Consultation on the European Pillar of Social Rights

We are replying as the organisation **European Federation of Neurological Associations**; registered as an ASBL in Belgium (0543319269), registered office Rue d'Egmont, 11, Brussels 1000. And as Pain Alliance Europe registered as an AISBL in Belgium (0843.489.142) at Grensstraat 7, 1831 Diegem.

The European Federation of Neurological Associations (EFNA) brings together European umbrella organisations of neurological patient advocacy groups, to work with other associations with similar aims including the European Patients Forum (EPF) and the European Brain Council (EBC). EFNA's aims are to improve the quality of life of people with neurological disorders, their families and carers by working in four strategic areas: Awareness – Advocacy – Empowerment – Engagement

Pain Alliance Europe (PAE) is a Pan-European organization of national and or regional associations involved in chronic pain regardless any underlying condition. At this moment PAE has 34 members from 17 different EU countries which in turn represent over 350.000 individual chronic pain patients. Those 34 associations are working together to achieve PAE's mission; To improve the quality of life of people living with chronic pain in Europe.

EFNA and PAE coordinate the MEP Interest Group on Brain, Mind and Pain. Working together, we follow EU initiatives, policies and legislative files in the healthcare and research arenas which may impact on those affected by neurological and chronic pain disorders.

Our reply is based on The Book of Evidence, a report we commissioned, and informed by our members, in order to support the activities of the MEP Interest Group. More information can be found on the website: www.brainmindpain.eu

We have limited our replies to the remit of the Book of Evidence (and actions arising), therefore we have not completed every section. However, we contributed towards the EPF consultation on the European Pillar of Social Rights and fully endorse the input of the EFNA member organisation; the European Multiple Sclerosis Platform.

Note: Both EFNA (321826714452-53) and PAE (397330615236-07) are registered on the European Commission Transparency register.

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EFNA
European Federation of Neurological Associations
Empowering Patient Neurology Groups

1. What do you see as most pressing employment and social priorities?

Across Europe, millions of people of all ages struggle with brain, mind and pain disorders. Neurological and chronic pain conditions arise from illnesses or damage directly affecting the brain, spinal cord or nerves, or as pain from a musculoskeletal injury or of unknown origin. These are long-term conditions that severely impact quality of life, often leading to considerable disability and sometimes to reduced life expectancy.

As a result they have an enormous impact on European economies, as well as on patients and their families. Collectively, brain disorders are the biggest economic challenge for European healthcare, costing around €800 billion each year[1], at least equal to heart diseases, cancer & diabetes *combined* or ~6% of GDP. Chronic pain may cost an additional 3% of GDP.

Much of the economic cost associated with these conditions comes from reduced employment of caregivers. Informal caregiving affects economic productivity considerably through lost opportunity for the caregiver to undertake paid work and a lack of tax revenues from the unpaid work. The total cost of dementia in the EU in 2008 was estimated at €160 billion, of which 56% (€90 billion) were costs associated with informal care[2]. Across Europe, caregivers of people with chronic pain provided an average of 27.5 hours of care per week. This ranged from 9.9 hours per week in France to 48.7 hours per week in Italy[3].

For many people, the biggest effect of their disorder is its impact on education and employment of themselves and their family members.

2. How can we account for different employment and social situations across Europe?

Employment is an important determinant of quality of life. People with neurological and chronic pain conditions may find it difficult to get or keep a job because of stigma and social biases or because of physical, behavioural or cognitive limitations that are symptoms of the disease or side-effects of treatment. Unemployment, under-employment, and leaving education early can worsen the situation for patients by impacting self-esteem, mental health and social interactions and increasing isolation. Conditions which affect young people can have a lifelong impact on their

[1] Olesen J et al. The economic cost of brain disorders in Europe. Eur J Neurol. 2012;19(1):155-62. & Gustavsson A et al. Cost of disorders of the brain in Europe 2010. Eur Neuropsychopharmacol. 2011;21(10):718-79 & Olesen J, Leonardi M. The burden of brain diseases in Europe. Eur J Neurol. 2003;10(5):471-7

[2] Wimo A, et al. The economic impact of dementia in Europe in 2008-cost estimates from the Eurocode project. Int J Geriatr Psychiatry. 2011;26(8):825-32.

[3] http://www.sip-platform.eu/tl_files/redakteur-bereich/Symposia/Focus Groups 2013/Focus Group 1/Presentations/05_BoI KL_JOHara.pdf. Accessed December 5, 2014.

education and employment options. For many patients, work is both a positive contribution to their life and a burden: finding suitable work is possible but likely to involve negotiating with employers[4]

A major driver of a person's ability to remain employed is access to diagnosis and then treatment that adequately controls their symptoms.

However, big health inequalities persist in the EU, and the existence of neurology resources and infrastructure (e.g. qualified neurologists, neurological intensive care units and specialist stroke units) differs considerably between Member States.

Many patients with neurological and chronic pain conditions cannot access effective treatment. Access to modern Multiple Sclerosis treatment ranges from 13% in Poland and 21% in the UK to 69% in Germany[5]. Across Europe, two thirds of people with brain disorders receive no treatment [6]and 40% of people with chronic pain report that it is not adequately controlled[7]. Uncontrolled symptoms worsen the impact of these disorders: up to 70% of people with epilepsy could lead normal lives if properly treated, but for a majority this is not the case[8]. Improving Europe-wide access to existing treatments and supporting the development of innovative medicines to better treat these conditions is an important part of supporting employment and economic productivity among the large number of European patients and their caregivers.

- In a UK study, half of people employed at the time they were diagnosed with multiple sclerosis gave up their job, and 37% reported that their standard of living declined[9]
- People with epilepsy are more than twice as likely to be unemployed as the general population[10] but this varies considerably between countries: in Poland, 49% of people with epilepsy are employed [11]compared with 77% in Germany. [12]
- In a recent survey of German patients with myasthenia gravis, 8% reported it impacted their choice of job, 21% experienced hardships in their job, and 28% were forced to retire early.[13]

[4] . Bossema ER et al. Characteristics of suitable work from the perspective of patients with fibromyalgia. Rheumatol. 2012;51; 311-318

[5] Wilsdon T et al. Access to Medicines for Multiple Sclerosis: Challenges and Opportunities. Charles River Associates, London, UK; 2014.

[6] Wittchen HU et al. The size and burden of mental disorders and other disorders of the brain in Europe 2010. Eur Neuropsychopharmacol. 2011;21(9):655-79.

[7] Breivik H et al. Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment. Eur J Pain. 2006;10(4):287-333.

[8]World Health Organisation. Neurological Disorders: Public Health Challenges. Geneva: WHO; 2006

[9] Clarke BM et al. Work beliefs and work status in epilepsy. Epilepsy Behav. 2006;9(1):119-25.

[10] Jacoby A et al. Uptake and costs of care for epilepsy: findings from a U.K. regional study. Epilepsia. 1998;39(7):776-86.

[11] Majkowska-Zwolińska B et al. Employment in people with epilepsy from the perspectives of patients, neurologists, and the general population. Epilepsy Behav. 2012;25(4):489-94.

12. Korchounov A et al. Epilepsy-related employment prevalence and retirement incidence in the German working population: 1994-2009. Epilepsy Behav. 2012;23(2):162-7.

13 Twork S et al. Quality of life and life circumstances in German myasthenia gravis patients. Health Qual Life Outcomes. 2010;8:129.

These statistics make it clear that the European Union and its Member States must 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.

3. Is the EU "acquis" up to date and do you see scope for further EU action?

There is considerable variation in the effect of these chronic conditions on employment in different Member States. To maximise economic productivity and minimise the economic and social impact on patients and families, European social legislation must be consistently implemented and access to rapid diagnosis and treatment must be available to all patients.

EU social legislation must be reliably and consistently applied across Member States, to support patients to live fulfilling and economically productive lives by maintaining the maximum level of employment and education possible for themselves and their caregivers.

Quality of life and employment should also be supported by ensuring universal and timely access to appropriate diagnostic services and the best currently-available treatments.

EU social and disability legislation is central to employment and educational opportunities for people with neurological and chronic pain conditions. The 2000 Employment Equality Directive obliges Member States to eliminate discrimination on grounds of disability in employment and vocational training. The European Disability Strategy 2010-2020 states that people with disabilities have the right to participate fully and equally in society and the economy.

However, there is no common definition of the term ‘disability’ across the EU. The Europe 2020 strategy and the Open Method of Coordination for Social Protection and Social Inclusion (Social OMC) are important policy frameworks in this area, and most Member States use European Social Fund money to translate disability employment policy into action, for example through work experience schemes, wage subsidies and temporary sheltered employment.

Therefore, we feel that – overall – the priority must be on the implementation of existing legislation, rather than the creation of new legislative texts. This will not only benefit patients, but wider society from a socio-economic perspective. Therefore, we suggest the use of the EU Semester’s country-specific recommendations to encourage Member States to implement cost-effective retention, reintegration and rehabilitation actions.

We would also ask the European Commission works in close cooperation with the Member States, 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

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4. What trends would you see as most transformative?

- ☑ Demographic trends (e.g. ageing, migration)

As statistics show, as the population ages, the prevalence of chronic pain and neurological disorders is increasing in society. This, combined with the fact that the age of retirement is ongoingly increasing, means that we need to ensure that people are healthy enough to work longer (*more below*). However, we also need to ensure that the retired community can continue to be active as volunteers; an important asset to any society. Activities can include looking after grandchildren, active participation in neighbourhood initiatives, acting in an advisory capacity to relevant institutions/organisations, etc. Therefore, rehabilitation and re-activation within the social structure is therefore of huge importance – in terms of work and beyond.

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5. What would be the main risks and opportunities linked to such trends?

As mentioned above, a focus on health at work is more important than ever due to the ageing workforce, later retirement and the increasing prevalence of chronic diseases. If people are expected to work longer, then more must be done to ensure that they are healthy and capable to do so.

Some examples of the societal implications of poor workforce health are:

- Reduced Productivity
- Early withdrawal from the workforce
- Increased social exclusion and poverty
- Impact on family and carers
- Reduced tax revenue
- Increased welfare spending
- Increased healthcare costs

At a recent meeting of our MEP Interest Group, a speaker from the Fit for Work Global Alliance quoted an occupational therapist working with schizophrenia patients, who said: 'People's aspirations are to have a girlfriend, a job, a new house. They don't say "I want less symptoms".'

Therefore, we feel, that there is now an opportunity for including work as a clinical outcome in all health investment decision-making (including HTA – which is also now open for consultation by the EC).

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, 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, there is now opportunity to demonstrate return on the investment through productivity, job retention or Return-To-Work.

To do this effectively, and to tackle the issues related to health at work, we will need to see a spanning of the current silos. We call upon 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.

As stated in the OECD's recently published Health at a Glance:
Although health and labour market policies are often formulated independently of one another, this chapter has shown the need for greater intersectoral collaboration. Both labour market and health outcomes would greatly benefit from improved policy integration.

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6. Are there policies, institutions or firm practices – existing or emerging – which you would recommend as references?

There are many examples of good practice which could be applied more widely in Europe; for example, **Finland** offers all employees with long-term illnesses the opportunity to work part-time. In **Austria** there is a programme called 'fit2work' which is a free-of-charge consulting service for employees whose job is endangered due to health problems; or for persons who have difficulties finding employment due to their health condition. The aim of the programme is to prevent morbidity and disablement and thus an early exit from the labour market. The programme is open for individuals in work, for the unemployed and for companies. This is an example of excellent practise which could be increased across Europe.

The Workplace/Equipment Adaptation Scheme in **Ireland** allows an employer to get a grant towards the costs of adapting the workplace or buying equipment.
- The Employee Retention Grant Scheme can help to retain an employee who has acquired an illness, condition or impairment that affects their ability to carry out their job.

The **German car manufacturers BMW** employed a research team to collect information from a group of employees on all the aches and pains they experienced on the job, as well as suggestions

on how conditions might be improved to reduce or eliminate these. None of the innovations were huge: they included items such as softer flooring, adjustable worktables, easy exercises and lighter work shoes. The health implications were, however, dramatic. Absenteeism due to sick leave dropped from 7% to 2%. The company also benefited financially.
Although the speed of the line was reduced by one-third, productivity increased by 7% and had an almost zero error rate.

Recently, EU-OSHA carried out a study on ´Rehabilitation and return to work: Analysis report on EU and MSs policies, strategies and programmes´. The results of this study – which highlights a number of elements around why certain national systems for rehabilitation and return-to-work are more successful than others – should be further disseminate and promoted.
