



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

Annual Report 2015

BMP ANNUAL REPORT 2015

The Member of the European Parliament Interest Group on Brain, Mind and Pain works:

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 European Federation of Neurological Associations (EFNA) and Pain Alliance Europe seek ways to influence policy and achieve concrete outcomes over the course of the current European Parliamentary term. To take this forward we launched the European Parliament the Interest Group on Brain, Mind and Pain in late 2014.

We were delighted when MEPs Marian Harkin, Jeroen Lenaers and Daciana Sârbu, agreed to be our co-chairs and almost 50 MEPs signed our Register of Supporters. For more information you can access the Interest Group website at: www.brainmindpain.eu



Daciana Sârbu MEP



Jeroen Lenaers MEP



Marian Harkin MEP

Our aim is to contribute to innovative, efficient and sustainable health systems 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 above.

From the outset it was important to provide a sound policy base and work towards positive policy outcomes. The Book of Evidence was commissioned by EFNA & PAE in order to inform and support the activities of the MEP Interest Group. It summarises evidence in four focus areas, along with case studies of positive activities from around Europe, and recommendations for action. The 'Book of Evidence' outlines why brain disorders must be a political priority. Data 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, is divided into 4 pillars:

- » **Stigma – Visible and Invisible**
- » **Quality of Life – Education and Employment**
- » **Improving Investment in Research**
- » **Patient Involvement**



Left: Joop van Griensven, President Pain Alliance Europe with Vytenis Andriukaitis the EU Commissioner for Health and Former EFNA President Audrey Craven

Below: Meeting MEP Cora van Nieuwenhuizen in Strasbourg



After the official launch event a subsequent meeting in the European Parliament focussed on Health Promotion and Prevention. Dr Jenny Barnett revealed that many neurological disorders which are deemed ‘unpreventable’, can be prevented – at least in part – through simple lifestyle modifications. She used the example of Alzheimer’s Disease in which approximately 50% of the risk of developing the disease is attributable to seven modifiable risk factors. This was supported by Prof. Wolfgang Oertel of the European Academy of Neurology who said that good sleep patterns – for example – could not be underestimated, and supported Dr. Barnett’s call for more education and awareness raising of these facts. Both emphasised the need to target young people, saying many of these diseases begin to develop during our youth, even if they do not obviously manifest until later life. References to the papers/research cited above, along with additional information, can be found in the attached presentation, available here: <https://goo.gl/L5056n>

Left to right: Prof. Giustino Varrassi, Dr Jenny Barnett, Audrey Craven, and MEP Damian Dragichi



Prof. Giustino Varrassi of the European League Against Pain then explained ways in which musculoskeletal disorders could be prevented, with a focus on the workplace – again through mostly simple, low-cost adaptations. Full presentation also available here: <https://goo.gl>

STIGMA

Stigma is another issue which unites many patients, not least those with mental health issues and for our next meeting we joined up with the Interest Group on Mental Health, Wellbeing and Brain Disorders. Following some powerful patient testimonies neurologist Prof. Matilde Leonardi informed the audience of the outcomes of a Patient Experience Survey of almost 5,000 patients.

One of the main findings was that 57% of the sample feels stigmatised at least occasionally and persons who think that their condition should have been diagnosed earlier perceive a significant higher workplace and social stigma and a worse overall well-being compared to persons who think that their condition was diagnosed on time.

Stigma is an old Greek word, and the figurative meaning of stigma is a mark of disgrace or infamy. Stigma and lack of public knowledge worsen the burden on patients and families by preventing people from seeking treatment and causing social exclusion.



MEP Nessa Childers and EFNA President Ann Little
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Michael Hübel, (European Commission, DG SANTE) underlined that if we want to truly tackle the issues around chronic disease, we need to look at mental as well as at physical health.

'Three quarters of EU health care cost are related to chronic disease and the proportion of brain disorders and mental health conditions within this is huge. This does not only relate to the direct costs of the conditions, but also to indirect costs, due to long term absence and early retirement. If awareness of these facts does not increase and if policy makers and service providers cannot be convinced that this is a serious issue, a situation where people will not reach their full potential will continue.'

'Stigma is a very important aspect in this respect. It often relates or leads to outright discrimination. There are several tools, such as the Convention of the Rights of People with a Disability, to which the EU has signed up. The Commission's Mental Health Pact, the Joint Action on Mental Health and the work carried out to address mental health in the work place are all useful actions taken by the EU level.'

'The workplace would seem to be an ideal setting to promoting mental health and well-being, because so much time is spent there. In terms of the organisation of health services, the general trend towards community care based services should be seen as an opportunity to bring mental and physical health services together. However, the philosophy upon which these services are based will determine how they deal with and combat stigma. Brain disorders can be prevented and we need more investment in policy and research.'

We were delighted the European Commission's message resonated with ours.

A POLICY OUTCOME

The workplace, therefore, was a common theme of all meetings in 2015 and thus – as an outcome – we contributed to the EU Strategic Framework on Health and Safety at Work report. We were delighted the amendment we worked on was passed on 25 November. It *'draws the attention of the Commission to the increased number of workers affected by chronic illness in the workforce; takes the view that accessible and safe jobs should be available for people affected by terminal illnesses, chronic and long-term conditions and disability; urges the Member States to focus on retention and integration of people affected by chronic diseases as well as to support reasonable adaptation of workplaces, which will ensure a timely return to work; calls on the Commission to promote integration and rehabilitation measures for people with disabilities and to support Member States' efforts by raising awareness and identifying and sharing good practices on accommodations and adjustments in the workplace;*' The report will be passed to the Council and the Commission. We are grateful for the support of MEPs Harkin, Willmott and Lenaers throughout.

BUILDING ON 2015 SUCCESS

On February 24th 2016 the Interest Group meeting will focus on Neurological and Chronic Pain Disorders at Work. Here we will present a Written Declaration on access to education/employment for those affected by brain, mind and pain disorders – which will be launched from March. If successful, we will work on a toolkit for its dissemination across the member states.

STIGMA... NEXT STEPS

THE FUTURE

- » The Interest Group plans to host a pilot event on public awareness and education in Romania in 2016. If successful we would like to see a series of multi-stakeholder roundtables roll out across the EU and would look to work with the European Commission on this.
- » The Interest Group will work with other stakeholders in the field in ongoing and future activities around self-management and patient empowerment e.g. European Patients Forum.
- » The Interest Group will work with partners, e.g. the European Brain Council, to build support for research to ensure that we can extend success to date in preventing certain chronic pain and neurological disorders. We will strive to ensure patient focus and involvement in initiatives by working with/in project consortia in this field, wherever possible.

DATES FOR YOUR DIARY:

**24 February BMP Interest Group Breakfast Meeting,
European Parliament, Brussels**

**Focus on the Workplace – we will launch a Written
Declaration on the topic of brain and pain disorders in the
workplace.**

**15/16 March Launch ‘Together Under the Umbrella’
during Brain Awareness Week, European Parliament,
Brussels**

**22 June BMP – Patient Involvement in Research –
European Parliament, Brussels**

**Autumn BMP – ICD-11 (TBC) European Parliament,
Brussels**