



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

Annual Report 2016

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Unless otherwise stated further information and links can be found at the Brain, Mind and Pain website:
<http://www.brainmindpain.eu>

You can also contact Heather Clarke, EFNA's Senior EU Policy Advisor at: euaffairs@efna.net

Brussels
8 March 2017



Dear MEPs, Dear Colleagues,

We are pleased to present the second Annual Report of the Member of the European Parliament Interest Group on Brain, Mind and Pain.

The Interest Group is coordinated jointly by the European Federation of Neurological Associations (EFNA) and Pain Alliance Europe (PAE). So many pain conditions are neurological in origin and so many neurological conditions feature pain as one of the most disabling symptoms.

The Interest Group also brings together MEPs and health policy makers across political divides and drawn from many institutions to work collaboratively on the issues outlined in our Book of Evidence: stigma, quality of life, research and patient involvement. It also provides a platform for our members, partners and key opinion leaders to meet, discuss and devise recommendations to overcome the challenges faced by the patient community we represent.

Our work would not be possible without the help of our three MEP co-chairs Marian Harkin, Jeroen Lenaers and Daciana Sârbu, grateful thanks go to them and their staff. Thanks also go to the additional MEPs who support our work, especially those who co-authored and signed our recent Written Declaration on Access to Employment.

More on our meetings and associated initiatives plans can be found throughout this document – encapsulating the busy and successful year that was 2016. We hope you find it valuable and interesting.

Ann Little, *President EFNA*

Joop van Griensven, *President PAE*

BMP ANNUAL REPORT 2016

The European Federation of Neurological Associations (EFNA) and Pain Alliance Europe (PAE) seek ways to influence policy and achieve concrete outcomes over the course of the current European Parliamentary term.

Since late 2014 we have provided a policy platform for our members and partners to highlight their concerns, work and examples of best practice via the Brain, Mind and Pain Interest Group.

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.



2016 was a busy year for the Brain, Mind and Pain Interest Group with four open meetings in the European Parliament, bi-lateral meetings with dozens of MEPs and a huge call for MEP signatures to support improvement of access to employment for those affected by neurological disorders and chronic pain conditions.

Our European Parliament meetings are informed by our members demands as outlined in our Book of Evidence. Data for the Book of Evidence was collated via literature reviews, focus groups with national and pan-European patient organisations, interviews with industry, health professionals and other stakeholders. The conclusions are taken to current EU policy files, see page 11, chapter 7.

Much of our work in 2016 focussed on the issue of employment. For many of our members the biggest effect of their disorder is its impact on the education and employment of themselves and their family.

‘Work impacts on social cohesion and on people’s quality of life. Thus, identifying first and then caring about workers with neurological disorders could benefit employers, thanks to tailored interventions. A healthier work environment can be a facilitator, and not a barrier, in helping to prevent increases in the levels of disability experienced by people affected by neurological disorders’.

DR. CHIARA SCARATTI, THE BESTA NEUROLOGICAL INSTITUTE, ITALY.

ACTIVITIES

1.

MEETING: Neurological and Chronic Pain Disorders at Work February 2016, European Parliament, Brussels

Jeroen Lenaers MEP opened the first meeting of 2016 saying that those affected by neurological and chronic pain disorders were at a 'double disadvantage' in terms of access to employment and education. He said the debilitating symptoms and side-effects of treatment can mean that for these patients it can be difficult to find and then remain in employment. Additionally, those who are successful then need to, not only contend with their condition, but also the stigma and social biases that it can create.

'Even minor adjustments to the working environment can help to combat the issues'. He drew the audience's attention to an amendment which he and our co-chair Marian Harkin put forward on our behalf to the EU Strategic Framework on Health and Safety at Work.



Jeroen Lenaers MEP



Who is most at risk of experiencing difficulties and stigma at work due to a neurological disease?

- Women
- Younger than 50
- Disease duration longer than one year
- Middle-low educational level
- Affected by a neurological disease causing pain

The slide features a graphic of several blue human figures standing around a central red sign that says 'RISK' in white letters.

A slide from the presentation by Dr. Chiara Scaratti

Dr. Chiara Scaratti of the Besta Neurological Institute, Italy then presented the results of a survey conducted by the European Federation of Neurological Associations [EFNA], which had almost 5000 responses from across Europe, covering a wide spectrum of brain disorders. The analysis of these results showed that stigma in the workplace was a common problem encountered by those living with neurological disorders. The paper was subsequently published in the prestigious European Journal of Neurology: <http://onlinelibrary.wiley.com/doi/10.1111/ene.13237/full>

Prof. Dr. Michiel Reneman of the University of Groningen called for the European Institutions to promote Vocational Rehabilitation, which he described as 'whatever helps people to return to work or stay at work'. He made a plea for health and employment departments at local, regional, national and European level to work together – rather than in silos.

Karin Hellsvik presented a case-study from Biogen Italy who had hired a person affected by multiple sclerosis [MS] as part of an internship programme – Believe and Achieve – coordinated by the European MS Platform. She said their biggest learning was that internal HR policies can inadvertently lead to a person being 'labelled', and over-compensating for stigma can exacerbate the problem.

Jane Whelan, a person affected by severe migraine, spoke about the impact that her disorder had on her career progression but outlined minor workplace modifications e.g. flexible working hours, regular breaks, extra time for travel, etc. which helped to ensure she could better prevent attacks and manage them when they occurred (as outlined in the amendment above). However, she said that disclosure to her boss and colleagues was necessary to ensure these adjustments were put in place and that the 'invisible' nature of the condition often led to scepticism, even amongst those who were aware of her diagnosis.

Finally, we heard from Matthijs Groenveld, attaché to the Dutch EU Presidency. He said that employment issues were at the heart of the European political agenda, and emphasised that a socially inclusive labour market was needed if we are to have a pan-European, job-rich economic recovery.



Jane Whelan (image from Twitter.com)

2.

MEETING: Patient Involvement in Research – How and Why those with Brain, Mind and Pain Disorders must be involved

June 2016, European Parliament, Brussels

‘Investment in research into neurological and chronic pain disorders is decreasing although incidence is rising’

DONNA WALSH, EFNA EXECUTIVE DIRECTOR

Marian Harkin MEP, introduced our June breakfast meeting by stressing how crucial it is that the huge challenges posed by brain and pain disorders are addressed through integrated, coordinated and co-operative efforts, both at the European and national level.



Marion Harkin MEP

Donna Walsh, EFNA Executive Director, reminded the audience that research was a central focus of the Interest Group. She stressed the huge unmet needs of patients affected by brain, mind and pain disorders. More research is needed – from basic to clinical to translational. However, due to the complexity of this research, the high failure rates and the lengthy development times (compared to other disease areas), many companies are downsizing or closing their operations in this area. She called for the EU to ensure that public funding through H2020 and the IMI ensured that they bridged this gap.

She also asked the EU to ensure that meaningful patient involvement was a feature of successful funding proposals. This is particularly important in brain, mind and pain disorders.

The next speaker – Isabelle Abbey-Vital of Parkinson’s UK – spoke about the UK system of patient and public involvement [PPI] as an example of best practice. She said, that while many researchers are open to patient involvement, they are not always sure where to start. This led to the development of Parkinson’s UK ‘Resource for Researchers’ which outlines how and why they should engage in PPI. In summing up, she called for:

- » **More emphasis on patient involvement in funding calls for research proposals**
- » **Increased availability of guidelines and training on patient involvement from the EU to researchers applying for grants**
- » **Improved support for patient organizations to facilitate involvement**



Further information from [The Parkinson’s UK website](#).

Prof. Judith Rosmalen of the University of Groningen, said that medical research is traditionally focused on diseases, but how we feel is determined by symptoms. Most symptoms remain medically unexplained, and many EU citizens live with their symptoms every day. She worked with her team to develop an eHealth system called Master your Symptoms, which will provide patients with personalized self-help guidance to manage their symptoms.

In the context of this project, the researchers asked professionals what interventions they considered most useful for

patients. They also asked patients what interventions they preferred. It was then discovered that the ideas of the professionals did not meet the patients' needs. One aspect which was particularly emphasised from the patients was the need for better communication with health care professionals.

Now, researchers are developing an online course to train professionals in communication with patients with medically unexplained symptoms. To ensure the patient perspective is heard throughout this project, Pain Alliance Europe will be actively involved.

Rachel Schindler MD, Vice-President, Neuroscience at Pfizer began by stating that there are many opportunities for bilateral exchange of information between patients and drug developers throughout the drug development process. She called on EU policy-makers to ensure that barriers are overcome to ensure that we:



Prof. Judith Rosmalen

- » **Involve patients early from product concept through clinical development, regulatory approval, and the product lifecycle**
- » **Enhance the patient experience in clinical development**
- » **Ensure medicines that are developed meet patient needs**

This involvement has multiple potential benefits, including:

- » **Drugs developed are more closely aligned with patient needs**
- » **Treatments are developed more quickly and efficiently**
- » **By being more involved, patients may have a greater awareness and interest in managing their health and well being**

The meeting finished with a fascinating, keynote presentation from Michal Boni MEP on the opportunities for greater patient involvement in research via e- and m-Health applications.

"This is – the new opportunity due to new technologies, due to digital game changer – to make the healthcare systems much more preventive, cost effective, patient centric, with high quality results of the therapies due to personalization of treatment. And with the new possibility: to collect more data, to process them in the direction to have more knowledge on specificities of some diseases," he said.

He particularly called for:

- » **Better and stronger cooperation between all stakeholders**
- » **A focus on increasing digital health literacy**
- » **Reasonable and flexible policies at all levels, particularly in the area of data**

He finished by pledging his support for the MEP Interest Group on Brain, Mind and Pain – saying: *'We need the leadership – common leadership and shared responsibilities. So, let's do this – together!'*

THIS MEETING LED TO:

- **EFNA and PAE planned participation – with partners – in IMI call on Improving the care of patients suffering from acute or chronic pain (subtopic on patient reported outcomes)**
- **EFNA launch of Training Initiatives for Neurology Advocates; empowering patients to be active participation in the R&D process and beyond**

3.

LAUNCH OF WRITTEN DECLARATION

On access to employment for those affected by neurological disorders and chronic pain conditions

October 2016, Working breakfast, European Parliament, Strasbourg

'We know integrating people with a chronic pain or brain condition in employment is socio-economically beneficial. Getting people who want to work, back to work decreases the volume of disability allowance and early retirement payments.'

AUSTRIAN MEP HEINZ BECKER OPENING THE MEETING

This meeting was convened to officially mark the launch of our Written Declaration on Access to Employment for those affected by neurological disorders and chronic pain conditions.

The agenda was based around the story of Manuela Messmer-Wullen, who told the group of six European parliamentarians and three advisors of her anger and loss of confidence after a stroke changed her life and how an understanding employer helped her regain her self-assurance. 'We need to look at examples of good practice for example flexible working for people with chronic illness,' she said.



Marian Harkin with Heinz Becker MEP

There was a lengthy discussion, chaired by Marian Harkin MEP, to plan a strategy for promoting and gathering support for the Declaration. During this session, Vice-Chair of the Employment committee Danuta Jazłowiecka MEP pledged her support, as did fellow Polish MEP Bogdan Wenta, the Slovakian MEP Jana Žitňanská and MEP George Bach from Luxembourg.

Following the meeting, members of the Brain, Mind and Pain secretariat staffed a stand in the European Parliament building to promote the Declaration - whilst also engaging in meeting with MEPs and visits to their offices. More on the Written Declaration can be found in section 5 below.



Danuta Jazłowiecka MEP



Jana Žitňanská MEP

4.

MEETING: #MAKEWORKWORK For Those Affected by Neurological Disorders and Chronic Pain Conditions

November 2016, Breakfast meeting, European Parliament, Brussels

‘Good work has been shown to improve health outcomes, and good health enables people to be productive workers. However, there is a lack of integration between health systems and employment and welfare policy – which must be addressed.’

ANTONELLA CARDONE, EXECUTIVE DIRECTOR, FIT FOR WORK GLOBAL ALLIANCE

MEP Jeroen Lenaers opened the meeting by commending – once again – the high turnout and ongoing interest in the work of the Interest Group.

He said that, so far, the Interest Group has been ‘more than just a talking shop’ and has achieved some tangible results in the form of amendments to the EU Strategic Framework on Health and Safety at Work, for example.

He said the recently launched Written Declaration **#MakeWorkWork** was another step forward in successful advocacy for those affected by neurological and chronic pain conditions, in relation to employment issues.

The first speaker for Antonella Cardone, who called for work to be regarded as a clinical outcome.

In theory, governments across Europe aim to take the societal perspective – which includes consideration of the impact of a healthcare intervention on the patient’s ability to work and the economic effect. In reality, she said, we see that a health care system perspective is taken – covering only those costs and benefits of immediate relevance to the health care system.

However, she said that:

- » **Return on the investment can – and should – be also shown through productivity, job retention or Return-To-Work.**
- » **Health investment decisions should consider the therapeutic benefits that good work can bring.**
- » **It should explore, too, how early interventions – such as reasonable accommodations at work – can play a significant role beyond drugs and devices.**

Boglárka Bóla, Project Manager, EU-OSHA spoke about the main findings from EU-OSHA’s ‘Rehabilitation and return to work: Analysis report on EU and MSs policies, strategies and programmes’.

Prof. Chris Wells, President of the European Pain Federation also spoke about the role of the medical profession in ensuring the return to work of patients. He said that this was one of the work-streams of the Societal Impact of Pain Platform (SIP). He gave his commitment to ensuring that European pain specialists focus on return to work as a patient preferred outcome of treatment.

The meeting was closed by MEP Elena Gentile, a co-author of the Written Declaration who encouraged all present to get involved in supporting this important initiative.

5.

THE WRITTEN DECLARATION: On Access to Employment for Those Affected by Neurological Disorders and Chronic Pain Conditions

The **Written Declaration** was launched with the support of MEPs Marian Harkin, Jeroen Lenaers, Daciana Octavia Sârbu, Elena Gentile, Jana Žitňanská, Heinz K. Becker, Jean Lambert, Ivo Vajgl, Glenis Willmott, Biljana Borzan, José Blanco López, Bogdan Brunon Wenta, Eva Kaili, Jutta Steinruck, Brian Hayes, Roberta Metsola, Miroslav Mikolášik, Sirpa Pietikäinen, Sofia Ribeiro, Cristian-Silviu Buşoi, Karin Kadenbach, and Merja Kyllönen.

With their help, we asked for MEP signatures in support of greater:

Access to employment for those affected by neurological disorders and chronic pain conditions.

Knowing that:

- » **Brain disorders and chronic pain conditions are two of the leading causes of long-term sick leave, and are growing in their impact as Europe's workforce ages.**
- » **Best practices for the retention and reintegration of people with chronic conditions are widespread.**
- » **Integrating people with chronic conditions such as these into employment is socio economically beneficial.**

We called upon:

- » **The Commission to use the EU Semester's country-specific recommendations to encourage Member States to implement cost-effective retention, reintegration and rehabilitation actions.**
- » **The Commission (DG SANTE, DG EMPL, DG REGIO and DG ECFIN) to collaborate on consolidating and consistently implementing EU legislation that will ensure equal access to employment for those affected by neurological disorders and chronic pain conditions.**
- » **The Commission in close cooperation with the Member States, to work, together with their social partners, to clarify patients' rights, highlight successful workplace adjustments and reintegration actions – e.g. flexible working hours – and promote the use of the European Social Fund for such actions.**
- » **The Commission and Council to encourage the Member States to acknowledge that accurate early diagnosis and appropriate treatment and management are necessary to enable employees affected by these chronic conditions to enjoy equitable employment opportunities.**

The Written Declaration provided many opportunities for working with EFNA and PAE members and developing our very active advocacy role within the European Parliament.

We had bi-lateral meetings with dozens of individual MEPs to gather support for our policy work including:

- Vice Chair of the Employment Committee
- Vice Chair of the Environment & Health Committee
- Vice Chair of the Women's committee
- Co-ordinators of the Employment and Environment & Health Committee

This was supplement by:

- Regular meetings with additional MEPs and assistants
- Weekly door-knocking and pigeon-holing of MEPs and assistants – supported by many of our members and supporters who gave their time voluntarily to be in Brussels or Strasbourg to promote the work
- Creation, translation and distribution of promotional materials both on and offline, including via social media
- Building of a comprehensive contact database for all MEPs
- Ongoing updating on www.brainmindpain.eu and associated social media channels

6.

COMMUNICATIONS

The [Brain Mind and Pain website](#) was maintained in 2016 staff of both EFNA and PAE, who ensured the news and events sections were updated, as well as the audiovisual content and extensive resources made available to MEPs and other supporters of the Written Declaration.

The Written Declaration was promoted widely using the [@brainmindpain](#) Twitter account, which offers a way of directly engaging with MEPs and other EU organisations.

A number of print and web materials were designed to promote the Declaration. These included a special #MakeWorkWork logo suitable for sharing through social media.

7.

MONITORING POLICY DEVELOPMENTS AND SEEKING TO INFLUENCE

by drawing on the Book of Evidence and recent outcomes from the Brain, Mind and Pain Interest Group

EFNA and PAE responded to the recent European Commission consultation on the:

- **European Social Pillar of Social Rights** - This high level, cross-cutting initiative focuses on needs and challenges in employment and social policies. Our response argued that there is now an opportunity for including work as a clinical outcome in all health investment decision-making.
- **Health Technology Assessment** - In the discussions around HTA we are asking that the societal impact and indirect cost-savings of treatments be incorporated in the economic modelling of HTAs productivity. Additionally, health investment decisions should consider the therapeutic benefits that good work can bring. It should explore, too, how early interventions – such as reasonable accommodations at work – can play a significant role beyond drugs and devices.

8.

Strengthening Partnerships

We strengthened partnerships with many other organisations working to provide solutions to the challenges raised at the interest group meetings including; The European Patient Forum; The European Brain Council; the Besta Neurological Institute, Italy; GAMIAN-Europe (Global Alliance of Mental Illness Advocacy Networks-Europe); the European Academy of Neurology; the European Pain Federation and the Societal Impact of Pain Platform, Fit for Work; OSHA amongst others.

CONCRETE OUTCOMES OF BRAIN, MIND AND PAIN WORK:

- Launch of EFNA's Training Initiatives for Neurology Advocates as an attempt to better enable patient involvement in decision-making, outcome of June meeting 2016.
- 50 MEPs actively engaged in the launch, at the Parliament, of our pan-European awareness campaign 'Together Under the Umbrella' – arising as an action point on the MEP IG meeting on stigma where the need to raise awareness was stressed.
- 180 MEPs supporting our calls for Access to employment for those affected by neurological disorders and chronic pain conditions – arising as an action point on the MEP IG meeting on stigma where the need to raise awareness was stressed.

** Foot note Written Declaration*

The Written Declaration did not reach the required number of signatures within the three-month time frame, so unfortunately it was not passed. However, due to the high level of support and interest amongst MEPs, we will continue to advocate for the implementation of its asks in the framework of a Call to Action: #MakeWorkWork. The resources created to support the promotion of the Written Declaration will be amended to reflect this updated approach.