

Pain Alliance Europe

the voice of people with chronic pain



2020

ANNUAL REPORT

Pain Alliance Europe



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Annual Activity Report Pain Alliance Europe (PAE) 2020

GENERAL

The year 2020 began with a lot of energy, ideas and plans. But due to COVID -19 we had to adapt and start over. Digital meetings replaced live meetings. Our work, which is primarily advocacy, was to meet and talk to people, not only by request, but also when we attended other meetings and events. With digital meetings, this aspect of advocacy was lost. Despite all these problems, we can say that this was a good year for PAE.



We have achieved a lot and our collaborative attitude is increasingly appreciated by the other associations and our counterparts as well as all other stakeholders.



This year we had five virtual board meetings and a General Assembly meeting held in a digital format on June 24. At this meeting, a new board member was elected: Ms. Gemma Fernández. Another election concerned the new member organisation de Maretak, which is an independent patient organization run for and by people with chronic pain in Belgium.

PAE's activities can be divided into three areas: Core Activities, Projects and Incidental Activities/Other Collaborations.

CORE ACTIVITIES

One of the core activities is to maintain and strengthen our relationships with organisations of healthcare professionals and patient organizations functioning at the European level, such as the European Pain Federation EFIC, EULAR (European League Against Rheumatism), EULAR/PARE (patient part), EBC (European Brain Council), EAN (European Academy of neurology), EFNA (European Federation of Neurological Associations), EPF (European Patient Forum). Other organizations with which we collaborate more on a more incidental base are GAPPA (Global Alliance of Partners for Pain Advocacy) and Gamian (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. This also includes making sure that all necessary administrative work for PAE is done from our office in Brussels.

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

These activities required many hours from the secretariat and board members, more hours each year, as we become more and more recognized as an active and important stakeholder.

PROJECTS

PAE develops its projects independently or in collaboration with other organisations and with financial or logistical support from our sponsors.

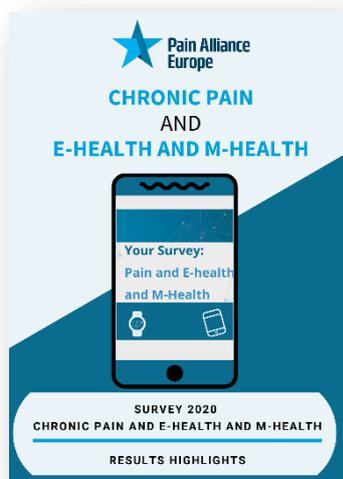
PAE's core projects are entirely managed by PAE and the results are used by PAE in its advocacy work and to develop collaborations with other existing initiatives.

PAE's core projects consist of a series of activities with defined scope and resources that take place within a development period of one year or more and may be cyclical in nature (e.g. the PAE Surveys, the BMP Grants).

CORE PROJECTS

PAE Europe-wide Annual Surveys

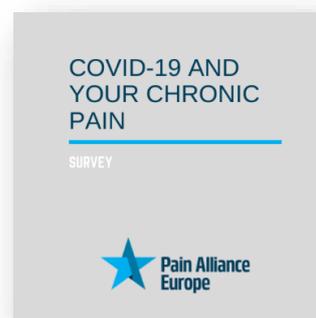
In 2020, the fourth pan-European survey entitled **Pain and e-health and m-health** was conducted.



The questionnaire was distributed through the network of member organisations of Pain Alliance Europe in many European member states and was available in the following languages: Czech, Danish, Dutch, English, French, German, Greek, Italian, Spanish, Norwegian, Portuguese, Romanian, Serbian, Slovenian and Swedish. In total, 1789 citizens from 28 European countries completed the questionnaire. To read the final report, please visit <https://www.pae-eu.eu/surveys>. The results of this survey were also [presented at the IASP Virtual Series on Pain & Expo - Virtual Poster Gallery](#) by PAE Board Member Ms Marian Nicholson.

Covid-19 and Chronic Pain surveys

PAE created an online [short survey about Covid-19 and Chronic Pain](#) to capture the current situation of chronic pain patients in Europe and what PAE can do to improve the situation. We received a total of 1556 participants from 19 countries over a period of 6 weeks. This was made possible through the help of volunteers within PAE member associations. The results of this survey were presented to our members at the PAE General Assembly in June 2020. Our President also presented these results at the EFIC webinar on "Pain Management during COVID -19".





At the end of 2020, PAE created an [in-depth survey on how chronic pain patients across Europe are affected by the COVID-19/coronavirus](#) pandemic. With this in-depth survey, PAE has looked more closely at this issue to see if there are any other points worth noting.

The results of this more thorough survey will be available in March 2021.

Brain, Mind and Pain Patient-Centred Innovation Grant

On June 24, 2020, we had the [BMP Grant Ceremony](#), which took place in a digital format, with 55 registered participants.

This Grant Ceremony is the final milestone of the BMP Grant 2019-2020 project, marking the end of the evaluation period and the announcement of the winner(s). The [Jury for the 2019-2020 BMP Grant](#) had the task of evaluating the eleven projects submitted. This task was made difficult by the overall high quality of the proposals, all of which focused on the interests of patients.

At this ceremony, each of the eleven submitted project proposals and the [achievements of the winners of the first edition](#) were shown and the [three winners of the second edition of the BMP Grant](#) were announced.



For more information about the Brain Mind and the Patient-Centred Pain Innovation Grant, please visit www.bmp-grant.eu.

COLLABORATION PROJECTS

Societal Impact of Pain (SIP)

The Societal Impact of Pain (SIP) has entered a new era as leadership of the project has passed to the European Pain Federation (EFIC) and Pain Alliance Europe (PAE). Under this new leadership, we aim to continue the hard work that the partners of SIP have done over these years and find new ways to change pain policy for the benefit of patients. As a partner of SIP, PAE will ensure that the patient voice is represented in the campaign. Learn more about the new team at SIP and who to contact at [this link here](#).

In 2020, the SIP team had the opportunity of meeting virtually with several MEPs, and in some of these meetings we were joined by our national colleagues from SIP Finland and SIP Spain, who have PAE Vice-President Liisa Jutila (SIP Finland) and PAE Board Member Soledad Garcia Penalta (SIP Spain) as patient representatives. The SIP team used these opportunities to talk about SIP policy priorities for 2020-2021 and to share the [SIP Cancer Pain Position Paper](#).



SIP related activities:

SIP Stakeholder Platform on the Health Policy Platform

The presence of the SIP group 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 responsibility as administrator of the platform with the European Pain Federation EFIC.

The platform is intended to be a place to share information on a specific topic and the fact that the societal impact of pain was considered by the Commission as a topic to be pursued is in itself a good recognition.

We encourage all our members to become members of this group by getting an EU login and requesting access. While the SIP stakeholder group is a closed group, access to the HPP Agora (the space shared by all closed groups on the platform) extends the reach of any news that is uploaded to it to 4000 representatives of mainly non-profit, non-governmental organisations, but also to representatives of decision-making bodies and institutions.

CHRODIS+

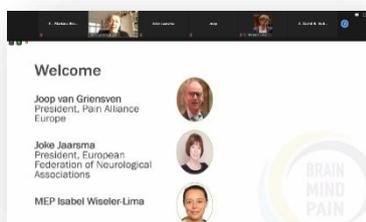
As a partner in Chrodis Plus, we have been particularly involved in Work Package 8 (WP8) on employment and chronic conditions. You can read more about this initiative and our work on WP8 [here](#). In 2020, we will participate in two conference calls, one on 2 March 2020 and another on 4 June 2020.

Chrodis Plus held its final online conference on October 27, 2020. This conference illustrated the impact that Chrodis Plus has had on public health systems in EU member states over the last 3 years. It focused on showing how the good practices, models and tools implemented through the project can be tailored to different national and local settings across Europe.

OECD PaRIS Working Group on Patient-Reported Outcome Measures (PROMs) for Hip Replacement and Knee Replacement Surgery:

The working group was constituted in April 2020. In 2020, some meetings were held virtually via web or video conference. The term of the current working group will continue until the publication of the report and recommendations to the HCQO Working Group, expected in late 2021.

Brain, Mind and Pain European Parliament Interest Group



In 2020, the MEP Interest Group on Brain, Mind and Pain was unable to meet in person due to the pandemic COVID -19. However, on 10 November 2020, the MEP Interest Group on Brain, Mind and Pain (BMP) organised a virtual event on the future of BMP advocacy.

Given the current context that is increasingly impacting the health policy landscape, the main objective of the event was to identify and advance public health priorities and actions for people affected by neurological and chronic pain conditions.



The event also aimed to provide an overview of the stakeholder group's new policy direction and was an opportunity to introduce a series of appendices to update the group's key policy document - the Book of Evidence. The event also aimed to gather feedback on its 'Roadmap to Change', an action plan for the next two years.

The virtual meeting brought together key stakeholders from the BMP community, other disease-specific groups, and relevant third-party organisations. High-level policy makers also participated, including: Dr Bente Mikkelsen - World Health Organisation, Mr Stefan Schrek - European Commission, Katarzyna Ptak - European Commission, MEP Isabel Wiseler-Lima (Romania, EPP), MEP Tilly Metz (Luxembourg, Greens/EFA) and MEP Marisa Matias (Portugal, GUE/NGL). MEP Sirpa Pietikainen (Finland, EPP) and MEP Kateřina Konečná (Czech Republic, GUE/NGL) also contributed and sent video messages. You can read the 2020 meeting [report here](#).



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Incidental activities / other collaborations:

QSPainRelief: QSPainRelief is an international collaborative research project funded by the European Commission, bringing together ten partner institutions from five 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 2 December 2020 with the first meeting of the working group composed of experts nominated by the European Academy of Neurology (EAN), the European Pain Federation (EFIC) and patient experts from Pain Alliance Europe (PAE). The results of the two-year case study of Chronic Pain will be published and translated into policy recommendations by the end of 2022. 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 the European Pain Federation and other organisations. The European Pain Forum aims to unite all medical, scientific and patient organisations relevant to pain, and its vision is to alleviate the suffering of people living with pain through an interprofessional approach that takes into account the biological, psychological and psychosocial aspects as well as the patient perspective and professional and socio-economic factors.

iSpine: The EU-funded iSpine consortium consists of 21 partners and aims to develop a novel therapy to cure lower back pain (LBP) due to intervertebral disc degeneration, a major contributor accounting for at least 40% of all lower back pain cases. By the end of the project, the aim is for the therapy to be in the first phases of pre-clinical testing in canines suffering to from back pain.

In 2020, Pain Alliance Europe's Vice President joined Patient Advisory Board (PAB) as a member.

Advisory Board for 'Healthy Ageing and improving Non-Communicable Diseases (NCD) outcomes: We are a member of the Patients' Advisory Board on 'Healthy Ageing and improving Non-Communicable Diseases (NCD) Outcomes.' The aims of this Advisory Board include identifying barriers and challenges to the diagnosis, care and management of NCDs for patients and carers in the post-COVID-19 era and advising on the increased role of digital tools to improve patient outcomes. In 2021, this Advisory Board will publish an article on "Digital Health Tools for Managing Noncommunicable Diseases During and After the COVID -19 Pandemic: Perspectives of Patients and Caregivers".

IASP (International Association for the Study of Pain): After incidental contacts in the past and an initial patient involvement in 2018, IASP launched a task force called GAPPA (Global Alliance of Pain Patients Advocates) in 2019. The goal of this task force is to increase patient advocate involvement within IASP. The task force continued its activities in 2020.

WIP Congress

The year 2020 did not stop Pain Alliance Europe (PAE) from working on its mission to promote chronic pain awareness on behalf of patients in Europe.

PAE submitted a poster on "Chronic Pain and Stigma across Europe" to the 10th World Congress of the World Institute of Pain (WIP), which was accepted.

In light of recent events, PAE will present its report in a digital format at the WIP Congress. PAE board member and co-author of the report, Ms. Marian Nicholson, was the presenter. The poster presentation is available [here](#).

Acknowledgements

PAE would like to thank its sponsors. Without their support, none of this would have been possible. We would like to thank EFIC for their support in organising and setting up the PAE office in their building. Last but not least, we would like to thank all the volunteers who made it possible for PAE to shine at a European level.