



2016 - Annual activity report Pain Alliance Europe (PAE)

The year 2016 has proved to be another important step in the growth of PAE. As an association we have not only been growing in numbers but also in our activities, as well as being known outside our own small community. Our commitment, our positive approach combined with our firm motivation to improve the situation for the chronic pain patients has made us a well-respected partner for different parties. This positive approach was shown by all the board members but also by you, our members.

Our core activities done by our secretariat such as the newsletter and our digital activities, website, Facebook and Twitter, have improved in quality and accuracy. The function of the secretariat as being the center of the association has been continued and as such recognized by more and more organizations.

PAE was involved in a couple of major activities focused on raising awareness and improvement of the quality of live of people living with chronic pain.

Societal Impact of Pain (SIP)

Early in the year 2016, PAE agreed with the European Pain Federation/EFIC a memorandum of understanding which made PAE a full cooperative partner in the organisation of SIP. This would not have been possible without our positive attitude and commitment towards cooperation and the mission of SIP.

This cooperation also greatly improved the visibility of PAE in the awareness of third parties such as DG Santé and other DGs when they were approached regarding SIP (Finance, Employment) – as well as Members of the European Parliament (MEPs). It was also shown in the huge involvement of PAE members and their members in the actual SIP Symposium, either as a member of the workshop managing teams or as a speaker during the two days of the event. The two-day event, which took place on May 23 and 24, was fully booked and highly appreciated by the participants. It also marked the start of the preparations for the next SIP in Malta. These preparations took us to Luxembourg, Brussels and Valetta (Malta) and is still a work in progress.

MEP Interest Group on Brain, Mind and Pain (BMP)

After a first successful year, the activities of this European parliament interest group continued at a high level. The cooperation between European Federation of Neurological Associations (EFNA) and PAE is getting stronger. The group was kept quite busy organizing the four meetings and preparing the 'written declaration on access to employment for those effected by neurological disorders and chronic pain conditions'. PAE's secretariat played an important role in this. Three of the BMP meetings were held in Brussels and PAE was visible in all three of them. The written declaration preparations were mostly done in Brussels but also involved a several trips to Strasbourg of the Board members, in February, October and December - including for the formal announcement of the written declaration at a fourth BMP meeting. As we writing this, the end result of the written declaration is not known yet. We will inform you about it during the General Assembly and in the summer 2017 newsletter.

Red Balloon project

This project, a cooperation between Boston Scientific (BSC) and PAE, aimed to raise the visibility of chronic pain. The project started during the first day of SIP and it was very successful as a lot pictures were taken of the SIP participants. Even on our way to the European parliament and inside the parliament the red balloons were visible. In the months following that, in several countries, activities were held where the red balloon was used as an emblem and captured in pictures/videos. Most of them can be found on the website www.theredballoonproject.eu

This project will run until SIP 2017 where it will be formally closed.

These were the three major time-consuming projects PAE was involved in. However, this wasn't all we have achieved. We have been looking ahead and found some opportunities to raise more awareness for chronic pain.

In 2016, a Dutch cooperation between different stakeholders amongst them members of PAE and PAE itself, organized "De week van de Pijn" (Week of the Pain). One of the biggest results of that was "The Health Deal", a cooperation between stakeholders including the ministries of Health and Economic affairs in the Netherlands. The second one, which was just as interesting for PAE, was a documentary on the road which different chronic pain patients had to follow to live a life which is acceptable for them. PAE managed to make a deal with the maker of the documentary to have this subtitled in the five main languages. This video will be made available to our members early next year, to use as they think appropriate.

Since SIP 2016, PAE has been talking with Grünenthal about creating a grant for innovative patient-centered projects. This grant will be lead by PAE with the support of EFNA, the Brain, Mind and Pain Interest group, scientific partners of the two patients' associations and Grünenthal. It would be a biennial grant and you will find more news on that in our 2017 newsletters, and you will be informed about this during our General Assembly.

Further on, individual board members were involved in meetings and other activities where they were able to present PAE and its mission.

Some were involved in project proposals, participating in projects, in meetings with sponsors, in activities from our members, giving lectures, attending meetings organized by the European committee or in the European Parliament, attending symposiums, giving interviews, exploring cooperation with other organizations, attending EMA activities.

In short those activities which provide us all with the opportunity of being the voice of chronic pain and work on the mission of PAE: "Improve the quality of life of people living with chronic Pain in Europe."

During the year, the board of PAE consisted of seven members, Joop van Griensven President, Liisa Jutila Vice-President, Marian Nicholson Honorary Secretary, Viorica Cursaru Treasurer, Maria Soledad Garcia Penalta Member, Mariano Votta Member, Hilda Wieberneit Member.

The board was supported by the secretariat. The first half year by Miruna Ursache and the second half year by Anca Pop.

The board had board meetings on February 23, June 21, November 28. Further to that the board had a Skype meeting on April 26. They had an informal meeting during the SIP in May.

Beside those personal meetings we kept each other informed by email and/or telephone talks.

The official address of PAE was Grensstraat 7, 1831 Diegem, Belgium.

AISBL number is 0843.489.142

PAE is registered in the transparency register 39330615236-07

In the beginning of the year PAE had 33 members from 16 EU countries. At the end we had 34 members from 17 EU countries. The members can be found on our website www.pae-eu.eu Follow us for more news on PAE and its activities on our Facebook page or on our Twitter account.

PAE Board