

Activity Plans 2022

General

Pain Alliance Europe (PAE) will always aim to improve the quality of life of people with chronic pain in Europe and to be "the voice of people with chronic pain". We must keep in mind, however, that all planning for 2022 is subject to obtaining the necessary funding, time and opportunities. Adjustments may be made during the year depending on the given situation.

PAE's activities can be divided into three areas:

- Core activities
- Projects
- Incidental activities

Core Activities

The core activities of Pain Alliance Europe are those activities necessary to keep the Alliance functioning and meeting its legal obligations. These are:

- Organising one General Assembly per year, organising Board meetings, keeping minutes, receiving and sending out mail and doing all other necessary secretarial work.
- Carrying out all necessary legal obligations that an organisation such as PAE is obliged to do under Belgian law.
- Keeping records of all financial transactions and presenting these records, audited by an accountant, to the General Assembly.
- To maintain and strengthen relationships with PAE's existing sponsors and also to recruit additional sponsors.
- Organising and maintaining PAE's website, Facebook and Twitter accounts and all other social media areas; keeping member organisations and other organisations informed of our activities through a newsletter.
- Build relationships with our current partners, both health care professionals and patient advocacy groups, and seek to expand them.



- Maintaining relationships in the political arena, such as with MEPs, policy makers at Directorate-General for Health and Consumers (DG SANCO), DG Research, DG Employment, DG Finance and so on; with the European Commission and the European Council. Also maintaining and developing relations with European institutions such as the EMA and the OECD.

Our reputation and standing has gained recognition and respect in Europe. This has ensured that we are more involved in scientific research projects seeking funding under Horizon 2020 / Horizon Europe / Innovative Medicines Initiative (IMI). We would not only be involved in scientific projects, but also serve on advisory boards, steering committees, and jury members for other stakeholders in the pain community.

Projects

Pain Alliance Europe has several projects that are carried out on an annual or biannual basis.

1. PAE led projects:

PAE Europe-wide annual surveys:

Pain Alliance Europe consults regularly its members and its members' members via survey campaigns meant to find out where the challenges are and how they evolve, noticing the differences between different health management systems at national levels and adapting every time the questions and the target according to the feedback thus received. PAE has been conducting annual surveys since 2017 and the topics addressed thus far are diagnosis and treatment, pain and working life, stigma, and digital health (e-health and m-health). In 2021 we repeated the diagnosis and treatment survey to compare the 2017 results. The 2022 survey will explore self-management of chronic pain. The results of previous surveys can be found at www.pae-eu.eu/surveys

Brain, Mind, and Pain Patient Centred Innovation Grant

The Brain, Mind and Pain 'Patient-Centred Innovation Grant' (BMP Grant) is an initiative of Pain Alliance Europe to identify, stimulate and encourage patient-centric and scientifically robust innovation in the domain of chronic pain and neurological disorders, to stimulate research and access to innovative treatments, to promote prevention and self-management approaches, to decrease stigma, and to work together to improve quality of life for people living with these disabling conditions. The sponsor of the project has decided that they can no longer be the sole sponsor of an activity, which means we needed to evaluate whether the project could continue as a multi-sponsor activity. With funding diversification in 2021, the project will continue and go into its third edition in mid-2021 with winner(s) announced by 2022. The Board's intention is to continue this initiative as it is important that patients are central in research projects: www.bmp-grant.eu

2. PAE partner projects:

Brain, Mind and Pain MEP Interest Group:

The Brain, Mind and Pain MEP Interest Group is an initiative of Pain Alliance Europe and the European Federation of Neurological Associations (EFNA), which aims to raise political awareness of the impact of neurological and chronic pain disorders in Europe and encourage patient centric policy solutions aiming to prioritise these disorders, decrease stigma, increase access to treatment, encourage research, promote patient empowerment, and improve quality of life overall. Following the 2019 elections, with the confirmation of MEPs and based on the mandate of the 2019-2024 Book of Evidence, the MEP Interest Group will continue in 2022. In the 2019-2024 mandate, the BMP initiative has collectively agreed to focus on the following thematic areas:

- Eradicate stigma, isolation and discrimination
- Ensure equitable access to treatment, services, and support
- Promote patient empowerment for increased involvement and engagement

PAE has provided increased secretarial and logistical support to the MEPs' Interest Group in 2021 and we plan to continue this in 2022. To stay up to date, please visit: www.brainmindpain.eu

Societal Impact of Pain (SIP)

The 'Societal Impact of Pain' (SIP) platform is a multi-stakeholder partnership led by the European Pain Federation EFIC and Pain Alliance Europe (PAE), which aims to raise awareness of pain and change pain policies. In 2018, EFIC and PAE were invited by the European Commission to organise a Thematic Network on the Commission's Health Policy Platform. The Thematic Network brought together a large number of health stakeholders to work on a Joint Statement on the societal impact of pain. The Joint Statement was the most comprehensive piece of policy advocacy that the partners had committed to paper, and therefore serves as the underlying basis for most of its work going forward. The Joint Statement covered the following areas:

1. **Pain as an indicator**
2. **Pain education**
3. **Pain in employment**
4. **Pain research**

SIP will most likely continuing with some of the 2021 activities into 2022. Learn more here: www.sip-platform.eu . From our previous SIP activities we have developed the following offshoots:

Social impact of the Pain Stakeholders group on the EU Health Policy platform:

PAE, together with EFIC, runs the SIP stakeholder group. The aim of this group is to get as much positive noise about chronic pain as possible to influence policy makers. The SIP Stakeholders' Group will remain active in the coming years.

3. Other collaborations & Participations:

ITN ETUDE: ETUDE stands for "Encompassing Training in Functional Disorders across Europe". This programme aims to identify underlying mechanisms, improve diagnosis and treatment and reduce stigma for patients with functional disorders. Functional Disorders (FD) are clusters of chronic somatic symptoms that currently cannot be linked to reproducibly observable pathophysiological mechanisms. Functional limitations are as severe in FD as in well-defined chronic physical illnesses. Direct medical costs and indirect costs as a consequence of sick leave and work disability are high. ETUDE will recruit 15 ESRs in the 10 academic and 1 non-academic institutions that make up the network, spread across six countries (Netherlands, Germany, UK, Denmark, Poland and Italy). In addition, 19 academic and non-academic partner organisations will support the training and secondment of ESRs. PAE will host some of these students/researchers in our Brussels office in 2022.

QSPainRelief: QSPainRelief is an international collaborative research project funded by European Commission that brings together 10 partner institutions from 5 European countries and the United States of America. The 5-year project started in January 2020 and uses an innovative quantitative systems pharmacology (QSP) approach to pain relief to develop an effective combination treatment for chronic pain in individual patients. We PAE are part of the scientific and Ethical Advisory Board of the QSPainRelief project

European Brain Council (EBC) Value of Treatment (VoT): the EBC VoT case study on Chronic Pain started on December 2, 2020 with the first meeting of the working group composed of experts from European Academy neurology (EAN), European Pain Federation (EFIC) and patient experts from Pain Alliance Europe (PAE). The results of the two-year case study on Chronic Pain will be published by the end of 2022 and translated into policy recommendations. These will be used for advocacy purposes and will help to improve the quality of life of people living with chronic pain.

European Pain Forum: PAE is pleased to be among the supporters of European Pain Forum, together with European Pain Federation and other organisations. The European Pain Forum aims to unite all medical, scientific and patient organisations relevant to pain. Its vision is to alleviate the suffering of people living with pain through a multidisciplinary approach that includes the biological, psychological and psychosocial aspects as well as the patient perspective and professional and socio-economic factors.

iPspine: The EU-funded iPspine consortium consists of 21 partners and aims to develop a novel therapy to cure low back pain (LBP) due to disc degeneration, which is responsible for at least 40% of all cases of low back pain. At the end of the project, the therapy is expected to be in the initial stages of preclinical testing in dogs suffering from low back pain. PAE is a member of the Patient Advisory Board (PAB) via PAE member and former vice-president Liisa Jutila.

EFIC Health Literacy Campaign: Health literacy is the theme chosen by the new president of European Pain Federation, Brona Fullen, for the presidential campaign. The 'Plain Talking' health literacy campaign is aimed at both clinicians and people living with pain. Over the next three years, the Health Literacy Working Group will raise awareness of the concept and impact of health literacy.



It will also focus on improving communication between people living with pain and clinicians by developing a range of materials and useful resources for all. Pain Alliance Europe is pleased to participate as a patient representative in this EFIC campaign which will continue into 2022.

Incidental activities:

PAE has often been asked to participate in short-term activities in the past, such as ad hoc advisory board meetings, giving presentations, and so on. PAE will continue these activities if they are felt to be of benefit to people with chronic pain or to PAE itself.

Conclusion

As described, it is the intent of the Board to take advantage of the reputation we have earned in the past and accomplish as much as possible for the benefit of people with chronic pain. We realise that we have set ambitious goals, but with everyone's support and the Board's determination, we believe we will have every chance of making this a success.

PAE Board