



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

Launch Meeting Report

February 24, 2015 from 18.00 – 20.30hrs
Thon Hotel EU, Rue de la Loi 75, B-1040, Brussels, Belgium

- *An initiative of the European Federation of Neurological Associations [EFNA] and Pain Alliance Europe [PAE], co-chaired by MEPs Marian Harkin, Jeroen Lenaers and Daciana Sârbu.*

Opening the meeting **co-chair MEP Marian Harkin** outlined that 1 in 3 Europeans are affected by a brain disorder and 1 in 5 by chronic pain. The annual cost of brain disorders in Europe is EUR 800 billion – this is 6% of GDP. The cost of chronic pain could add a further 3% of GDP. However, she highlighted that public awareness, research and funding for these disease areas is not equivalent to the burden and impact. In fact, public research funding for brain disorders equated to only 0.2% of the cost, with the industry investing just a further 0.8%. Something must be done now, she said, before this problem becomes too difficult to handle – including putting these issues onto the political agenda at an EU and Member State level.

EFNA President Audrey Craven said she hoped the Interest Group could be the vehicle through which this happened and outlined the aim of the Interest Group, which is 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 Interest Group will focus its workplan under four pillars: Stigma, Quality of Life, Research and Patient Involvement. Based on these topics it calling on European policy-makers – via the Institutions and Members States – to:

1. Support patient-led campaigns to educate, eradicate stigma and raise awareness of neurological and chronic pain disorders
2. Support research into the development of innovative prevention and treatment options within a regulatory framework which facilitates equitable access to affordable therapies
3. Strengthen patient involvement in this research, and in policy-setting and decision-making
4. Implement relevant European social legislation to ensure appropriate support for people living with neurological and chronic pain disorders

She then read a statement of support from **Health Commissioner Andriukatis** who said he welcomed the intention of the Interest Group on Brain, Mind and Pain to focus on supporting concrete action. ‘Today’s presentation of the “Book of Evidence” is an important step to map priorities for action and to launch a call for action,’ he said, ‘This is indeed what Europe is about:

Identifying what works in one part of the EU, sharing knowledge, encouraging and supporting evidence-based policies.’

Ms Craven said that the Interest Group was to be a ‘working group not a talking shop’ and that each subsequent meetings would have a specific topic which would end with concrete conclusions/recommendations and measurable outcomes. She also stressed the desire of the Interest Group to work with other related groups in the sector towards common goals. This was supported by Pedro Montellano, President of GAMIAN (who run the MEP Interest Group on Mental Health and Wellbeing) in a comment from the floor.

She then launched the aforementioned Book of Evidence which outlines why neurological and chronic pain disorders should be a political priority – with exemplars and case-studies of replicable good practice. This can be accessed at www.brainmindpain.eu

The next speaker was **co-chair MEP Daciana Sarbu**: ‘I am especially convinced of the need for preventive measures and information campaigns for the general public. Some of these disorders can be prevented with the right lifestyle choices’ she said. ‘Prevention is an important part of health care policy, along with research, access to treatments, and patient involvement. I believe that health care policies which give due consideration to prevention are the most effective for patients, and the most cost-effective for national healthcare systems.’

MEP Sarbu will host the next Interest Group meeting on June 24th 2015. This will focus on Health Prevention and Promotion and will explore raising awareness of common risk factors (e.g. obesity, poor nutrition, smoking, sedentary lifestyles, etc.), outlining what can be done at an EU-level and strategies for rolling out awareness campaigns on this topic in the EU Member States. The Commissioner has been invited to give the keynote address.

Also, prevention was one of the key focusses of the next presentation from **Prof. Wolfgang Oertel** of the European Academy of Neurology who said that with sufficient commitment – including adequate funding – many neurological disorders, for example Parkinson’s Disease, could be pre-empted and treated.

He also called on the European Institutions to:

1. Undertake a benchmarking exercise to assess current neurological infrastructure in Europe
2. Develop a plan to implement acceptable standards of neurological services and care
3. Routinely compare new and existing healthcare structures, diagnostic tests as well as treatments before rolling them out across Europe
4. Find ways to attract and retain the best young European clinicians and scientists for brain research and brain health

Joop van Griensven, a chronic pain patient and President of Pain Alliance Europe spoke from his own personal experience of the impact of living with an invisible disorder and the need for ‘The Right to be Believed’ to become a central focus if we are to eradicate stigma around chronic pain and neurological disorders. He also spoke about the impact of his disorder on his working life and stressed the need for European social legislation to be implemented to ensure that those affected by these disorders are not stigmatised and socially excluded.

A meeting on the topic of stigma and social inclusion will be held on October 14th. Here representatives of patient groups will be invited to highlight examples of where EU social legislation is not being implemented which leads to stigma and social exclusion. These exemplars will be taken forward by our MEP supporters in the form of written questions, etc.

The industry perspective was presented by **Eva Grut Aandahl of Pfizer**. She said that the combination of access and scientific challenges makes this a difficult area to invest in at present. For this reason, sustained and effective public funding is needed for basic research that continues to increase our understanding of these diseases – both via EU research funding from Horizon 2020 and via coordinating the activities of member states.

Nevertheless, she said the Innovative Medicines Initiative [IMI] was an example of an initiative supported by the European Commission which allowed companies to continue to invest in searching for new therapies that can help improve people's lives. She illustrated this point by referencing the working of the Pfizer Neusentis lab in Cambridge: <http://www.imi.europa.eu/content/stembanc>

She said the research outlook has another bright point on the horizon: increasing engagement with patients and patient organisations in the design and conduct of clinical trials. This is particularly important in neurological and chronic pain conditions, where symptomatic relief often has to be reported by the patient rather than objectively observed by a physician. However, she stressed that policymakers have a role in enabling active patient involvement though ensuring patient organisations have a supportive environment in which to work in.

The discussion and debate session was chaired by **Maggie Alexander, Chief Executive, European Multiple Sclerosis Platform**. She invited **Catherine Berens, Head of Sector Neuroscience at DG Research and Innovation** to take the floor to speak about current and prospective research in these disease areas. Here comments will be made available on: www.brainmindpain.eu as it is developed in the coming weeks. Other comments from the floor included the need for healthcare policy to be more closely intertwined with social and economic policy. This was addressed by **co-chair MEP Jeroen Lenaers** who will *host the third meeting of the MEP Interest Group in early 2016 to coincide with the Dutch Presidency of the EU and will focus on Employment and Social Affairs issues facing those affected by chronic pain and neurological disorders – and will pick up on the results of the October meeting and any responses received to the written questions.*

NEXT STEPS

- **Following the launch, each of the three MEP co-chairs will now take responsibility for hosting a meeting on a particular topic contained in the Book of Evidence and in line with their parliamentary priorities (see topics and dates above).**
- **These will be targeted, interactive and focussed meetings with the aim of identifying measurable outcomes and developing a workplan to reach these identified goals. We are currently inviting interested parties to send us an expression of interest in participation or to submit agenda items, suggested speakers, etc.**
- **Meetings on these topics will be replicated annually allowing us to assess progress and set further milestones.**
- **We also invite other groups in the field to express an interest in partnership/collaboration.**
- **The group is coordinated by a fulltime Policy Officer, Heather Clarke, who is tasked with advancing the workplan between meetings. She can be contacted at: euaffairs@efna.net**