

19 April, Rome, Italy

Venue: Hilton Rome Airport Hotel

More than 180 delegates from 28 countries were there to hear about the plans under way for three clear areas of training and education: a certificate level course that by 2017 will produce 100 patient experts drawn from across Europe; less detailed online education for 10,000 patient representatives; and an Internet library with information for anyone with an interest in medicines R&D.

Delegates heard a series of presentations outlining the vision of the project and a number of talks from people around Europe who have been implementing innovative practices in patient partnership.

Read more about the conference...

Impressions

As the conference was scheduled to start early I arrived the day before and made use of the opportunity to meet with the people from Pfizer about funding PAE for 2013 and 2014. although the attitude towards chronic pain wasn't changed the budget they have was cut down with an huge amount. Beside the cutting of the budget Pfizer is also ruled by reorganizations which was the reason why our application was so late answered although it was received by the original person in charge. It seems that from now on all advocacy projects / findings will be judge by the American Office which makes things more complicated.

Basically it will come down that we are going to receive probably no more then 15.000 dollar. Maybe with some more luck it can be renamed into euro but still it will be less as we had counting on. for the upcoming years it doesn't seem that this will be more but we will see how things develop. After that I had a meeting with Konrad, Marriano about the continuity of the Pain Patient Pathway project, as the response on the questionnaires was not satisfying. Not for us as PAE, not for ACN and not for Grunenthal. Especially it were the ministries, and the health care professionals who did not reply successfully. Agreed we would try to find and name the problems and see whether there is a solution possible.

After all these talks I prepared myself for the welcoming diner were I did meet several people already known to me but also new ones. One of the known one's was John Lindsay. But also I met a Danish professor and some patient representatives from Poland.

The next day had an early start as the registration started at 08.00 and the day ends at 17.00 It was fortunate that the venue was near the airport so I could walk to that. The day it self had some good but also some less presentations but lacked in depth interaction between participants. There was room for discussions but it is difficult when you have a crowd of 200 people. However the day was for me successful as I did speak to different participants with different backgrounds. In any way it stays important to stay involved with them because they do have influence on as well industry as legislators.

Was able to catch the 19.55 flight back home and arrived on my overnight address at around 01.15. Although these days are always very tiring it stays useful to participate in order to get more exposure of PAE and get more attention for chronic pain.

Joop van Griensven
President PAE

Healthy brain: healthy Europe

A new horizon for brain research and health care, 27-28 May, Dublin

Convention Centre Dublin

This conference brought together renowned experts to highlight why policy-makers across the EU member states and associated countries should devise, or refine, national strategies on brain research and healthcare. Key stakeholders, such as policymakers, representatives from ministries, funding agencies, industry, patient organisations, researchers and health professionals were among the participants.

This conference aimed to deliver policy recommendations for brain research and healthcare, since of all diseases, brain disorders present Europe's largest health and socioeconomic burden.

Read more about the conference...

Impressions

Arriving on Sunday in a sunny Ireland, on Monday morning the rain accompanied me to the conference centre, which was fortunately only a couple of hundred meters away.

Enda Connolly, the chair, welcomed everyone and introduced the Irish minister of health to do the official opening. Maire Geoghegan, commissioner for Research, Innovation and Science underlined that Europe had an obligation to support this kind of research. This session was ended by an American politician speech of Patrick Kennedy, Co-founder of One Mind for Research. After this opening ceremony, the program continued with the first session: the fascinating brain. The speakers in this session (C. Blakemore, A. Roepstorff, M. Brune) gave excellent explanations of the multi-dimensional and social brain. The second session, the brain challenge, started with John Golding, president of the European Multiple Sclerosis Platform (EMSP) talking about being a patient. The session was closed by Mary Baker, president of the European Brain Council. She held an inspiring speech on the social impact of brain disorders. The last session, Europe's best brains, was a very technical one: Andre Syrota talked about the scientific strengths in European brain research and Giovanni Frisoni spoke about the infrastructure of brain research in Europe. After this, I was able to speak to Mary Baker, Audrey Craven, Donna Walsh and also some other participants (one of them the director of the Karolinski Institutet Innovations AB from Stockholm who was interested in Chronic pain and ways to involve them in projects).

Day two started with speeches from the Ireland minister for healthcare, Kathleen Lynch, followed by Isabel de la Mata, director general for health and consumer protection at the European Commission. She mentioned the economic circumstances that put pressure on the mental healthcare by increasing the numbers of suicide and depression. The key note speaker was Fabien Calvo, deputy general director of the national cancer institute of France. He gave a presentation of the cancer plan of France - "Learning from the cancer example", an example for good practice of implementation of research in actual actions in the healthcare system. The next session had the topic the Innovating brain. The first speaker started with addressing the economic benefits in addition to the health improving or the societal benefits. The second speaker addressed the fact that industry is declining the investment in clinical research for the development or creating of new drugs., which decreases the need to innovate the research. The third speaker, Martin Harter , explained the German project of collaboration with the purpose to improve the quality and the speed of treatment of patients with involvement of patients and patient families (www.psychenet.de). The last speaker of this session was Adriana Maggi, Director centre of excellence on neurodegenerative diseases, who talked about the costs of the brain disorders and the difficulties on research, the missing of the tools and the lack of funding - in this respect, cooperation would be the answer for the future. In the next session, the inclusive brain changing paradigms, Luca Pani, Director general Italian medicines agency (AIFA), talked about the regulatory view of the quest for new medicines in brain disorders. The difficulties of the balance of the interests of the patients and the interests of the industry.

Because of travel arrangements I was not able to follow the program to the complete end. I did however could follow the final session which was a recap by the chairs of the sessions on the discussed subjects. The following discussions and the end conclusion I'm afraid I missed. During this two days I had the opportunity to speak and renew friendship with different people (one of them was Mary Baker).

Joop van Griensven
President PAE

PAE

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Improving the quality of life of people living with chronic pain in Europe

For PAE, quality of life for a chronic pain patient means giving the patient the right to choose the best possible solutions and support to live his life according to his possibilities and wishes. It aims to promote awareness for chronic pain, to promote a European policy on chronic pain and to reduce the impact of chronic pain on the European society on all areas.

The strategic objectives of the organisations are to promote awareness for chronic pain, to promote an European policy on chronic pain and to reduce the impact of chronic pain on the European society on all areas. These are to be achieved by:

★Working in close relation with the other stakeholders

★Gathering and distributing relative information on chronic pain from the patients' point of view

★Establishing a good relation with potential sponsors

★Promoting/ initiating research on chronic pain

★Growing the association

★Obtaining visibility through events, website, media coverage

Future events

★ 3rd International Conference On Interventional Pain Medicine & Neuromodulation 2013, 14-16 June 2013, Warsaw, Poland—more info

★ Workshops and Conference "Generations in Action - The Role of Intergenerational Learning for Active Ageing", Bruxelles - 17.-18.06.2013 - http://goact-project.eu

★ 9th International Symposium on Pediatric Pain, June 17-20, Stockholm, Sweden - http://www.ispp2013.org

★ **25 June: PAE Board Meeting, Brussels**

★ 4th International Symposium for the Study of Chronic Pain and Fibromyalgia (FIBROSYMPOSIUM2013). Palma de Mallorca, 18-19 of July 2013 - www.fibrosymposium.org

★ EFIC Congress 2013 "Pain in Europe VIII", October 9-12, Florence, Italy - http://www1.kenes.com/efic/