



## APPENDIX 2

# Pain Alliance Europe Annual Activity Report 2018

### General remarks

In 2018, PAE achieved the recognition of the value of the patients' presence in the policy-making background, thus enhancing the reputation of the organisation. This meant a busy agenda and therefore lots of work hours.

We can proudly say that chronic pain is mentioned more and more frequently in relation to the policy areas that PAE focuses on: awareness, employment, access and accessibility of therapies, education and research.

As a result of this raised awareness, PAE was able to increase the extent and degree of cooperation it has with other organisations.

All of these activities are possible with the back-up of our secretariat office and the full commitment of the board members. We work together to achieve all the basic activities necessary to running an organisation; to have good communication with our members and with other interested parties, and especially to maintain our social media communication.

The Board came together twice for meetings on February 20 and November 20, 2019 in Brussels. The board members met also online in a video conference on August 8<sup>th</sup>. As well, there were incidental contacts and a lot of e-mail traffic.

PAE's 2018 General Assembly took place on June 19<sup>th</sup> in Brussels.



We started the year 2018 with 36 members from 17 European countries and ended with 41 members from 18 European countries.

## Activities

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

### Core Activities

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One of the basic activities we undertake is maintaining our relations with the European Medicines Agency (EMA). PAE Board members participated in two of the workshops organised by EMA in 2018.

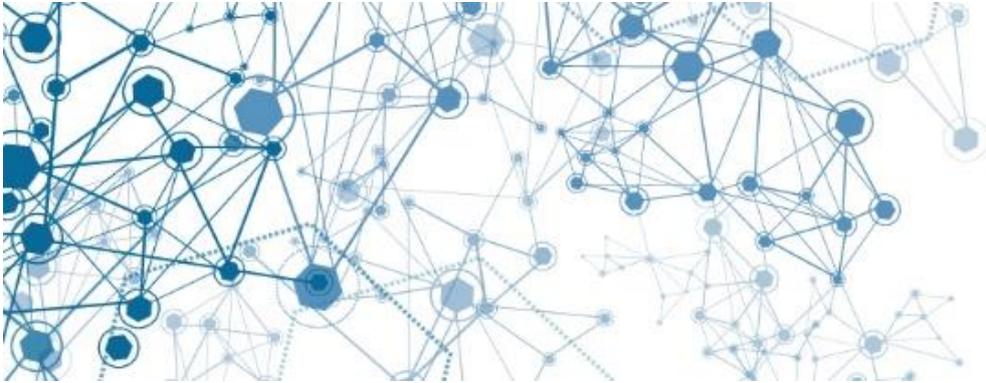
- HMA/EMA workshop on availability of authorised medicines - 9 November 2018
- EMA/HMA/EC workshop on electronic Product Information (ePI) - 28 November 2018

Of equal importance, we are building further on a strong relationship with healthcare professionals by working closely with the European Pain Federation (EFIC) on various projects, and by being involved in their internal committees as advisors.

We are perceived by EFIC as their first source of information when it comes to patient awareness or patient involvement. An example of this collaboration is the European Pain Forum - a platform for healthcare providers to exchange and cooperate on issues where the different organisations involved share a common scientific understanding of pain. PAE's participation as expert patient consultants is considered *very important* by the initiators in order to ensure the success of this project.

Following an internal restructuring process that EFIC is currently implementing, PAE was invited to take part in two of the newly-formed committees.

Other core activities consist of building on our relationship with European Federation of Neurological Associations (EFNA) and their professional counterpart EAN. We are in good



relations with the European League Against Rheumatism (EULAR) and their patient counterpart PARE. We also collaborate with European Brain Council (EBC). Our relationship with the European Patient' Forum (EPF) is improving and we are working on the relation with Global Alliance of Mental Illness Advocacy Networks (GAMIAN). We cooperating more frequently with Global Alliance for Patient Access (GAFPA).

## Projects

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PAE develops its projects in collaboration with other organisations or independently and with 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 Survey, the BMP Grant)

### Societal Impact of Pain (SIP)

As in previous year, during 2018 PAE cooperated in the SIP activities as a partner. Concretely, that means that PAE participates in the Steering Committee and also in the partners' meetings, where the strategic decisions of the platform's development are taken.

PAE helps with the operational part. While the group is assisted by the BCW communication agency in drafting its documents and graphic materials and campaigns, 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 represented by the development of the national SIP platforms; the other is to strengthen our position within the European Institutions.

Regarding the national platforms' strategic development, we were happy to note PAE members in six countries have created a national SIP-like platform. Although operating under the SIP flag, they all have their own priorities and needs. The activities provided by the PAE Board towards this development consisted mainly in participation at meetings as advisor/supporter, with occasional participation in the meetings of the national platforms: Malta, Portugal.



On the European strategic development, PAE has proved to be present in many of the activities organised to sustain this line of action. This included a visit to the European Committee for Standardization (CEN) to discuss the option of having standardisation for chronic pain.

But mainly we were busy with the offspring of the SIP achievements of previous years.

## 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 main platform administrator responsibilities with 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.

We strongly recommend all our members to learn to communicate at a European level at all times. PAE needs to reinforce its ambassadorial role in this respect but with this platform, member organisations can have themselves access to a European level forum.

The HPP Agora Newsletter is the instrument which could bring your news to all these 4000 stakeholders, and as a member, representatives of any participating organisation can publish their own events and news to be shared with this community.

The newsletter is also the means for the EU Commission to publish news (e.g. DG EMPL Newsletter around the European Pillar of Social Rights). It is a means of staying informed and informing the community about your activities in the same time.

## The 2018 Thematic network on the Societal Impact of Pain

Especially for our secretariat, these activities were a large but rewarding burden. The Thematic Network is one of the 2018 projects which brought us into a closer collaboration with EFIC. With



the logistic support of Grunenthal, a lot of work has been done to create the Joint Statement, the framing paper supporting it with all information on pain and its impact on society, on policy and actions taken by organisations, society and official institutions. The Joint Statement contains our common position (97 organisations endorsed the document) on four dimensions related to pain in policy: indicators, research, employment and education.

The project also strengthened the position of SIP and PAE as important stakeholders and partners in the discussions about health, pain in particular and also patients' contribution to the policy-making process.

The work done on the SIP thematic network was recognized as valuable by the EU Commission partners/representatives, several MEPs who support the joint statement and this initiative.

The contact with the Commission has also created synergies with existing actions and SIP has been invited and will be represented by PAE in the CHRODIS PLUS joint action, as collaborative partner.

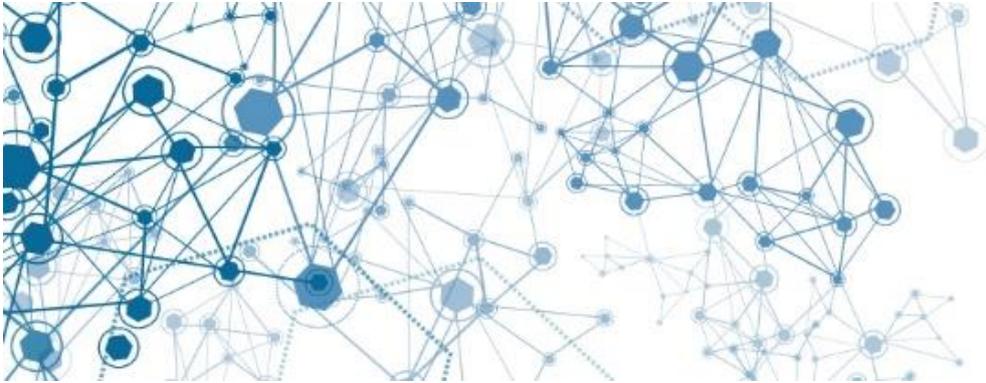
PAE members who want to endorse the Joint Statement can address this request to the Secretariat.

## 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, on July 24th. This resulted in the involvement in the PaRIS (Patient-Reported Indicators Survey) hip/knee replacement working group, in relation with 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 this collaboration will continue in 2019.

## CHRODIS+

Indirectly this is a follow-up from SIP, but more precisely it arises from the Thematic Network. The SIP partners were invited to nominate someone to participate in the CHRODIS+ project and specially in Working Package 8 on the topic of employment. The SIP partners decided that the PAE president would be the best representative for this. Our actual activities related to CHRODIS PLUS start in February 2019. This is the description of the project:



The CHRODIS+ Joint Action is a three-year initiative (2017-2020) funded by the European Commission and the participating organizations, that involving a total of 42 beneficiaries representing 20 European countries.

The overarching goal of CHRODIS+ is to support Member States through cross-national initiatives identified in JA-CHRODIS to reduce the burden of chronic diseases (CD), increase the sustainability of health systems and develop human capital. The focus will be on tangible trans-national activities with a potential to trigger health and CD policies in Member States with the prospective to improve health outcomes.

In specific terms, the aim of CHRODIS+ is to promote the implementation in several countries of innovative policies and practices for patient empowerment, health promotion and prevention, and fostering quality management of CD and multimorbidity as well as for improving the adaptation of the employment sector to chronic patients, in pilot actions that can be validated before scaling them up.

CHRODIS+ combine the selection of best suited good practices or recommended interventions with the support given to policy makers and organisations for the long term sustainability them. These organisations and policy makers may be operating at national, regional or local level. The practices or interventions will fit their needs. This JA includes the following 8 work packages:

- WP1: Coordination
- WP2: Dissemination
- WP3: Evaluation
- WP4: Integration in national policies and sustainability
- WP5: Health promotion and disease prevention
- WP6: Pilot Implementation of Integrated Care Model for multimorbidity
- WP7: Fostering quality of care for people with chronic diseases
- WP8: Employment and chronic diseases: health in all sector

The inter-sectorial relationship of the employment sector and workers with CD will be explored from two perspectives: as a place for preventing the onset chronic conditions and as a place where people with chronic conditions work.

Four pilot implementations will be conducted for WP8 Employment & chronic diseases: in Finland, Italy, Netherlands, Spain

[PAE Europe-wide Annual Surveys](#)



The second pan-Europe survey was conducted in 2018, entitled “Survey on Chronic Pain and Your Work Life.” We received more responses (4403) than had been achieved for the first survey, and 14 countries supplied sufficient responses to be included in the final report: see <https://www.pae.eu.eu/surveys>

Since the survey respondents are self-selected, it was not surprising that the report found that chronic pain had very much affected their working lives. Half the respondents were employed in public administration which is probably less active work, nevertheless nearly 51% reported that their chronic pain had prevented them from work, many had to change their employer, and one third had asked for adaption to their work to enable them to continue. Despite this, and the fact that some reported they had received occupational rehabilitation, two thirds of respondents had seen their income drop, with one in ten saying it was now under 10% of what it had been before the painful condition affected them.

PAE plans to repeat this survey in three years’ time, when we hope that public awareness will have improve the situation somewhat.

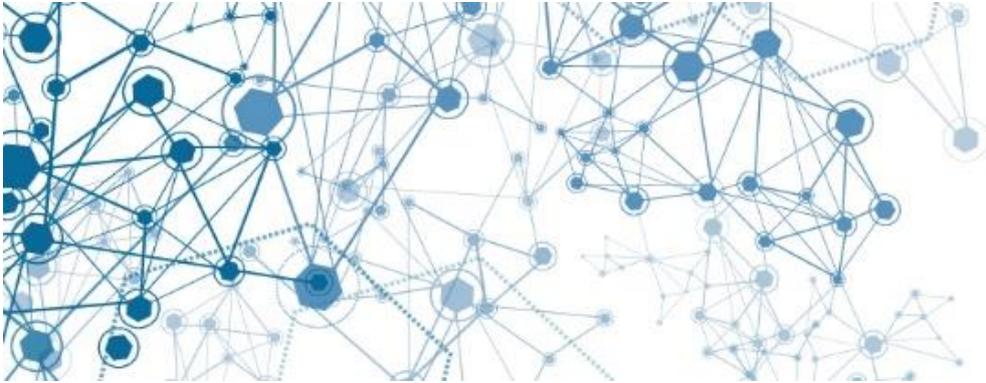
## Brain, Mind and Pain European Parliament Interest Group

During the year the partners, EFNA and PAE, of this MEP interest group organised three meetings in the EU Parliament which were very well-attended, not only by the MEPs show support our work but also by other MEPs. the meetings took place on February 21, June 20, and November 21. As indicated below, the main subjects were reflected of the Book of Evidence, as presented to MEPs at the start of the interest group.

21/02/18 - How can the EU #MakeWorkWork for young people affected by brain, mind and pain conditions? Hosted by MEP Marian Harkin, with the active participation of MEPs: Jana Zitnanska and MEP Rory Palmer, the meeting was supported by Mrs Emmanuelle Grange, Head of Unit, Disability and Inclusion, DG Employment, Social Affairs and Inclusion, European Commission on the existing EU Commission initiatives

20/06/18 - Optimising Patient Relevant Outcome Measures for sustainable healthcare systems and strong economies

21/11/18 - Future of Healthcare in Europe - What next for brain, mind & pain? – hosted by MEP Marian Harkin and MEP Merja Kyllönen



The reports of all the meetings are available on the website of the BMP MEP Interest Group: [www.brainmindpain.eu](http://www.brainmindpain.eu)

## Brain, Mind and Pain Patient-Centred Innovation Grant

In 2018 PAE inaugurated the BMP Grant. This project is being entirely run by PAE and we provided information on the preparations at the 2018 General Assembly.

The first edition was successfully finalised with three winner projects which are currently under development using the funds received from the Grant. The details of the three projects are published on the BMP grant website: [bmp-grant.eu](http://bmp-grant.eu).

PAE follows the development of these projects and publishes news about their advancement. On the basis of regular reporting and achieved milestones, PAE follows up with the payments of the remaining amounts as per the agreement with each winning organisation and the sponsor Grünenthal Group.

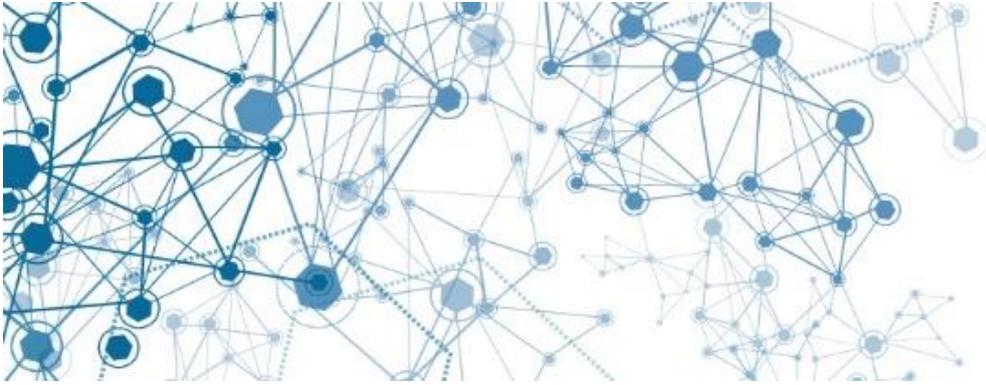
A methodology has been set for the project allowing us to prepare even better for the next edition, in 2019-2020. Following the experience gained, we will search for improvements in terms of efficiency, documentation of the process and internal best practices.

The project was presented as an abstract/ poster presentation at the EBC Industry Day on the 21 November 2018 and was submitted to the 2019 ACN (Active Citizenship Network) Prize for Best Practices.

## UP campaign

During the year we were asked by a Pfizer/Lilly alliance to work with them on the development of a campaign aimed at Low Back Pain (LBP). They asked PAE and EFIC to act as vice-chairs of the Steering Committee of the project. Pfizer/Lilly organised a first patient advisory meeting in London on April 24 for which PAE provided candidates. The meeting was followed by a meeting with different experts in Brussels on June 14. The outcome of those meetings, together with questions for a survey were discussed during a steering committee meeting in Brussels on December 19.

In the meantime, several online meetings have been organised between the Pfizer/Lilly alliance representatives and the vice-chairs to discuss the progress of the project. The project will continue in 2019.



## Incidental activities

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These activities are one-offs but have the potential of growing into basic activities or projects.

### IASP (International Association for the Study of Pain)

For the first time in its history, patient groups were invited to take part in the IASP symposium. Special “patient villages” were created for patient organisations programs and PAE had the opportunity to highlight its activities such as empowering projects and work at the political field. Once again warm cooperation with EFIC was seen when PAE was able to show off its activities by working from the EFIC stand.

### IAPO (International Alliance of Patients' Organizations)

PAE was invited to the IAPO meeting as an observer. The atmosphere for the discussion was open and it was clear that participating organisations from all over the globe are facing the same kind of healthcare obstacles - but that they are also feeling the winds of change.

Presentations indicated that health is also a political choice, and that although there are the same kind of problems around the world, there are also similar solutions.

Politically empowered patients can advocate more effectively. Education empowers patients and it is beneficial for all via the health value chain.

### EU Commission – DG Research

In November 2018, PAE presented the patient perspective on the societal and economic burden of pain at the DG Research workshop: *Towards Transatlantic Co-operation in Pain Research*.

This participation demonstrates the increasing importance given to patient involvement to create a better pain policy and the actions that are needed to better align research and innovation with the needs, values and expectations of society. It also recognised once again PAE as a reliable partner in discussions at this official level.

### European Parliament Activities

During the year we visited several activities, working with ACN, EBC, EULAR and so on. This is to enable us to improve existing relations or to try to create new ones. The future will show if these were successful attempts.



## Research projects

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Due to the fact that PAE is developing 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 2018 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.

## Acknowledgements

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PAE would like to thank their sponsors. Without their support all of the above would not have been possible. We also thank HARE Consulting for their help during the past year. Last but not least, we thank all the volunteers who made it possible for PAE to shine at a European level.

PAE Board