EFNA
EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

MEP INTEREST GROUP ON BRAIN, MIND AND PAIN

2018 PROJECT PROPOSAL

BRAIN MIND PAIN
Member of the European Parliament Interest Group

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INTRODUCTION

In 2015, EFNA – along with our partners at Pain Alliance Europe – launched a Member of the European Parliament Interest Group on Brain, Mind and Pain.

This group is scheduled to run over the course of the current parliamentary term and the aim is to allow us to contribute to the innovative, efficient and sustainable health systems as desired by the European Institutions; by providing a forum to share and exchange best practice, encourage debate and discussion, and lead to tangible actions in the areas outlined in the Interest Group mission statement:

> *To encourage research into and access to innovative treatments, promote prevention and self-management approaches, decrease stigma and work together to improve quality of life for people living with these disabling conditions.*

The group is co-chaired by MEPs Marian Harkin, Jeroen Lenaers and Daciana Sârbu, with almost 50 additional MEPs already signing a Register of Supporters. For more information you can access the Interest Group website at: www.brainmindpain.eu

The Interest Group covers topics as set out in our 'Book of Evidence'. Data for this document was collated via literature reviews, focus groups with national and pan-European patient organisations, interviews with industry, health professional and other stakeholder groupings, etc. The Book of Evidence (which can be downloaded from the website: https://goo.gl/zv0CDG) is divided into 4 pillars:

1. **Stigma – Visible and Invisible**
2. **Improving Investment in Research**
3. **Patient Involvement**

BRIEF SYNOPSIS OF PROGRESS TO DATE

The below is a brief overview of some of the progress in our work to date, since the group was launched in 2015. Should you require further information do get in touch. An annual report of the activities of the group in 2017 is currently in production and will be available at the next MEP Interest Group meeting in February 2018.

- **Nine meetings in the European Parliament with an average attendance of 40-50 participants from a multi-stakeholder background.**
- **Over 50 MEP supporters for the Interest Group – as well as Commissioner Andriukaitis, who met the group and issued a statement of support.**
- **Launch of a Written Declaration, supported by almost 180MEPs on access to employment.**

- **Submissions to consultations on European Social Pillar, EU Cooperation on Health Technology Assessment, etc.**
- **Accepted amendments to the EU Strategic Framework on Health and Safety at Work and the Joint Statement on Employment for People with Chronic Diseases.**
- **Over 50 MEPs actively engaged in the launch, at the Parliament, of an EFNA pan-European awareness campaign 'Together Under the Umbrella'- arising as an action point from our meeting on stigma where the need to raise awareness was stressed.**
- **Launch of EFNA's Training Initiatives for Neurology Advocates as an attempt to better enable patient involvement in decision-making – as discussed by the group.**
- **Development of partnerships with other organisations to provide solutions to the challenges raised at interest group meetings e.g. support for the European Brain Council's Call to Action for EU National Brain/Plans, political dissemination of their Value of Treatment white paper, endorsement of their Consensus Document on Brain Research, etc. Also, support to the European Patient Forum's campaigns on access and empowerment.**
- **Increased opportunities to work closely with colleagues at GAMIAN -Europe (Global Alliance of Mental Illness Advocacy Networks-Europe), as well as with the European Academy of Neurology and European Pain Federation who co-hosted a 2017 meeting.**
- **Provision of a policy platform for our members and partners to highlight their concerns, work and examples of best practice.**
- **Representation by the group at external events and high-level meetings.**

PLANS FOR 2018

MEETING 1: YOUNG PATIENTS - #LIFEGOALS vs. #POLICYPRIORITIES

The first meeting of 2018 will focus – for the first time – directly on young people living with neurological disorders and chronic pain conditions.

During the EFNA Annual Partners' Meeting in summer 2017, there was consensus that patient organisations, policy makers and other stakeholders often overlook the needs of young patients – with priority often directed to the ageing population. Additionally, much of the advocacy work of the MEP Interest Group in 2017 looked at issues which affect young people: early intervention, access to employment, social rights, etc. Therefore, this meeting will bring together these strands of our past advocacy to explore policy solutions to the issues identified by young patients in Europe. This will include implementation of current EU social legislation, for example – the European Social Pillar.

As an outcome of this meeting, EFNA plans to launch a survey to assess the needs of young patients, raise awareness of these and build towards a political campaign in 2019 when the newly elected Parliament takes it seat.

MEETING 2: OPTIMISING PATIENT RELEVANT OUTCOME MEASURES FOR SUSTAINABLE HEALTHCARE SYSTEMS AND STRONG ECONOMIES

The second meeting will look at how Patient Relevant Outcome Measures can be better integrated into EU funded research but also into regulatory processes and HTA decision-making. This will build on ongoing EFNA work which is mapping neurology patient engagement in HTA in six European countries – but also the EU Commission's report on EU cooperation in HTA.

Representatives from the EMA, EUnetHTA and European Commission will be invited to explain how they are better capturing PROMs, and how this practice can be extended to the national level. This will be supplemented by presentations from the patient perspective on 'What matters most to me?'

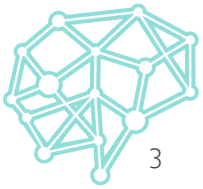
The outcomes will be used to advise EFNA's work in advocating for more meaningful patient involvement in policy and decision-making, and to inform its empowerment agenda.

MEETING 3: WHAT DOES THE FUTURE HOLD FOR ME? *PERSPECTIVES FROM THE FIELD OF NEUROLOGICAL DISORDERS AND CHRONIC PAIN CONDITIONS*

The final meeting of 2018 will be an opportunity to reflect on the work of the MEP Interest Group since its inception, as we move into the final six months of the current parliamentary term. This meeting will be used to set the advocacy agenda for the group, as it plans to relaunch with the newly elected Parliament in 2019. All stakeholders will be invited to participate in this interactive and lively session, which will explore how EU policy can be used to improve the lives of those with neurological disorders and chronic pain conditions today and in the future.

The outcomes will be used to shape a political campaign in 2019 on the issues affecting young people with neurological disorders and chronic pain conditions.

The event will coincide with EFNA's advocacy awards and an EFNA workshop for young patient advocates.



ESTIMATED COSTS 2018

€24,000	Costs of Secretariat Incl. Senior Policy Officer – MEP Interest Group Coordinator (Annual Salary)
€15,000	Cost of Interest Group Meetings (€5000 x 3 - Provisionally: February, June and November - incl. speaker expenses, catering, photographer, advertising)
€3,000	Funds for additional Planning Meetings
€3,000	Funds for Printing/Communications Activities/etc.
€5,000	External Representation at Partner Events (e.g. Societal Impact of Pain Symposium, medical congresses, member events, etc.)

€10,000 EFNA 20% administrative cost

TOTAL €60,000

A piece of research arising from an Interest Group Meeting may be commissioned should additional/ sufficient funds be received.

FUNDING/LEVELS OF SPONSORSHIP

A consortia of three industry partners has been approached for sponsorship of this initiative. Benefits will include:

- **Company's name and logo on the website: www.brainmindpain.eu.**
- **Invitation to attend and participate in each meeting of the Interest Group at the European Parliament**
- **Opportunities to contribute to the associated publications being produced to support the work of the Interest Group**

CONTACT: Heather Clarke, EFNA Senior EU Policy Officer, coordinates the group and is tasked with advancing the workplan between meetings. She can be contacted at: euaffairs@efna.net.