

## PAE 2014 Annual Activity Report

*In its third year of existence, Pain Alliance Europe (PAE) was again faced with several challenges. However this year also proved that although young in years, PAE has become a strong organization with a committed board and members. Together we succeeded in getting the name of PAE known across the European institutions - a result of which we may be proud.*

*Joop van Griensven  
PAE President*

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## GENERAL

### GENERAL ASSEMBLIES

In 2014, PAE organized two General Assemblies: one in April 9<sup>th</sup> in the Thon EU Hotel in Brussels (Belgium) and the other one in November 17<sup>th</sup> also in the Thon EU Hotel in Brussels (Belgium). The second one was combined with the SIP meeting held in the European Parliament the day after.

### BOARD MEETINGS

During the year there were three board meetings in February 20<sup>th</sup> in the Thon EU Hotel in Brussels, in July 8<sup>th</sup> at the office in Diegem and the last one in November 17<sup>th</sup> in the Thon EU Hotel before the General Assembly.

### SECRETARIAT

In November 2014, the person in charge of PAE Secretariat Georgiana Huiban resigned. From that moment two people manage the Secretariat. Andreea Per, based in Bucharest, became the person in charge of Communications and Cristina Fernández, based in Brussels, became the person in charge of EU Public Affairs and Governance.

## BOARD MEMBERS

In the beginning of 2014, PAE started with 5 board members: Joop van Griensven (president), Viorica Cursaru (treasurer), Liisa Mikkonen, Marisol Garcia Penalta and Mariano Votta. In the General Assembly of April, PAE members accepted the proposal of Marian Nicholson and Hilda Wieberneit-Tolman of becoming part of the PAE Board.

A maximum of 7 board members allowed, as per the statutes of association. In that moment, there were 5 board members, so 2 more can be added. Since the workload is increasing, all the support received was very much appreciated, therefore a large Board was considered ideal.

During the second General Assembly of the year, the re-election of the President and two board members were discussed. The members re-elected were Joop van Griensven as President and Viorica Cursaru as Treasurer and Liisa Mikkonen as Board Member.

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## BOARD ACTIVITIES

### JANUARY

On January 7, Pain Alliance Europe (PAE) launched a petition for gaining awareness and addressing the pressing need of putting chronic pain in the attention of the European Union and national policy-makers.

"We urge European politicians to include chronic pain and the role of chronic pain as a priority in all current and future reviews and framework programs on chronic diseases. "

### FEBRUARY

Seeing the PAE petition addressing the European Union and national policy-makers in January 2014, Ms. Anna Kleszcz from Poland, contacted the PAE Secretariat to get informed about her petition on chronic pain. She had the 5 minutes presentation in the Parliament (PETI Committee Meeting) on February 10. Jarosław Leszek Wałęsa (EPP, PL) suggested putting this petition on hold in order to wait for more information on procedures. Erminia

Mazzoni (EPP, IT), chair, agreed to make a request for more information on this matter. A decision will therefore be made at a future meeting.

On February 19th, the lunch event “Out of the office”, hosted by MEPs Marian Harkin and Linda McAvan – in conjunction with the leading European Patient Organisations in the area of Brain, Mind and Pain: European Federation of Neurological Associations, GAMIAN Europe and Pain Alliance Europe, took place in the Members Salon of the European Parliament. The event marked the official launch of a research from the Economist Intelligence Unit on the economic and social cost of work-place absenteeism in Europe and had interventions from the European Commission’s Head of Unit for Health, Safety and Hygiene at Work.

## MARCH

The PPPR Project was between the 5 finalists in the “Eye for pharma” award ceremony in Barcelona, took place on the 18th of March. It stands in the category of “Customer Innovator Award” for the unique insight it brings on chronic pain, collecting information from different stakeholders—patients, healthcare providers and policy-makers—in 18 European countries. The finalists were given the possibility to send a video on the content and the reason of the project. This will be shown during the ceremony, so will generate awareness on the project and the main partners (Pain Alliance Europe, Active Citizenship Network and Grunenthal).

## APRIL

At the initiative of Pain Alliance Europe, an exhibition and cocktail reception hosted by Petru Luhan, Member of the European Parliament and winner of the MEP award for Health 2013 was organized in the European Parliament in April 10th. On the occasion, a multi-stakeholder platform of patient organizations, academia and industry, called on EU institutions and national authorities to recognize the societal and individual burden of chronic pain and to take adequate measures against it.

Following the Societal Impact of Pain (SIP) meeting in 2012, the three partners: EFIC, Grunenthal and PAE jointly submitted a commitment to the European Commission’s European Innovation Partnership on Healthy and Active Ageing. This initiative brings together EU regions, industry, health professionals and patients in order to improve the quality of life of older people, by working in six thematic Action Groups.

**the voice of people with chronic pain**

The 6th meeting of the Action Group B3 on Integrated Care (AG B3) took place in Brussels on the 2nd of April 2014 as a satellite event to the 14th International Conference on Integrated Care.

On April 2nd, Soledad García Penalta attended the EUPATI annual workshop in Warsaw, Poland.

## MAY

On May 30– June 2, Pain Alliance Europe joined EFNA (European Federation of Neurological Associations) at the Joint European Congress on Neurology. There, numerous opportunities arose for Pain Alliance Europe: raising awareness at the patients' corner, participation in a scientific panel, contacts and possible future collaborations

Pain Alliance Europe was represented at the exhibition that took place throughout the Congress by Viorica Cursaru, PAE Board member, together with Georgiana Huiban, PAE Communications Officer. Nearly 10 000 participants were at the Congress—scientists, doctors, industry representatives. This ensured a great visibility for the work of Pain Alliance Europe and encouraged through the common umbrella of EFNA for greater patients involvement, collaboration and joint initiatives.

## JUNE

The questionnaire had almost 100 respondents. It had open questions on: what condition was diagnosed, therapies tried, how often pain medication is used, what therapies the doctor recommended, the experience with those therapies, the recommendations to a chronic pain patient, suggestions for improving pain management in his country.

The results were very insightful and had real life experiences, emotions, suggestions and interesting statements. An elaborated report will be released to comprise all the results on June 15.

## SEPTEMBER

EFNA, PAE's close partner on Brain, Mind and Pain Advocacy, will organize a workshop in Brussels on September 24th and 25th for national patient associations, as a preparation for the MEP Interest Group referred to in the previous page. This aims to highlight the issues

and challenges that are affecting associations and the patients they represent nationally, as well as to showcase the good work that is happening across Europe that could be replicated elsewhere.

On Saturday, the 27th of September 2014, over 100 Italian cities and 12 countries from 5 continents, will celebrate the 4th edition of the World Day “Hundred Cities Against Pain”, thanks to the initiative and organisation of ISAL Foundation ([www.fondazioneisal.it](http://www.fondazioneisal.it)). The aims of this celebration are to inform people about chronic pain treatments and pain centres, to raise funds for scientific research and to sensitize political and health institutions about chronic pain as a main public health issue.

Soledad García Penalta attended the joint PCWP-HCPWP meeting on 16 September and the Workshop on benefit/risk communication on 17 September 2014 at the EMA offices in London and the ISAL Foundation Press Conference last September 18 and 19 in Rome to present their International Day Against PAIN.

## OCTOBER

On 4 October 2014, Myeloma Euronet Romania organized the 5th annual conference for the patients suffering from multiple myeloma.

The conference was attended by 60 MM patients and their care takers and it was held at the Colentina Hospital. The speakers, both Romanian and EU prestigious medical doctors, made presentations about benefits of autologous transplant, communication between patients and doctors and specific treatments administered to MM patients in Romania .

Prof. Dr. Werner Linkesch, University Hospital of Graz, Austria, made an extensive presentation about novel treatments, clinical trials and ongoing researches in the field aiming to make multiple myeloma a treatable disease.

For the first time, we invited speakers from other medical departments to talk about the benefits of multidisciplinary approaches in diagnosing the patients.

Likewise, during the conference, we discussed about the co-payment system, which in Romania is not well received by the patients’community.

On 4th and 5th October, Myeloma Euronet Romania , organized the 3rd training session for the nurses working the the haematological units.

Myeloma Euronet Romania published the second edition of How to live with Multiple Myeloma, Viorica Cursaru attended the sessions for Clinical Trials organized by EMA which has designed a new portal for CT together with the EU Health Commission. In addition to other stakeholders, EMA values a lot the input made by the patients' representatives.

## NOVEMBER

The Societal Impact of Pain Symposium 2014, the last stage of this multi-stakeholder project, consisted of endorsing and promoting the Recommendations developed in October 2013, as well as the questionnaire results these are based on. This will help raise awareness to the general public and also to the decision-makers. Several press conferences will be organized nationally for this, and will open with an European one in Brussels, on November 17.

At the end of the European Day On The Right To Health and after the signing of the European Charter of the rights of citizens over 65 with chronic pain, the PAE president, Joop van Griensven, received an award handed over by the Italian Minister Of Health Beatrice Lorenzin for his and PAE's efforts to improve the quality of life of people over 65 with chronic pain.

On November 22th, Federanziani, an Italian association who advocates for the rights of people over 60, organized the European Day for Health Rights in Rimini, Italy with the presence of the Italian Minister of Health, Beatrice Lorenzin. During this day several working groups of professionals in health care and PAE were discussing important health issue for the people over 60.

Webminar Improving the Involvement of Patients in Clinical Research Activities on November 5th 2014 was attended by Soledad García Penalta, as well as the Workshop "Dor e Sociedade" (Pain and Society), November 11 in Santiago de Compostela, organized by SERGAS( Galician Health Service).

At the EMA headquarters in London, García Penalta and Mariano Votta also attended the EMA Training session for patients On Tuesday 25 November 2014 and PCWP meeting with all eligible PCO organizations on Wednesday 26 November 2014.

## DECEMBER

PAE officially created a Twitter account (@pain-europe) for the Alliance - and all our members were invited to follow PAE.

While venturing into the new territory of Twitter, PAE is also taking care of its usual outlets: PAE's website and our Facebook page, both of which have been updated recently.

## OTHER ACTIVITIES

Marian Nicholson attends events promoting awareness of pain in the UK. At the launch of the new patient resource "www.helppain.org", a result of the work of the Pain Summit consortium of British Pain Society, Royal College of Anaesthetists, the Chronic Pain Policy Coalition and Royal College of GPs, she was able to promote the work of Pain Alliance Europe.

At the end of the year, some meetings between PAE, the European Federation of neurological Assotiations (EFNA) and different MEPs took place in the European Parliament in Brussels and to look for support and advice for the launching and first actions to do concerning the Member of the European Parliament Interest Group Brian, Mind and Pain. At the same time the logo, the visual identity, some deliverables and the website were created.

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# SECRETARIAT ACTIVITIES

## SECRETARIAT ACTIVITIES

The secretariat is based in the office building of Glocal Solutions, Grensstraat 7 Diegem Belgium, and was managed by Cristina Fernández. Andreea Per, based in Bucharest, supports Fernández as secretary and is the person in charge of Communications. They were, together with Georgiana Huiban who was the secretary since November 2014, responsible for:

- Communication: website, social media, newsletter, brochure, flyers etc.
- Meetings: organizing board meetings, General Assemblies, PPPR Workshop
- Stakeholder relationships: efforts of getting PAE known, good relationships developed with EFNA (European federation of Neurological Associations), EULAR

(European League Against Rheumatism), Grunenthal, still in development with EFIC, EPF, EUPATI, EMA, European Institutions, etc.

- Governance: Transparency Registry, European Parliament passes, registrations
- Online questionnaire coordination: every 3 months, with results in the Newsletter
- Projects support: PPPR
- Sponsorship support: materials, meetings
- Advocacy: co-organizer of Parliament event