

## 2015 Activity Report Pain Alliance Europe

The board of PAE is proud to present this Annual Report 2015 on its activities.

In 2015, the 4th year of its existence, PAE achieved increasing public awareness. We are beginning to gather the fruits of our hard labor over the past years. More doors open when we knock and we are getting more invitations to participate in projects/activities.

### General

#### General Assembly

The GA was held on June 23 in the Thon EU Hotel Brussels. This meeting was combined with a Brain, Mind and Pain (BMP) meeting in the European Parliament on June 24.

#### Board meetings

During the year the board of PAE came together for four official meetings: February 25, July 22, October 15 and December 16 – as well as the general assembly on June 23. Board meetings were held at the office in Diegem. The dates of these meetings were mostly chosen, so as to combine with other activities where the Board's presence was appreciated, such as the BMP meetings held on 24 February, June 24 and October 14, respectively.

#### Board members

We started and ended the year 2015 with the same 7 board members: Joop van Griensven President, Liisa Mikkonen Vice-President, Viorica Cursaru Treasurer, Marian Nicholson Honorary Secretary, Mariano Votta, **Soledad** Hilda Wieberneit-Tolman.

#### Members

We started the year 2015 with 31 members from 15 different countries. At the General Assembly we accepted two new members, so at the end of 2015 we now have 33 members from 16 different EU countries.

#### Secretariat.

During the year we faced a change of personnel: Christina Fernandez left and her place was taken by Miruna Ursache. Miruna is based in Bucharest but often comes to Brussels / Diegem. The official address of PAE continues to be: PAE, Grensstraat 7, 1831 Diegem (Brussels), Belgium

## **Ongoing projects**

### Brain Mind and Pain interest group (BMP)

After the successful activities to start up the interest group in 2014, this year we finalised preparations and held three meetings: the launch on February 24, the 'lifestyle' meeting on June 24, and on October 14, a meeting with the main topic of 'stigma'. As a warm-up and to encourage more visitors, we organised the Pain Box event in the European Parliament during the day of February 24 – and the Pain Box was also present at the launch that evening.

Before the actual launch, we had a hectic visit to Strasbourg to gain more support from MEPs. We accomplished that and on the website ([www.pae-eu.eu](http://www.pae-eu.eu)) you can find the full list of endorsers with their pictures. There are over 40 MEPs.

The BMP meetings themselves were very well attended and a video of the launch is also available on the PAE website.

For more news on the Brain Mind and Pain interest group please visit the website

([www.brainmindpain.eu](http://www.brainmindpain.eu)), where you also can find their annual report with detailed report of the activities. After the last meeting in October, we started preparing for the 2016 meetings.

## **New projects in development during the year**

### Target Project

At a meeting on April 8th, we were asked by MAC Clinical Research in cooperation with Janssen Research & Development, to participate in a research project aimed to develop more specific personalised medication. This would be a 4-year project in which PAE would be responsible for the dissemination of the results in self-organised events or participate in events organised by others. Also PAE will provide a report on the project aimed at patients.

At this moment the project has been submitted and we are waiting for approval, scheduled for early January 2016.

### Pain Patients Burden Project

This was discussed at the General Assembly of June 23. Recently, following discussions with potential sponsors, the project itself has been upgraded from an informal survey to one with scientific validity, still under the supervision of PAE. The first draft has been presented to the PAE board and a recap to the potential sponsors. We are now waiting for some professors to reply to our request for additional information.

## **Board activities**

### January

During January 12-14, a delegation of the Brain, Mind and Pain steering group went to the European Parliament in Strasbourg in order to seek support for the BMP interest group. In a couple of hectic days, we managed to speak with about 9 MEPs and gained written support and pictures of almost 40 MEPs. Joop van Griensven, Maria Soledad Garcia Penalta and Christina Fernandez took part on behalf of PAE.

## February

19th: the steering group of BMP had a meeting with the European Commissioner on Health Issues, Vytenis Andriukaitis at the European Commission building in Brussels. This was a successful meeting. Joop van Griensven and Christina Fernandez were present.

24th: the Pain Box event during the day in the European Parliament building was supported by the board, and they all attended the Launch event of the BMP interest group in the evening of February 24 at the Thon Hotel EU Brussels.

## March

4-5th: Maria Soledad Garcia Penalta and Liisa Mikkonen attended the EMA meetings in London. Joop van Griensven attended the German Pain Congress in Frankfurt, where he delivered a speech on patients' rights across Europe.

## April

8th: there was a meeting with MAC and Janssen on the target project at the Diegem office.

14th: the whole board took part in a Skype meeting.

## June

4th: Board meeting at the Diagem office on on-going issues followed by a meeting with Janssen at their office on possible cooperation.

8th: Meeting in Brussels re BMP preparations for the June and October meeting.

10-13th: A visit to the EULAR conference in Rome and developing relations with the EULAR/PARE section. Meeting Giustino Varrassi about progress of EULAP on June 12.

15th: teleconference with Pfizer on sponsoring and changes in their organisation.

16th: teleconference with Burson-Marsteller on cooperation Maltese presidency as a joint effort.

23rd: PAE general assembly in Brussels at the Thon EU Hotel. Followed the next day (June 24) by a meeting with MundiPharma and the BMP event in the European Parliament on Lifestyle items.

20-23rd: Viorica Cursaru organised and staffed [IS THIS RIGHT?] a booth at the Congress of the European Academy of Neurology in Berlin, Germany, and attended EFNA's AGM.

## July

1st: a teleconference with the EMA on projects which PAE wants to cooperate in.

22-23rd: Board meeting of PAE at the office in Diegem.

28th: BMP interest group meeting on preparations and review of the past events in Brussels.

## August

11th: first meeting with TEVA representative on possible cooperation, Berkel-Enschot

19th: SIP group meeting about the activities to be done and the closer cooperation between EPF/EFIC and PAE in this setting, Brussels

## September

PAE represented by Liisa Mikkonen and Viorica Cursaru, participated at the European Pain Federation/EFIC annual congress with a booth and actively during a session on patients involvement.

There was also a meeting with Boston Scientific on a possible side event during the SIP congress in 2016.

## October

13th: the EULAR EP event about the cross-border directive. During the evening, the first EPF/EFIC liaison committee meeting on possible cooperation between patients' representatives and EPF/EFIC.

14th: the BMP EP event on Stigma, followed by a meeting with Jeroen Lenaers MEP about the next meeting (2016). After that a meeting in the EP with SIP representatives.

15th: Board meeting at the office in Diegem.

27th: PAE was present at the Multi Morbidity meeting organised by the European Commission in Brussels.

## November

11th: PAE was present during the presentation in the European Parliament of the European Charter of the Rights of Citizens over 65 with Chronic Pain. PAE was involved and mentioned in this charter. The president of PAE delivered a speech during the presentation and was involved in the press conference afterwards.

[Did LIISA also speak – I think so, check...] Later that day there was a meeting with Medtronic on collaboration.

12th in the morning there was a meeting between representatives of SIP and the Slovakian health attaché on getting pain on the European agenda.

18th: Viorica Cursaru, Norbert Van Rooij (Grünenthal) Chrystel Geevels (EFIC) and representatives of Burson-Marsteller had meetings with EU MEPs and Commission delegates to create awareness around SIP 2016 and see whether they were interested in attending the event. This was a very good occasion to advocate for PAE's goal to have chronic pain recognised as a disease in its own right

24-26th Liisa Mikkonen and Maria Soledad Garcia Penalta attended the EMA meetings in London where they also met Joop van Greinsven, who was at these meetings in another function.

In November we also reached out to the WHO on the subject of chronic pain in the topic of Global Strategy and Action Plan on Aging and Health. This is an ongoing activity.

## December.

1-2nd: PAE was asked to participate in the TEVA Advisory Board meeting about the use and abuse of opioids in Europe in Amsterdam.

2nd: Marian Nicholson represented PAE at the first meeting of the jury for the European Civic Prize on Chronic Pain.

3rd: PAE was present during the SIP steering group meeting in Diegem

16th: Board meeting at the office in Diegem.

## Collaboration

PAE's mission 'to improve the quality of life of people living with chronic pain in Europe' means that PAE is always looking for possible collaborations with others to achieve that mission. Therefore, we worked together with different organisations: the European Pain Federation / EFIC (EPF/EFIC in the SIP

constellation, with the Patients liaison committee, and participated and had a booth during the EPF / EFIC congress.)

In the SIP constellation we did a lot of work with EPF/ EFIC, Grünenthal and Burson-Marsteller to lobby with politicians and European representatives in order to get more attention for chronic pain during the Maltese presidency and other presidencies. We enlarged this group with ACN and the Maltese Health Association and the No Pain Foundation to reach that goal.

With EFNA we are working together in the Brain Mind and Pain interest group and we participated in their general assembly. We also are involved with the ENA.

With EULAR/PARE we inform each other on things of interest and we participated in their annual congress and their annual EU meeting on October 13<sup>th</sup>.

PAE is actively involved in EMA's activities. We attend their joint meetings. We participated in workgroups on training and visibility and we act as patient expert for EMA.

PAE was actively involved in the discussions on the use and abuse of opioids organised by TEVA Pharmaceutical.

We supported the ISAL foundation with a statement on their 'Hundred Cities Against Pain' campaign and participated in the awareness video.

Together with Boston Scientific and EPF/EFIC we are trying to organise a side event during the SIP 2016. Preparations are ongoing.

PAE's President was asked to be a guest speaker during the German Pain Congress which was a very successful event.

During the year we reached out to the IASP to get more involved in their activities. The first signs are looking positive.

#### **Final remarks**

Pain Alliance Europe would like to express their appreciation to all of those who made the work of PAE possible. A special word of thanks goes to our sponsors who make this all financially possible.

The board of PAE