

## **Appendix 2 - General Assembly 2023**

### **Activity Plans 2024 and 2023 Activity Updates**

Pain Alliance Europe (PAE) continues to aim to improve the quality of life of people living 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 2024 is subject to obtaining the necessary funding, as has been in the recent years. Adjustments made be made during the year depending on the given situation.

PAE's activities can be divided into two areas: core activities and the three Pillars that make up the main body of our work: Societal Impact of Pain (SIP), PAE Patient-Centred Innovation Grant (formerly BMP), Research collaborations.

#### **• Core Activities:**

The core activities of Pain Alliance Europe are those necessary to keep PAE 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 X (formerly: Twitter) accounts and all other social media areas; keeping member organisations and other organisations informed of our activities through our 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 Food Safety (DG SANTE), DG Research, DG Employment, DG Finance and so on; with the European Commission and the European Council; and supporting members through the semester. Also maintaining and developing relations with European institutions such as the EMA and the OECD.

PAE 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 Europe/Innovative Medicines Initiative (IMI). We have not only been - and continue to be - involved in scientific projects, but

also have been serving on advisory boards, steering committees, and jury members for other stakeholders in the pain community.

- **Activity Plans 2024:**

Core activities:

- Maintain PAE offices, legal requirements, and 1 organisational employee salary
- Membership of EU Stakeholder Groups
- Investment in PAE membership recruitment
- Attendance to EU Policy and Scientific Events in relation to Health and Societal Impact

PAE Projects:

- Patient survey on Self-management and Mental Health
- Launch of remodelled BMP Grant based on survey, and application call
- Multi-stakeholder Webinar on Self-management and Mental Health
- Patient Educational Event and General Assembly

- **2023 Activity Updates**

**Three Pillars of PAE work:**

1. The Societal Impact of Pain (SIP) platform

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. The platform provides opportunities for discussion for health care professionals, pain advocacy groups, politicians, healthcare insurance providers, representatives of health authorities, regulators, and budget holders.

**SIP has position papers in 4 policy areas:** SIP Cancer Position Paper (2020), SIP Workplace Integration and Adaptation Position Paper (2021), SIP Digital Health: Pain Assessment and Quality Indicators Position Paper (2022), and SIP ICD-11 Position Paper (2023).

In 2023, the platform's focus is on the following areas: Pain and Digital Health, ICD-11 - both targeting the EU Health Data Space; Pain and Mental Health - targeting the European Parliament Mental Health Report and the European Commission Mental Health Strategy; and Access to Treatment - SIP Book of Evidence on the Burden of Pain.

In 2023, SIP issued Joint Statement on Pain and Mental Health. An in-person meeting for SIP National Platforms (NPs) took place at the EFIC 2023 Congress in Budapest, Hungary.

Upcoming events:

- 10 October 2023 - SIP event on Pain and Mental Health at the European Parliament, Brussels
- 03 November 2023 - SIP Stakeholder Forum - an in-person meeting at the EFIC/PAE office
- 28 November 2023 - SIP National Platforms meeting - online

For more details about SIP's 2023 activities and plans for 2024, please see Appendix 3, which contains Ángela Cano Palomares' presentation shown during the PAE GA 2023.

PAE will continue the collaboration within SIP 2024. Learn more here:

<https://europeanpainfederation.eu/sip/>.

## 2. Remodelled BMP Grant

Providing that the funding for the fourth edition of the Grant is secured, the Grant will be announced and launched in 2024.

The Grant will change its current Brain, Mind and Pain Patient-Centred Innovation Grant name to a new one, yet to be established, that will cover all pain conditions and will not be limited to the theme of Brain, Mind and Pain. Pain Alliance Europe will be fully responsible for the Grant, as in the Grant's third edition.

Before the next edition is launched, PAE will re-model the Grant by surveying all Grant stakeholders' experience with the Grant's call, application, and selection processes. The theme for the fourth edition will be likely linked to the PAE 2024 survey on pain, self-management and mental health.

## 3. Research collaborations and own PAE survey

- PAE 2024 Survey: Pain, self-management, and mental health.

PAE aims to launch the next survey subject to available funding. The survey will be independent of the industry influence\*. PAE held a focus group on 08 March 2023 with Members who volunteered to participate, followed by additional commentary via email after the focus group meeting. The scope of the survey has been established. Once the survey is fully prepared, PAE will disseminate it within the Membership and PAE media channels to collect responses.

### **Research collaborations - 2023 and ongoing:**

#### **EFIC Campaigns:**

- **Plain Talking** - immediate past European Pain Federation (EFIC) President Brona Fullen's campaign focusing on improving communication between people living with pain and clinicians by developing a series of materials and useful resources for all. PAE's involvement in the campaign included organising a focus group with patients to inform the Plain Talking Working Group (WG) lead on the patient perspective and feedback and ongoing dissemination of the materials. PAE Board Member Nadia Malliou (NM) was also part of the WG. More details and resources are available here: <https://europeanpainfederation.eu/efic-plain-talking/>

**ERA-NET NEURON:** a network of 35 research funding organizations and ministries from 28 countries that support basic, clinical and translational research in the diverse field of research into the brain and its diseases: <https://www.neuron-eranet.eu/>. PAE participate in the following ERA-NET NEURON projects:

- **AGORA** (Advancing Guidelines with Original Research Achievements in pain) - the project aims to improve the effectiveness of therapy of chronic neuropathic pain (CNP) and rate of responders in future clinical trials delivering the treatment to targeted subgroups of patients. The societal aim of the project is to improve the quality of life (QoL) of patients and their families through improved diagnosis and

treatment, optimising the cost-effectiveness of pharma-company investments and healthcare system improving quality and reducing costs of public assistance. The project runs for 12 months from June 2023 to June 2024. Details can be found here: <https://www.neuron-eranet.eu/projects/AGORA/>.

- **ITPain** (Improving Translational Research for Chronic Pain? Data alignment in preclinical and clinical studies) - the project aims to overcome the large heterogeneity of protocols in preclinical and clinical studies by harmonising protocols and aligning them in a translational approach to improve trial design and to facilitate the translation of research findings into clinical practice in order to bring new treatment targets and improve patient stratification for treatment response. The project runs for 12 months from September 2023 to September 2024. Details can be found here:

<https://www.neuron-eranet.eu/projects/ITPain/>

- **PRISE** (Pain Research Strategy for Europe) - the project aims to enable high-quality and meaningful research, to maximise its translation into European policy and practice, to lead to enhanced solutions for chronic pain, and to increase the profile of pain research in Europe and advocate for increased and sustained funding for research in this field. The project runs for 12 months from September 2023 to September 2024. See the project's details on page 15 here:

[https://www.neuron-eranet.eu/wp-content/uploads/Neuron-NL42\\_final.pdf](https://www.neuron-eranet.eu/wp-content/uploads/Neuron-NL42_final.pdf)

- **STIMCODE** (Brain Stimulation Reconsidered) - an international project aims to develop a Code of Conduct for the use and research of non-invasive brain stimulation for the European Union in collaboration with experts from society, science, politics and industry. PAE President Deirdre Ryan provided patient feedback during a workshop in April 2023. The participatory results of the workshops organised by the consortium serve as a basis for further discussion and elaboration with experts from different relevant disciplines. A Code of Conduct will be derived with the different perspectives taken into account. The project is to be finished in October 2023. More details are available here: <https://www.cerri.iao.fraunhofer.de/en/projects/stimcode.html>

**ETUDE - ITN:** a Marie Skłodowska-Curie Innovation Training Network (ITN), funded by the European Commission, Horizon 2020 Program, designed to train the next generation of researchers in Functional Disorders. More details are available here: <https://etude-itn.eu/>.

PAE hosted secondments for two Early Stage Researchers (ESRs) in 2022 and helped in patient recruitment for their research focused on fibromyalgia diagnosis and stigma. DR provided a workshop for two network-wide training events in 2022 and 2023. The International Training Network (ITN) ETUDE hosted their final training seminar in September 2023 for the whole ITN. PAE will continue supporting one of the ESRs in patient recruitment for her research.

**INTEGRATE-Pain** (Innovative Medicine Initiative [IMI] and National Institutes of Health [NIH] Transatlantic Emphasis Group on Research and Translation-to-care Efforts): created in 2020 as a US-EU (United States–European Union) consortium to advance the pain field, to enhance development of treatments, and to facilitate transfer of existing and new treatments into clinical practice, ultimately improving the lives of people with lived pain experience in the United States and European Union. PAE's involvement so far include the recruitment of participants with lived pain experience for a three-round Delphi voting process that ended in early 2023, and the dissemination of the Delphi process results at the EFIC 2023 congress. Further steps include publications (the results have been submitted), webinars for research, clinical, and advocacy organizations, and educational materials for people with lived

experience of pain that will be co-produced with lived experience expert members of INTEGRATE-Pain Advisory Committee. More details are available here: <https://integrate-pain-domain-meeting.com/about/>.

**OECD PaRIS** (Organisation for Economic Co-operation and Development [OECD] Patient-Reported Indicator Surveys [PaRIS] Working Group on Hip and Knee Replacement Surgery): the 2019 initiative where countries work together on developing, standardising and implementing a new generation of indicators that measure outcomes and experiences of patients managed in primary care across countries. The PaRIS survey aims to fill a critical gap in primary healthcare, by asking about aspects like access to healthcare and waiting times, as well as quality of life, pain, physical functioning & psychological well-being. PAE President Deirdre Ryan (DR) contributed to the Working Group (WG) as a European patient representative. DR proposed to the WG to survey how the patients are informed about existing registries, data use, consent for participating in the registry, and similar. The most recent findings of the OECD Patient-Reported Indicator Surveys (PaRIS) Working Group on Hip and Knee Replacement Surgery are available here:

[https://www.oecd-ilibrary.org/social-issues-migration-health/international-assessment-of-the-use-and-results-of-patient-reported-outcome-measures-for-hip-and-knee-replacement-surgery\\_6da7f06b-en](https://www.oecd-ilibrary.org/social-issues-migration-health/international-assessment-of-the-use-and-results-of-patient-reported-outcome-measures-for-hip-and-knee-replacement-surgery_6da7f06b-en)

**PANDOS** (An Observational Study on Pain AND Opioids after Surgery in Europe): The aim of the PANDOS Research Group is to improve pain management and perioperative opioid use after surgery. PAE Board Member Liisa Jutila (LJ) is involved in the project to provide patient perspective and feedback. PAE organised a focus group for the project in July 2023. More details about PANDOS are available here: <https://www.esaic.org/research/research-groups/pandos/>

**PAREA** (Psychedelic Access and Research European Alliance): the multistakeholder and multidisciplinary partnership's mission is to integrate psychedelic therapies into European mainstream health services in a safe, modern, and ethically responsible manner, where those novel treatments are an additional therapeutic option, accessible and affordable for all, as registered and reimbursed medical treatments. PAE recognise that novel therapies may impact chronic pain treatment and/or management for people living with pain. PAREA continues to secure trust and active involvement from the scientific and clinical communities in integrating psychedelic care into everyday clinical procedures. PAE President Deirdre Ryan is Vice-Chair of PAREA and contributed to advancing the field of psychedelics in the realm of pain management. More information on PAREA's work is available here: <https://parea.eu/>.

**PHOTOTHERAPORT** (Phototheraport luminescent implants as ports for light-based therapies): The project's aim is to develop a novel technology to treat neuropathic pain based on inhibiting neuronal activity locally and on demand by means of light. PAE was included in the application in March 2023. Some of PAE's involvement will be participating in yearly meetings advising the consortium about the results achieved and future plans, and disseminating the outcomes. More information will follow soon.

**QSPainRelief** (Effective combinational treatment of chronic pain in individual patients by an innovative Quantitative Systems Pharmacology [QSP] pain relief approach): the 5-year-long EU-funded research project continues despite initial delays during the COVID-19 pandemic. The project's goal is to identify alternative combinational treatment paradigms, with improved pain relief and reduced adverse effects, and validate the most promising combinational medication paradigms in preclinical models, in healthy volunteers, and in clinical practice. DR is on the consortium's Advisory Board. The QSPainRelief consortium will hold a patient event on 06 December 2023 at the Centre of Human Drug Research's auditorium from 14:00-16:00 in Leiden, the Netherlands, for Dutch-speaking participants. The event is

open to pain patients, relatives, and interested laymen. More updates and information are available here: <https://qspainrelief.eu/>.

**VOT** (the Value of Treatment for Brain Disorders): a health economics and outcomes research project coordinated by the European Brain Council (EBC). Some of the project's goals are to target unmet needs to achieve high value for patient and conduct cost-effectiveness analyses in health care and assess the benefits of seamless, coordinated care by examining health services, patient outcomes and patterns of multidisciplinary care focusing on 3 types of pain: diabetic neuropathy, low back pain and fibromyalgia. PAE President contributed patient narratives to the project. More details are available here: <https://www.braincouncil.eu/projects/the-value-of-treatment/>

**SAFEPOLYMED** (Improve Safety in Poly medication by Managing Drug-Drug-Gene Interactions): the project, funded under the HORIZON Research and Innovation Actions (RIA) scheme, aims to generate a systematic documentation of the health status using patient-reported outcome measures (PROMs) to help identify problems with adverse drug reactions (ADR) early and improve the communication between patients and healthcare providers. PAE will be involved in the project as a member of the Patient Engagement Hub. The project started on 01 June 2022 and is to be completed on 30 November 2025. More information is available here: <https://www.safepolymed.eu/>.

#### **New and potential research collaborations:**

**BACK-Track** (Tackling low back pain burden and inequality. An interventional epidemiology platform to inform policy): proposal submitted under the HORIZON Research and Innovation Actions (RIA) funding scheme. BACK-Track will advance diagnosis and management of low back pain (LBP) by creating the first interventional epidemiology LBP platform to inform policy. The project has potential to transform LBP outcomes via innovative diagnostics and digital person-centred solutions. PAE is a partner in the proposal. The proposal's results are to be known mid-December 2023.

**DIPST** (Digital Innovation in Pain Science and Treatment): The proposal has been revised and will be re-submitted in October 2023 after its initial rejection in October 2022 by COST (European Cooperation in Science and Technology), a funding organisation for research and innovation networks. DIPST will develop and establish a Pan-European, intersectorial, and multidisciplinary network of excellence and will serve as a hub for patients, academia, healthcare, and industry, to jointly accelerate the advancement of pain care and research on digital behavioural health to support people living with chronic pain across Europe. PAE participate in the proposal as a secondary proposer. More news will be available soon.

**FRESCO4NoPain** (Frontier RESEARCH COMpetences for Neuro-modulation and Oscillations in Pain): the Doctoral Network proposal will be re-submitted for EU funding opportunities in November 2023. The project's scope includes training 10 uniquely skilled Doctoral Candidates (DCs) who will become the future generation of pain scientists, fully equipped to address unmet challenges within chronic pain. If successful, the research's goal is to deliver urgently needed non-pharmacological therapeutic concepts for chronic pain and build on fundamental scientific insights regarding the role of neuronal oscillations in the brain processing of pain. The DCs will be integrated in a one-of-a-kind network-wide training infrastructure conducting frontline research on non-invasive brain stimulation that targets persistent pain. PAE is an associated partner in the application, and - if the application is approved - will assist in the research dissemination and provide lived experience feedback.

**Tafalgie Therapeutics**: the innovative biopharmaceutical research company approached PAE in September 2023 with an invitation for a future partnership in grant applications (e.g., EU-funded, European Innovation Council Grant), presence on the clinical advisory board (PAE President Deirdre Ryan), and other long-term collaboration. More details will be available soon. More information on the company is available here: <https://tafalgie.fr/>.



**VITALITY** (Virtual Integrated Technology for Active Living and Improved Quality of Life Through Geriatric Screening and Prevention of Falls, Pain, and Social Isolation): the proposal was submitted for EU-funding in September 2023. The aim of VITALITY is to develop innovative and person-centred care, via a multi-entry platform system, for older adults (65+ years old). VITALITY will focus on personalised screening, prevention and rehabilitation of the three most impactful health conditions affecting this age group: injurious falls, chronic pain, and social isolation. PAE's involvement will require presence on the advisory board. The proposal's results are to be known mid-December 2023.

**Conclusion:**

As described, the Board intends to continue the reputation that PAE have earned so far and accomplish as much as possible for the benefit of people living with chronic pain. PAE realise that the goals are ambitious and with everyone's support, funding, and the Board's determination, PAE believe in every chance we have of making this a success.