



Pain Alliance Europe Activity Plans 2020

General remarks

Pain Alliance Europe has to take into account that making the plans for 2020 these will always be under restriction that we will receive the needed funding. However, starting from a positive attitude, the following will be the goals for 2020. Adjustments can be made during the year following the situation but always with the aim to improve the quality of life of people living with chronic pain in Europe and being “the voice of people with chronic pain”.

The activity plans can be divided into two sections. One being the core activities and the second one being the project activities. These could run for one or more years.

Core activities

The core activities of Pain Alliance Europe are those activities which are necessary to keep the alliance working and follow their legal responsibilities. More concretely:

organising one or two general assemblies, organising board meetings, keep records of minutes and in and outgoing post and doing all other necessary secretarial activities.

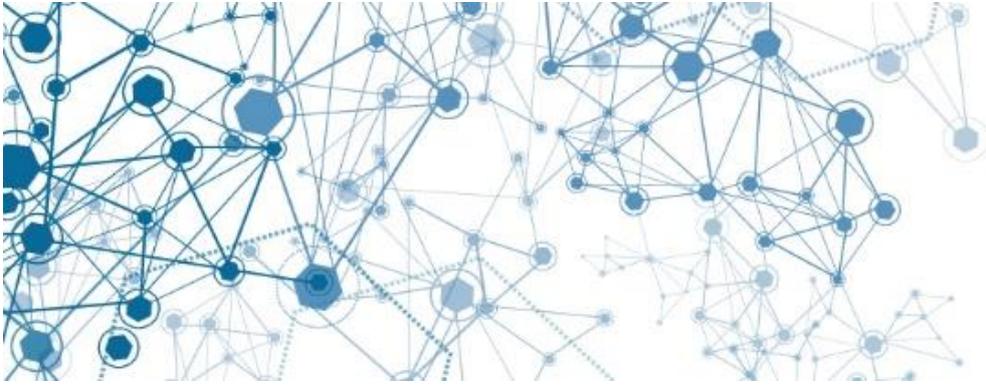
Keep records of all financial transactions and present them, audited by an accountant to the general assembly.

Organise and maintain the website, the Facebook account the Twitter account or any other social media domain of PAE.

Inform members and relations by means of a newsletter and news flashes.

Maintain and strengthen relations with the Sponsors of PAE and in addition try to find more of them.

Building on relations with our present partners both healthcare professionals as patient associations and try to extent them. Within this it needs mentioning that our relation with



the European Pain Federation has strengthened during the past years and is looking for more opportunities to combine forces where we think that combining forces will benefit both parties but more specifically the individual patients.

Maintain the relations with the political arena such as MEP's, policy makers of DG SANTE DG research DG Employment DG Finance and so on. With the European Council and support the members with the Semester.

Maintain and build on relations with European institutions like EMA, CEN and EUROSTAT.

Strengthen our relations with the industry in order to participate in new developments.

Strengthen our relations with the scientific world in order to get more involved in fundamental and specific research projects.

The above list may not reflect the many hours of extensive work necessary to perform the mentioned activities to generate influence and meaning. Both board members and the secretariat are spending a lot of time on these basic activities. They are proud they may do this for you, our members.

Running Projects

Brain, Mind and Pain Interest group (BMP)

After a successful meeting with sponsors of the interest group the next step in 2019 is to find supporting MEP's and MEP's willing to co-chair the meetings after the May elections. At the start of 2020 the program of the Interest group for the next mandate of the Parliament will be decided along with the co-chairs. Although PAE input will be focussed on chronic pain in areas in which the Parliament can have an influence, we must keep in mind reality and the voice of our partners. EFNA, MEP's Sponsors. www.brainmindpain.eu

Societal Impact of Pain (SIP)

After becoming a cooperative partner of SIP in 2016 our involvement in SIP has increased. In 2020 we will follow up on our earlier activities in previous years and recommendations from the steering group. 2020 we will be aiming at implementing more National SIP-alike platforms and at the same time advocate on a European level trying to achieve interactions with the European presidency in that year. With the elections behind us we will have a challenge to maintain so much support within the European parliament. The results on a European level will be shared to the national platforms with the request to reach out to their



national semester for seeing how implementation has taken place and the influence on the financial status of member states. www.sip-platform.eu

BMP Patient-Centred Innovation Grant

Started in 2017 this biennial grant is a PAE lead project. PAE is supported in this project by the BMP interest group, European Network of Neurological Associations (EFNA) the professional counterparts of PAE and EFNA, European Pain Federation and the European Academy of Neurology. This project is made possible with the financial and other support of Grünenthal. In 2020 it will have its winning ceremony for the second edition with the title: *Stop stigma: Reduce stigma to improve quality of life for brain, mind, and pain patients*. This project aims to stimulate projects initiated by patients for patients to improve their quality of living. www.bmp-grant.eu

Annual Surveys

Having done the first circle of annual surveys, 2020 asks for a review on the past ones and a decision on how to proceed with the following circle. The results from the surveys gave us good insights on how to adjust our advocacy policy and means to gain publicity on a European level. Results of the previous ones can be found on: www.pae-eu.eu/surveys

Social impact of Pain Stakeholders group on the EU Health Policy Platform

Together with EFIC PAE is running the SIP Stakeholders' group. The aim of this group is to get as much positive noise on chronic pain as possible in order to influence the policy-makers. The SIP Stakeholders' group will remain active during the upcoming years. <https://webgate.ec.europa.eu/hpf/group/index>

Thematic Network on the Societal Impact of Pain

After a successful Thematic Network activity, these recommendations will continue to play a major influence in our advocacy efforts towards European institutions. The Thematic network project itself has stopped in 2019, but the work is continued on the SIP Stakeholders' Group on the EU Health Policy Platform.

OECD

As a political outcome of our surveys and our involvement in SIP, PAE is asked by the OECD to participate in a PaRIS working group on Hip and Knee replacements. The final report of the working group is published in 2019 but the understanding is that the cooperation can be



continued in other working groups working to improve patients reported outcome in daily practice and bench marketing.

Chrodis+

As one of the follow ups on our involvement of the Thematic network PAE is asked to participate in the Chrodis+ project and more precise in working group W8 on Employment.

UP Campaign

PAE is been asked by a consortium of Pfizer and Lilly to play a leading role in the awareness campaign about Chronic Low Back Pain (CLBP) called UP (Understanding Pain). As a basis for this campaign is a survey done by the consortium with scientific advice from a steering group co-chaired by the presidents of PAE and EFIC. The cooperation on this level will continue in 2020.

Research projects

PAE is for 2020 and later involved in a couple of research projects as expert advisors or member of the respective consortiums.

The Council of Coaches project, Myself project, IMI Pain care, Target Project.

New projects

PAE is always trying to get involved in the developing of new projects with several consortiums within the Innovative Medicines Initiative IMI, Horizon 2020 or its successor calls. When granted these projects will have their influence on the activities of 2020 and beyond. However, the chances of having projects granted are rather low (less than 5%).

In this chapter should be mentioned also that the EU is discussing how to continue the research projects after Horizon 2020. Together with our partners we presented a position paper on that to the commission. We will continue to get as much contact and influence in that process as possible.

Next generation of board members



As presented to you in the plans for 2019 the present board will search for continuation of the board after 2021. 2020 will be used to provide to candidates the insights on the association's activity by being invited for the board meetings. Members are kindly requested to nominate candidates for either board member or president function.

The board has already started looking for candidates. We understand this will take time and also some additional costs, but all with the good reason of ensuring continuity of our mission and of our executive activity.

Special activities

During any year there will be some specific one-time activities in which participation of PAE is wanted. These requests will always be looked at so to evaluate if in the end it will benefit the patients and if it is within our core activities. An additional point will be if the cooperation will provide visibility for PAE and its work and provides the opportunity for a longer relation.

Conclusion

As you may all read this is a very tough program ahead of us and we can only do that if we, as members of PAE work together and give all our support to PAE in any way one can, at the end of the day we really can say: Pain Alliance Europe is the voice of people with chronic pain.

PAE Board