

Annual activity report for Pain Alliance Europe (PAE) 2019

GENERAL

The year 2019 was a hectic one for PAE. The board had some difficult choices which needed a lot of discussion. The one with the most impact was the decision on whether to move PAE's office. Other ones were about our involvement in projects and what should be our criteria for that.

- We had to decide what to prioritise because of a growing workload as a consequence of our past work.
- We need to look for more diversity within the pharmaceutical industry regarding our sponsors
- We need to consider the changing position of the pharmaceutical industry as a consequence of the opioids crisis in the US and Canada
- We have to deal with the attitude of the press towards patient charities working in the field of pain
- We have to make contacts again amongst members of the new European Parliament and the new Commission

To face all these challenges the board had face to face meetings on March 5th, June 18th in Diegem and on December 16th in Brussels. Further to that, we had a lot of e-mail traffic on several subjects and we met informally during the EFIC congress in September in Valencia where we made presentations.

The 2019 General Assembly took place on 19 June in Diegem. At the beginning of 2019, we had 41 members from 18 different European countries at the end of the year we had 43 members from 19 different European countries.

PAE's activities can be divided into three parts: core activities, projects, and incidental activities.

CORE ACTIVITIES

One of the core activities is to maintain and strengthen our relations with organisations of healthcare professionals and patient organisations active on a European level such as the European Pain Federation EFIC, EULAR (European League Against Rheumatism), EULAR/PARE (patients' part) EBC (European Brain Council), EAN (European Academy of Neurology), EFNA (European Federation of Neurological Associations) and EPF (European Patient Forum). Other organisations we are working



with on a more incidental base are GAPP (Global Alliance of Pain Patient Advocates) and GAMIAN-Europe (Global Alliance of Mental Illness Advocacy Networks-Europe).

Another core activity of PAE is to provide information to our members and sympathizers through our newsletters, social media and website channels. Our office is required to carry out all the necessary administrative work for this.

Further to this, a core activity is maintaining connections with European institutions such as the European Commission (DGs), the European Parliament (MEPs) and EMA (European Medicines Agency).

These activities require many hours from the secretariat and from board members, even more than in previous years, as we are becoming more and more recognised as an active and important stakeholder.

Another time and energy-consuming activity was moving the office to Brussels where we found an office in the same building as the European Pain Federation (EFIC). This also meant that we had to say goodbye to familiar faces, Anca and Hans, in the Diegem office who have helped PAE so well in the past years.

PROJECTS

PAE develops its projects in collaboration with other organisations or independently and with the financial or logistic support of our sponsors.

PAE's core projects are entirely lead by PAE and the results are used by PAE in its advocacy activities and to develop collaborations with other existing initiatives.

PAE's core projects consist of series of activities with defined scope and resources which take place within a period of development of a year or more and which may present a cyclic character (e.g. the PAE Surveys, the BMP Grants).

CORE PROJECTS

PAE Europe-wide Annual Surveys



The third pan-European survey was conducted in 2019, entitled “Pain and Stigma.” We received more responses (6069) than had been achieved in the previous surveys, and 20 countries supplied sufficient responses to be included in the final report: see <https://www.pae-eu.eu/surveys>

The results of the survey were presented during the European Pain Federation EFIC Congress in Valencia, 4-7 September 2019. These were addressed during the BMP meetings and were subject to a master class (workshop) on November 6th 2019 in Brussels.

Brain, Mind and Pain Patient-Centred Innovation Grant

In 2018 PAE inaugurated the BMP Grant which started its second edition in 2019 with the preparations and call for projects on the subject: “Stop Stigma”.

During the year we also followed up on the winners of the first edition and their progress on the projects. Reports on this were presented to the Steering Committee for review.

More info on the Brain Mind and Pain patient centred innovation grant can be found on www.bmp-grant.eu

COLLABORATION PROJECTS

Societal Impact of Pain (SIP)

As in previous years, during 2019 PAE collaborated in the SIP activities as a cooperative partner. PAE participates in the Steering Committee and also in the partners’ meetings, where the strategic decisions of the platform’s development are taken.

Partners are European Pain Federation (EFIC), Active Citizen Network (ACN) and Grünenthal. PAE helps with the operational part, we contribute to the content of the communications on all channel and follow-up with the members.

The SIP steering committee decided that the activities should continue on a dual basis. One is the continuation of the development of the national SIP platforms; the other is to strengthen our position within the European Institutions and organise a 10-year anniversary symposium in Brussels. PAE was actively involved in the program and the preparations of the Symposium.

SIP related activities:

SIP Stakeholders platform on the Health Policy Platform

The SIP Group's presence on the Health Policy Platform run by the DG Santé started at the end of 2017 and PAE was involved from the beginning, sharing the responsibilities as main platform administrator with the European Pain Federation (EFIC).

The Platform is intended to be a place to exchange information on a specific theme and the fact that the Societal Impact of Pain was considered by the Commission as a topic to follow is a good recognition in itself. We encourage all our members to become a member of this group by getting an EU login and requesting access. While the SIP Stakeholder group is a closed group, getting access to the HPP Agora (the space shared by all the closed groups present on the platform) enlarges the outreach to 4000 representatives of mainly non-profit, non-governmental organisations but also to representatives of the decision-making bodies and institutions.

OECD (Organisation for Economic Co-operation and Development)

Another outcome of the SIP activities is a collaboration that PAE has started with the OECD. This began after we presented our survey results at the meeting of a SIP delegation with OECD representatives in Paris, in July 2018. This resulted in the involvement in the PaRIS (Patient-Reported Indicators Survey) hip/knee replacement working group, in relation to the patient-reported outcomes. Although that project had already been running at the time that PAE joined, we were able to add our contribution during 2018 and 2019. The project was finalised in November 2019 with the publication of the report in which PAE wrote a piece.

CHRODIS+

Within the Chrodix+ project, PAE is involved in WP8: Employment and chronic diseases: health in all sectors. For that, we attended two meetings and followed several teleconferences. The meetings were February 28th in Rome and May 15th in Budapest. Further to this, there was a presentation in the European Parliament on November 12th.

At this moment, projects are being carried out in a couple of countries and data coming out of that will be used in the further development of the toolkit.

Brain, Mind and Pain European Parliament Interest Group

In this the year, the partners, EFNA and PAE, of this MEP Interest Group were confronted with the European Parliament Elections in May. We had the final meeting within the "old" Parliament on March 6th on the theme of *Fighting discrimination at work for those affected by neurological disorders and chronic pain*.

In the period before the elections, we worked on a revised version of the Book of Evidence to function as a guideline for the 2019 – 2024 mandate of the European Parliament.

After the elections in May, we prepared an outreach program in Strasbourg Parliament to involve as many MEPs as possible. These outreaches were continued in Brussels. On November 6th we had the first meeting in the “new” Parliament on the theme: *Ensuring equitable access to treatment, services, and support.*

Reports of the events and the new Book of Evidence are available at www.brainmindpain.eu

Incidental activities

UP campaign

This project initiated by the Pfizer / Lilly partnership started in 2018 and was finalised in 2019 with a presentation and meeting during the European Pain Federation (EFIC). It included a European-wide Survey. PAE president together with the European Pain Federation (EFIC) president were the vice-chairs of this project.

IASP (International Association for the Study of Pain)

After incidental contacts in the past and first patient involvement in 2018, in 2019 IASP started with a task force called: GAPP (Global Alliance of Pain Patients Advocates). The objective of this task force is to increase the involvement of patients advocates within IASP. The task force will continue their activities in 2020 at least until the IASP congress in August in Amsterdam.

European Parliament Activities

During the year PAE was present during several activities in the European Parliament and there were contacts with MEPs across the spectrum. This is to enable us to improve existing relations or to try to create new ones. Because of the new parliament, the activities were focused on the beginning and the end of the year.

EU Commission

During the year the contacts with the DGs (Directorates General) were only at the beginning of the year. This because of the elections and the long process of forming a new Commission. Towards the end of the year, the first initial contacts were made.

Pain Alliance Europe – General Assembly 2020

24th June 2020, 13h00

Presence at member activities

During the year representatives of the board of PAE were present at several meetings organised by our members. We were present at the Sin Dolore World park event in Menorca, at the No Pain Foundation meeting “Il Dolore Cronico; Inscindibile Legame tra la Sfera Sociale E Quella Clinica” in Bologna, at the conference for “Chronic Pain & Rheumatic Musculoskeletal Diseases” in Athens.

RESEARCH PROJECTS

Due to the fact that PAE has developed a reputation as a reliable, sensible and trustworthy partner, we are contacted on a regular basis to get involved in research projects and invited to be involved in calls for funding within the European Framework or IMI (Innovative Medicines Initiative).

In 2019, we were actively involved in the following projects: Grip (MySelf), Pain Out, Council of Coaches, Impate, Target.

The role of PAE is mostly to provide the patient view and to judge the projects on their patient-friendly, patient-centric character.