



Member of the
European Parliament
**INTEREST GROUP ON
BRAIN, MIND AND PAIN**

EU ADVOCACY GUIDE

FOR NATIONAL NEUROLOGY ADVOCATES

BACKGROUND AND INTRODUCTION

At least 1 in 3 people will experience a brain disorder in their lifetime. The total annual cost of brain disorders in Europe is estimated to be around €800 billion each year. As life expectancy increases across Europe, the prevalence and cost of these conditions are anticipated to grow.



Neurological diseases were the largest cause of disability adjusted life years (DALYs) in 2015, making up 10.2% of global DALYs¹



Neurological diseases are the second largest cause of global death, leading to 16.8% of global deaths¹



Between 1990-2015, the number of deaths from neurological disorders increased by 36.7%¹

That is why the European Federation of Neurological Associations (EFNA), and its partners at Pain Alliance Europe (PAE), launched the MEP (Member of the European Parliament) Interest Group on Brain, Mind and Pain (BMP) disorders and the broader BMP initiative. It aims to identify and implement European Union (EU) and national policy solutions to tackle this growing burden.

Coordinated EU and national action must be taken in order to ensure that these policy solutions for people with BMP disorders are implemented in line with patients' preferences and that their meaningful involvement is enshrined, and supported, in all policy initiatives.

In addition to activity at EU and national level, it is also important for the BMP initiative to be placed within the wider context of healthcare priorities at the global level. Historically, neurological disorders have struggled to be included in initiatives on non-communicable diseases (NCDs). Now, with the global priority turning more and more towards NCDs, we need to ensure that neurology is part of this conversation – looking beyond the EU Institutions and to the WHO and the OECD, for example. It is also important that neurological health is integrated in the implementation of the Sustainable Development Goals addressing health and NCDs (SDG 3.4).

¹ The Lancet Neurology, Global, regional, and national burden of neurological disorders during 1990-2015: a systematic analysis for the Global Burden of Disease Study 2015, 2017, [www.thelancet.com/journals/lanneur/article/PIIS1474-4422\(17\)30299-5/fulltext#seccestitle80](http://www.thelancet.com/journals/lanneur/article/PIIS1474-4422(17)30299-5/fulltext#seccestitle80)

THE BRAIN, MIND AND PAIN INITIATIVE

The aim of the BMP initiative is to raise awareness of neurological (but also chronic pain and mental health) conditions in Europe, underpinned by a strong patient-centric approach intended to prioritise these disorders, encourage research, increase access to innovative treatment, improve quality of life and decrease stigma.



ABOUT THIS ADVOCACY GUIDE

This advocacy guide has been developed for patient advocacy groups and based on the Book of Evidence (BoE) of the BMP initiative, which outlines some of the key challenges facing people with neurological disorders and chronic pain conditions. By providing key messages and highlighting tactics for engagement with MEPs and other EU policymakers, this toolkit is designed to help you raise awareness and promote change for the benefit of people living with these conditions, as well as their families, carers and society as a whole.

KEY OBJECTIVES OF THE ADVOCACY GUIDE

- ✓ Outline the messaging of the BMP initiative on the key challenges faced by people with BMP disorders in the 2019-2024 EU mandate
- ✓ Provide policy recommendations to support targeted engagement with EU stakeholders in the 2019-2024 mandate
- ✓ Provide information on how to identify and engage with EU policymakers



Use this advocacy guide to inform your engagement with EU policymakers, to support people with neurological conditions in your country

THE ADDED VALUE OF EU LEVEL ADVOCACY

The engagement activities that this toolkit should enable you to undertake with EU level stakeholders add value and are complementary to your national work for the following reasons:

EU POLICY MATTERS AT NATIONAL LEVEL

Numerous health policy files at EU level will have direct implications for people with BMP disorders at national level. This covers policy in areas specific to health, such as EU cooperation in Health Technology Assessment (HTA), research, digital health, but also areas with a broader focus such as employment and social rights. In many cases, once a policy has been proposed by the European Commission and agreed amongst MEPs and the Council of the EU, it is the responsibility of Member States to implement the policy, which enters into EU law or non-binding policy recommendations

EU POLICYMAKERS HAVE A NATIONAL REMIT

Key actors at EU level have direct links to Member States, notably MEPs and health attachés in the Council of the EU. To demonstrate the significance of engaging these actors, we will provide examples of how the health policy focused activity of these actors at EU level has been reflected in national level debate and policy change

CAMPAIGN BUILDING AND AWARENESS RAISING

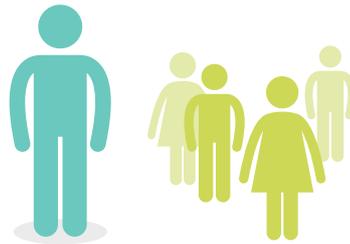
EU policymakers routinely contribute to pan-European campaigns at EU level. Such campaigns, which bring together national stakeholders from across Europe, promote the sharing of experiences and information which, in turn, may facilitate benchmarking and greater awareness of best practice examples that can inform and shine a light on national activity

KEY MESSAGES AND POLICY RECOMMENDATIONS FROM THE UPDATED BOOK OF EVIDENCE

This section of the advocacy toolkit outlines the headline messages of the BMP initiative's main policy document – our Book of Evidence – per thematic area. It will help you to discuss the key challenges and then tailor the content to your country/disease area.

Maximise your efforts by using your national expertise and additional resources such as the facts and figures document provided by EFNA

1 STIGMA, ISOLATION AND DISCRIMINATION



- » Most people living with BMP conditions experience some level of **stigma** owing to **a lack of public knowledge and misconceptions**, as well as a poor level of awareness amongst employers, educators and healthcare professionals regarding BMP disorders. This enhances the burden of BMP disorders on patients, their families and carers
- » Stigma and discrimination mean that **the true scale of BMP disorders is underestimated**, thus, the **prevalence and economic impact is not fully known** by policymakers, healthcare systems, payers and research funders, resulting in **insufficient national and EU budgets**, policies and initiatives dedicated to these conditions
- » The **stigma and discrimination** attached to long-term BMP disorders can seriously impact educational and employment opportunities in studying and working age citizens
- » People with epilepsy are **more than twice as likely to be unemployed as the general population**, but this varies considerably between countries: **in Poland, 49% of people with epilepsy are employed, compared to 77% in Germany²**
- » **Improving social attitudes** towards BMP conditions will not only reduce stigma and associated isolation and discrimination, but will be highly **cost-effective**

WE CALL FOR more public awareness initiatives at both EU and national level to increase the understanding and awareness of BMP conditions, reduce stigma amongst the general public, employers, educators and healthcare professionals, and showcase the benefits of prioritising neurological and other BMP disorders on national and EU agendas



WE COMMIT TO running regular awareness initiatives on the prevalence and impact of neurological disorders to improve public knowledge and social attitudes as well as raise awareness amongst employers, educators and healthcare professionals



Up to **eight out of ten** people affected by brain disorders remain untreated...



...even though **effective treatments exist** in many cases

2 EQUITABLE ACCESS TO TREATMENT, SERVICES AND SUPPORT



- » Large **health inequalities persist in the EU** and many patients do not receive timely diagnosis and access to effective treatment. An estimated **three to eight out of 10 people living with a brain disorder are inadequately treated** or untreated despite the fact that effective treatments exist³
- » Inequalities and limited access are linked to significant underfunding and suboptimal organisation of national health systems, clinical research programmes, and other systematic issues including HTA, reimbursement procedures and the lack of patient involvement in these processes
- » Ensuring equitable access to treatment, services and support is thus a key concern, together with **further investigation of patients' needs and treatment preferences**
- » Better **health service organisation** at national level, as well as **clinical research and HTA processes** both at the national and EU level would ensure better access to treatment, services and support

WE CALL UPON national and regional governments to assess access to healthcare in their health systems, specifically in regard to:



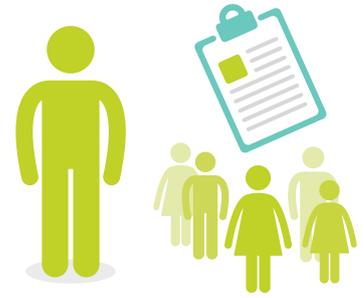
- Access to the right existing treatment at the right time, based on patient preferences
- The full recognition of the added value of innovative treatments, beyond purely clinical considerations, taking into account the socio-economic benefits of access to treatment
- The consistent implementation of guidelines on ensuring meaningful patient input in health policy, clinical research, regulatory matters and health technology assessment



WE COMMIT TO collecting and sharing good practice on ensuring equitable access to treatment in EU Member States – this includes the promotion and dissemination of National Brain Plans with the aim of supporting brain health, promoting brain research and improving the quality of and access to treatment and care, including rehabilitation

3

PROMOTE PATIENT EMPOWERMENT FOR INCREASED INVOLVEMENT AND ENGAGEMENT



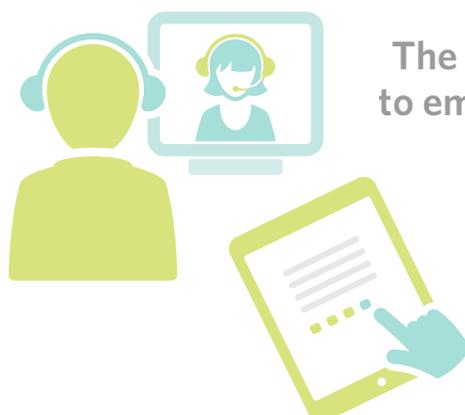
- » **Patients with chronic conditions such as BMP disorders are considered the most under-used resource in the health system.** Patient-centred care models contribute to better quality of care and potential long-term cost-effectiveness. Thus, **patient empowerment (better engagement and involvement in key areas such as research, HTA, policy and delivery of health services)** is vital to provide effective healthcare
- » **Patient involvement in policy discussions must be guaranteed** and any agreement must facilitate timely patient access to innovative treatments
- » The BMP initiative calls for a **“Horizon Europe” budget of at least €120 billion. Active patient engagement in the research funding proposals should be a key principle** and pre-requisite for successful funding policies
- » **Patient involvement is key to unleashing the potential of digital health.** Digital solutions can empower patients with BMP conditions to take control of their healthcare data, manage and personalise their care as well as interact with health-care professionals (HCPs) and other people with the same or similar conditions

WE CALL FOR EU level education and knowledge sharing programmes to support BMP patient empowerment and facilitate meaningful patient engagement and involvement in research and policy to ensure that any agreements on relevant EU policy and research funding:

- Reflect meaningful input from patients with BMP disorders
- Facilitate timely patient access to innovative treatment, services and support



WE COMMIT TO providing training to patients/patient advocates to make them better understand and engage in R&D, policy and decision-making and the self-management of their own disease, including increased digital literacy



The potential of digital solutions to empower patients to take more control over their care

ENGAGEMENT TACTICS



This section is intended to help you to deliver the key messages and pursue the calls to action above by identifying and engaging with policymakers. Although there are opportunities for engagement activities prior to the EU Elections in May 2019, meaningful and long-term relationships will most likely be established and maintained after the elections when EU policymakers mandate for 2019-2024 will be in place.

WHO'S WHO?

Mapping the right policymakers will enable efficient outreach and establish forward-looking, meaningful relationships. Find out who within the EU policy scene can be of valuable support to your advocacy efforts and follow relevant health policies, information and services.

MEMBERS OF THE EUROPEAN PARLIAMENT (MEPS)

The European Parliament is made up of MEPs elected in each of the Member States of the EU. They are allocated on the basis of the population of each Member State and grouped by political affinity. MEPs divide their time between their constituencies, Strasbourg (where 12 plenary sittings a year are held) and Brussels (where they attend additional plenary sittings, as well as committee and political group meetings). It is important for your engagement plans to identify and consider the constituency weeks when MEPs go back home and work on national matters.

Find out who your MEPs are at www.europarl.europa.eu/meps and check the European Parliament 2019 calendar at www.europarl.europa.eu/ireland/en/european-parliament-calendar

THE EUROPEAN COMMISSION

The European Commission is the EU's politically independent executive arm. It alone is responsible for drawing up proposals for new European legislation, and it implements the decisions of the European Parliament and the Council of the EU. The Commission is the sole EU institution which tables laws for adoption by the Parliament and the Council. It also manages EU policies & allocates EU funding, enforces EU laws and represents the EU internationally. The European Commission is divided into specific departments (DGs) and External Agencies which deal with specific policies.

THE COUNCIL OF THE EUROPEAN UNION AND NATIONAL PERMANENT REPRESENTATIONS TO THE EU

The Council of the EU is the institution representing Member States' governments. It is where national ministers from each EU country meet to adopt laws and coordinate policies. The presidency of the Council rotates among the EU Member States every 6 months. During this 6-month period, the presidency is responsible for driving forward the Council's work on EU legislation, ensuring the continuity of the EU agenda, orderly legislative processes and cooperation among Member States. Policy discussions in the Council are split into two committees: COREPER I and COREPER II.⁴ For health-related matters, COREPER I is the relevant committee.

Contact details for your Permanent Representative and COREPER I can be found at www.europa.eu/whoiswho

NATIONAL HEALTH ATTACHÉS

Health Attachés are the civil servants working within the Permanent Representations of the Member States to the European Union and focusing on health-related matters. Establishing a relationship with your national health attaché is a good opportunity to raise awareness of issues facing people with BMP disorders in your country, using the messaging above, and pursue potential policy recommendations at EU level/policy implementation at national level. Consider engaging as well with other attachés dealing with fields such as research and employment.

Use WHO IS WHO as a useful search tool available in your language to get familiar with the European Institutions and identify the right people with whom to engage www.europa.eu/whoiswho

⁴COREPER stands for the 'Committee of the Permanent Representatives of the Member States of the European Union'

KEY ACTIVITIES

POST EUROPEAN ELECTION CORE ENGAGEMENT ACTIVITIES

Map the right policymakers and **investigate who** within the EU policy scene can be of a valuable support to your advocacy efforts. Consider EU core institutions for your engagement activities:

EUROPEAN COMMISSION

- **Monitor open policy files** and **current works in the area of health** at www.ec.europa.eu/info/departments/health-and-food-safety
- **Identify opportunities in the calls for open public consultations** – when the European Commission reaches out to EU citizens to consult health-related policy files. Find out more at www.ec.europa.eu/info/law/contribute-law-making
- **Consider participation in one of the EC's working groups** and contribute to assessing policy proposals – stay in touch with EFNA who may be aware of the latest openings
- **Launch a European Citizens' Initiative**
Find out more at www.ec.europa.eu/citizens-initiative/public/welcome
- **Make a formal complaint** if you think EU law is not being applied properly in your case. Find out more at www.ec.europa.eu/info/about-european-commission/contact/problems-and-complaints but also consider sharing things you appreciate about the EU and the effect that health policies might have on you or those in your surroundings. While engaged with your national MEPs, encourage them to pose a written question to the EC addressing major challenges faced by people with BMP disorders. Be prepared to draft the question for them

EUROPEAN PARLIAMENT

- **Find out** who your national MEPs are and their contact details at www.europarl.europa.eu/meps
- **Connect with them** on social media and sign up to their newsletters
- **Check the European Parliament agenda** to identify constituency weeks, ie the weeks in which MEPs concentrate exclusively on the activities in their home countries and plan engagement activities accordingly at www.europarl.europa.eu/ireland/en/european-parliament-calendar
- **Find out** who of your national MEPs have an interest in health-related topics or other relevant policy hooks
- **Identify neurology champions** on specific issues and share with the EFNA network
- Think of ways to **engage them in your work** (eg raising awareness by distributing key messages, establishing national platforms, developing Declarations of Support)
- **Thank and publicly acknowledge** any expressions of interest/support
- **Engage other patient and stakeholder groups** nationally and at the European level – think how you can weave your policy priorities/asks into their broader agendas
- **Build a two-way exchange of information** with organisations such as EFNA to ensure that you can leverage EU level policy in your national work, and vice-versa
- **Secure a pledge** from MEPs in a key messages document



THE COUNCIL OF THE EUROPEAN UNION AND ITS STAKEHOLDERS

- **Identify your National Permanent Representation to the EU** – the body which has a direct impact on the Council's decisions and has the ability to put major national issues on the EU agenda
- **Find out who the National Health Attachés are**, as these are the policymakers that influence health-related files driven by the Council – **engage** with them, **present the importance of the BMP initiative** and **address the need of support** required by the BMP community
- **Monitor and leverage the Council Presidency** which rotates amongst the Member States every 6 months (currently Romania followed by Finland, Croatia, Germany etc). To find out when your country holds the Presidency, please visit www.consilium.europa.eu

ADDITIONAL OPPORTUNITIES PRIOR TO THE EUROPEAN ELECTIONS

- **Identify and contact prospective candidates** by leveraging the ongoing political campaigns ahead of the European elections to engage with your local policymakers to secure concrete pledges to advocate for the BMP community at EU and national level
- **Use supporting documents** to help outline key challenges to candidates
- **Collaborate with other relevant national campaigning organisations and professional groups** to ask about their experiences and recommendations for improving outcomes for BMP patients
- **Share knowledge and objectives.** National advocates are encouraged to communicate with each other and EFNA regarding their links with national MEPs, other policymakers and their priorities

ADDITIONAL RESOURCES TO HELP MAXIMISE ADVOCACY EFFORTS

Website of the MEP Interest Group on Brain, Mind and Pain: An initiative of the European Federation of Neurological Associations (EFNA) and Pain Alliance Europe (PAE), currently co-chaired by MEPs M. Harkin, J. Lenaers and D. Sârbu
www.brainmindpain.eu

The Book of Evidence on Brain, Mind & Pain
www.brainmindpain.eu

Key messages document for policymakers based on The Book of Evidence on Brain, Mind & Pain
www.brainmindpain.eu

The Council's Directive on Establishing a General Framework for Equal Treatment in Employment and Occupation
www.eur-lex.europa.eu

The European Social Fund – EU's main tool for promoting employment and social inclusion
www.ec.europa.eu/social

The European Pillar on Social Rights
www.ec.europa.eu/social

The European Parliament's database for monitoring the EU decision-making process
oeil.secure.europarl.europa.eu/oeil

The European Parliament's Public Register of Documents
www.europarl.europa.eu/RegistreWeb

The Council's Public Register of Documents
www.consilium.europa.eu/en/documents-publications