

# Pain Alliance Europe

## 2013 Annual activity report

*In its second 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*

### **GENERAL**

#### **GENERAL ASSEMBLIES**

In 2013, PAE organized two General Assemblies: one at May 15<sup>th</sup> in Brussels (Belgium) and one at November 28<sup>th</sup> in Diegem (Belgium). The first one was combined with the SIP meeting. The second was originally scheduled for London but because of funding difficulties it was moved to Diegem.

#### **BOARD MEETINGS**

During the year there were 4 board meetings. 15-1, 12-3, 25-6 and 24-10. They were all held at the office in Diegem

#### **SECRETARIAT**

In February 2013, we started with a professional secretariat at Glocal Solutions, Grensstraat 7, Diegem Belgium to support PAE in its activities. We are also using this as the official address of PAE. As a consequence of this, we had to change the statutes because the official language of our statutes should be Dutch according to the region we are registered. The approval for the change of statutes was given in the General Assembly of May.

#### **BOARD MEMBERS**

In the beginning of 2013 we started with 5 board members. For personal reasons, Judy Birch and Teresa Petrangolini resigned during the year. We managed to find two new board members, Marisol Garcia Penalta and Mariano Votta, who were officially elected during the General assembly of November 28. At the end of 2013 we still had 5 board members - Joop van Griensven (president), Viorica Cursaru (treasurer), Liisa Mikkonen, Marisol Garcia Penalta and Mariano Votta. They had the assistance of Georgiana Huiban, as secretariat and as communication and public affairs officer.

## PPPR PROJECT

After the initial start of this project at the end of 2012, the project evolved well during 2013. The responses on the questionnaires were higher as expected with the total involvement of 18 European countries. In May, the first draft was presented during the SIP meeting. This was followed with a meeting on the 23 / 24 October to come to draft recommendations. With over 40 people attending this also was a successful activity. In the last months of the year we worked on the fine tuning of the recommendations and on how to go further with this project.

For PAE, Joop van Griensven and Georgiana Huiban were the most involved persons as for ACN it was Mariano Votta. The logistical support from Grunenthal was coordinated by Konrad Labuschang.

## PRESIDENT NOTES

The president represented PAE on several occasions during the year:

- He was at the EUPATI meeting in Rome which will have a follow up in 2014. When he was there he also had a meeting with Pfizer to talk about funding of PAE for 2013 and further.
- He attended the EBC (European Brain Council) meeting in Dublin 27 / 28 of May, where he spoke to several people including Mary Baker and Audrey Craven. He discussed ways to collaborate together.
- He was at the EULAR conference in June in Madrid. He came across different members over there and also representatives of known other patient associations and professional associations.
- He also represented PAE during the EMA meetings of February and December in London. He acted during the year as a patient expert for the EMA which included giving response from a patient point of view on question regarding medication issues in the field of chronic pain of for general purpose. He also prepared the answer on the chronic pain guidelines which were discussed during the November GA.
- He had a meeting with Pfizer and Donna Walsh (EFNA) in Amsterdam on cooperation for a Parliament event and sponsorship of PAE activities.

During the year there were also close contact with ENFA on cooperation and common issues. Also the relation with EULAR / PARE was intensified.

He was involved in the search for sponsors and had several meetings with the secretariat in person, by phone and by Skype.

## SECRETARIAT

The secretariat is based in the office building of Glocal Solutions, Grensstraat 7 Diegem Belgium, and was managed by Georgiana Huiban. She was 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

## TREASURER'S NOTE

In 2013, In addition to the contribution to the two General Assembly meetings, four board meetings, SIP Conference, and sponsorship efforts, she attended the following meetings on behalf of PAE:

- March 24, 2013, the conference organized by the SZPICZAK, the Polish Organization for multiple myeloma patients suffering from pain. During the conference, she presented Pain Alliance Europe, its goals and objectives and at the end, Roman Szadzuga, the President of SZPICZAK expressed their intention to join PAE.
- 30 May – 1 June, the EURORDIS MEMBERSHIP MEETING in Dubrovnik, Croatia. The Conference was very inspiring. It triggered some thoughts which need to be shared such as: Coordinated actions of the patients must 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 Organizations, Researchers and Academics, Pharma and Official Institutions 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

- 21-25 September 2013, the World Congress of Neurology in Vienna, Austria. As a representative of PAE, she attended the EFNA General Assembly in Vienna and promoted PAE's goals and mission at the Patients' corner, organized during World Congress of Neurology 2013. The PAE leaflets and brochures enjoyed great attention and interest from professionals and patients alike. Moreover, 5 representatives of patients organizations and health care professionals have expressed their interest in joining PAE and, in this respect, they filled the enrollment questionnaire.
- In November, she made a presentation about Access to healthcare at the BORDERS TO CROSS Conference in Amsterdam, organized by the Dutch Ministry of Interior, Ministry of health and Ministry of Social Affairs. The presentation touched upon the needs of the patients, in general, and pain patients in particular, to have proper access to treatments.