

**Intersectoral Global Action Plan
on epilepsy and other neurological disorders**

EMHA contribution to the discussion paper first draft

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1. Do you have any comments on the background and scope?

EMHA, the European Migraine & Headache Alliance welcomes the Action Plan first draft and would like to make a few additional comments.

EMHA is a non-profit umbrella organization, with over 30 patient associations for migraine, cluster headache, trigeminal neuralgia and other headache diseases, across Europe. The Alliance advocates for the rights and needs of the 138 million people living with headache disorders in Europe.

While the Plan will not focus on specific diseases and use epilepsy as an entry point (#14), it is important that all brain diseases benefit from the Plan. People with migraine represent an important part of the population affected by brain diseases (41 million people in Europe), it is a life-span disease that often begins at puberty and mostly affects people aged between 35 and 45 years. It is three times more common in women and most troublesome during people's most productive years (late teens to 50s)¹.

Migraine leads to lost working time: 60% of employed people with severe migraine miss on average a week of work per month. This has an impact on career advancement and earnings (reduced lifetime earnings). It can also lead to job losses or missed job opportunities².

Loss of school days: migraine also has an impact on children at school. In a European study of women with migraine³, nearly three quarters (74%) were prevented from functioning fully at work or school and nearly half of them (46%) lost working or school days in the past 6 months. Children who have migraine are absent from school twice as often as those who do not.

EMHA's 'Access to Care survey' preliminary results that will be presented in Q4 2021 show that migraineurs in the EU do struggle to get an accurate diagnosis and receive treatment. Inequalities exist among the EU Member States when it comes to access to treatment.

As such, the Action Plan must develop actions that will allow for an accurate migraine diagnosis at an early stage, ensure that migraineurs have access to the available treatments that are recognised to relieve pain and reduce the number of attacks and consequently allow them to participate fully in society. Not only will this improve migraineurs' quality of life, it will tackle the stigma, discrimination and inequalities they have to overcome (#8).

The Action Plan clearly must clearly recognise that brain is a complex organ with a significant impact on the individual and society. As such, significant funding should be dedicated to brain research and care to match the level of urgency.

The impact of neurological disorders on family patterns is also important and need to be addressed in the Action Plan. Migraine, for example, can condition women's family choices. Women with migraine may choose to avoid pregnancy because of their disease. Migraine can have a ripple effect on children of parents with migraine and affect parent-child relationship⁴. Parents with migraine are caregivers who must not be left out of the Action Plan.

¹ Stovner L.J., Andre C., On behalf of the Eurolight Steering Committee. Impact of headache in Europe: a review for the Eurolight project, J Headache Pain (2008) 9:139-146- <https://doi.org/10.1007/s10194-008-0038-6>

² Craven A., Quintana R., Carboni V , et al. Living with migraine: a report from the My Migraine Voice survey. Poster presented at the 12th European Headache Federation (EHF) Congress, 28-30th September 2018, Florence, Italy

³ Dueland AN, Leira R, Burke TA, Hillyer EV, Bolge S. The impact of migraine on work, family, and leisure among young women - a multinational study. Curr Med Res Opin. 2004 Oct;20(10):1595-604. doi: 10.1185/030079904X3357. PMID: 15462692.

⁴ Women and Migraine in the EU: Bringing women out of the shadows, EMHA, 2021, 24 p. <https://www.emhalliance.org/wp-content/uploads/Women-M-Policy-Paper-FINAL23MARCH.pdf>

2. Do you have any comments on the vision?

The Action Plan's vision brings some responses to EMHA's priorities and policy advocacy campaign to make migraine a EU and national health priority through its Call To Action launched in 2020, The Migraine Movement Manifesto and The Migraine Movement involving four specific groups (family members, healthcare workers, employers and policy makers) who work together to improve migraineurs' life.

3. Do you have any comments on the goals?

EMHA embraces Strategic Objective #22.4 to foster research and innovation and strengthen information for neurological disorders. This is one of EMHA's high priorities to tackle the burden of migraine on both individuals and society.

4. Do you have any comments on the guiding principles?

EMHA subscribes to all guiding principles.

In #23.1, it will be important to specify what is meant by 'affordable' and who is concerned (the social systems? the individual patient?). In the end, the guiding principles must ensure that people with migraine have **equitable access without discrimination or risk of financial hardship** to **diagnosis** of their disease, **preventive and relief treatment**, as well as **tailored care**. This will respond to the principles of Universal Health Coverage and Human Rights approach, as well as to #24 (Objective 1) on the prioritisation and strengthening the governance for public health

The partnerships mentioned in the Intersectoral Action and the empowerment of persons with neurological disorders are a major asset to ensure the Action Plan actually brings solutions to all affected by brain disorders.

The gender, equity and human rights approach is also fully in line with EMHA's work and policy recommendations (the Women and Migraine: Bringing women out of the shadows paper launched in march 2021 presents how migraine impacts women's lives and provides policy recommendations).

OBJECTIVE 1: TO RAISE THE PRIORITIZATION AND STRENGTHEN GOVERNANCE FOR NEUROLOGICAL DISORDERS

1.1 ADVOCACY

General comments

It is of utmost importance to raise awareness about brain diseases in general and about specific diseases in particular (like migraine that affects 41 million Europeans and ranks as the second largest contributor (16.3%) of DALYs after stroke (42.2%) and before dementia (10.4%)).

Almost 60% of participants (including EMHA) at the OneNeurology Global Advocacy Workshop in June 2021 felt that policy makers in their country did not fully understand the burden of neurological disorders and the need to act now. This fully resonates with EMHA's and the migraine community experience, whence EMHA's EU policy advocacy campaign to make migraine a European and national health priority.

Raising awareness of brain health could be better linked to raising awareness of neurological disorders. The hurdles people living with neurological disorders have to overcome and their needs must be broadly brought to the attention of policy makers. This recommendation does relate to the need to have a deeper insight into the costs of the disease, how different population (young, adults, male, female...) are affected and what are the diagnosis, treatment and care gaps.

Considering recurrent awareness-raising activities is needed to fully grasp the needs and barriers. They also allow progress monitoring. We already have learnings from The Dana Foundation (who is behind the yearly Brain Awareness Week taking place in March and focusses on the importance of neuroscience) and from the 'World Brain Day' (supported by the World Federation of Neurology on 22 September). This can be backed by individual disease days. For example, EMHA has been organising a EU Migraine Day of Action (12 September) for a number of years now as one of the organisation's awareness-raising and policy advocacy activities. Making links between these various activities is paramount to harmonise the messages and make an impact. The European institutions should also play a significant role in raising awareness.

Another example of EMHA awareness-raising activity is its Migraine Work-Place Label project. The Label will be granted to work-places who are making the necessary steps to provide a migraine-friendly work environment. Not only is this an awareness-raising initiative, it is also an initiative that helps employers respect human rights and tackle discrimination at work.

1.2 POLICY, PLANS AND LEGISLATIONS

General comments

EMHA initiated a European policy advocacy campaign in 2020 with its Call To Action to make migraine a EU and national health priority, The Missing Lesson webinar and paper and the recent Women and Migraine: Bringing women out of the shadows paper. They all propose policy recommendations that will improve the quality of life of people with migraine, their families and the health systems.

Considering the disease burden on individuals and society and the number of people impacted, EMHA's Call to Action calls upon the European Commission to ensure migraine is fully included in its work (health and social policies, research priorities (including a 'Brain Mission in Horizon Europe) and funding, gender mainstreaming in all policies, the development of artificial intelligence, long-life learning. EMHA also calls for the development of national migraine strategies with the involvement of migraine patient associations.

#1.2.40 about the collaboration between different stakeholders is a welcome formulation. However, this needs to be matched by financial support, especially for those organisations (like health NGOs) who are all too often struggling to secure the necessary funds that enable them to represent their constituency at national, European and global level. The patients' added value to the discussions is largely acknowledged by policy makers,

professionals, businesses... It is now time to make sure that **all** patient organisations are on equal footing and can benefit from national, EU and global funding to support their activities, be invited at important meetings such as WHO's World Health Assembly. This would give the patient community a really positive signal and significantly enrich the discussions and decisions.

1.3 FINANCING

General comments

Balancing the cost of non-treatment and cost of treatment must be fully studied. For example, migraine costs the European economies as much as € 50 billion a year. In 2011, the mean per-person annual costs were estimated to be €1,222 for migraine (93% being attributed to indirect costs)¹. Indirect costs associated with reduced productivity represent a substantial proportion of the total cost of migraine.

The cost per patient/year from an observational, cross-sectional analysis of data from migraine patients in Spain in 2020 were € 16,578.2 for chronic migraine and € 6,227.8 for episodic migraine. A reduction of one migraine-day per month decreased average total costs by € 744.14 per patient/year for episodic migraine and € 663.20 per patient/year for chronic migraine. A reduction in the number of migraine-days by 50% would result in economic savings of € 2,232.44 per patient/year for episodic migraine and € 6,631.99 per patient/year for chronic Migraine².

Thinking about investment rather than cost must become a reality. Patients must be fully involved in HTA discussions: their disease experience combined with their approach to new treatments that relieve symptoms and thereby improve their situation and allow them to contribute to society are valuable insights to consider.

#1.3.60 about support for the participation of people with neurological disorders in decision-making processes reinforces the comments made above for #1.2.40 about the collaboration between different stakeholders.

Generating evidence on the return of investment of dedicating sufficient time to the brain and brain diseases in the medical curriculum and providing life-long learning about the brain to the health professionals will significantly relieve the migraine community (better diagnosis and access to treatment and care).

¹ Linde M., Gustavsson A., Stovner L.J., et al. The cost of headache disorders in Europe: the Eurolight project. (2011) <https://doi.org/10.1111/j.1468-1331.2011.03612.x>

² Irimia P.M, Garrido-Cumbrera S., Santos-Lasaosa O., et al. Estimating the savings associated with a migraine-free life: results from the Spanish Atlas. Eur. J. Neurology, (2020) <https://doi.org/10.1111/ene.14431>

OBJECTIVE 2: TO PROVIDE EFFECTIVE, TIMELY AND RESPONSIVE DIAGNOSIS, TREATMENT, AND CARE FOR NEUROLOGICAL DISORDERS

General comments

Diagnosis of migraine comes too late as patients testify in EMHA's [The truth behind migraine](#) video. The organisation's 'Access to Care' survey preliminary results reinforce evidence of late diagnosis and late access to treatment. Early detection of neurological disorders and early intervention are essential to reduce stigmatisation, discrimination, marginalisation and chronification of the disease.

Improved diagnosis and better care coordination could be integrated with rare diseases. There are examples from which we can learn to improve the life of migraineurs: the European Reference Network that pools resources for rare diseases and the Undiagnosed Diseases Network International.

2.1 CARE PATHWAYS

Digital tools need to be further expanded to support migraineurs. These tools must be developed in collaboration with the migraineurs themselves who are well-placed to express what is most needed and in what form.

2.2 MEDICINES, DIAGNOSTICS AND OTHER HEALTH PRODUCTS

General comments

Equitable access to quality care for neurological disorders was voted as another key area for improvement during the [OneNeurology Global Advocacy Workshop](#) in June 2021 and in which EMHA participated.

This is certainly the case for migraine. Diagnosis of migraine needs to be greatly improved. EMHA's preliminary results of its Access to Care survey that will be presented in Q4 2021 clearly show that 34% of migraineurs had to visit between 4 to 5 and 8 specialists before obtaining a proper diagnosis. There are disparities within EU countries regarding the number of specialists visited before getting a diagnosis. It is difficult to find a specialised migraine centre. When patients do find one, their situation does improve. Treatment of migraine badly needs to be improved too. As an example from the survey, new anti-CGRP treatment (preventive treatments) are prescribed late.

2.3 HEALTH WORKERS' CAPACITY BUILDING, TRAINING AND SUPPORT

General comments

Training primary care practitioners to detect migraine is an entry point to diagnosis that can lead patients to avoid self-medication for headaches and the consequent 'chronification' of the disease. Medical education on neurological disorders must be improved. This was clearly called for in EMHA's [The Missing Lesson](#) webinar and webinar report: the lack of knowledge about migraine among the healthcare providers is an issue. This is explained by the lack of necessary medical education on migraine: only 4 hours of under-graduate medical education and 10 hours in specialist training are dedicated to headache disorders. Other reasons are that headache is not on the medical curriculum of all European medical schools and the training programs for generalists and neurologists do not contain the minimum knowledge about headache. **Life-long learning for health professionals must be promoted to fill the medical education gaps.**

OBJECTIVE 3: TO IMPLEMENT STRATEGIES FOR THE PROMOTION OF BRAIN HEALTH AND PREVENTION OF NEUROLOGICAL DISORDERS

General comments

Many neurological disorders share similar risk factors with other diseases and can also be associated with other diseases (migraine and dementia for example). It is important to better understand the risk factors associated with other NCDs in order to improve our understanding and lead to the development of better disease-modifying strategies.

Bridges must be made with environmental actions (like the EU Green Deal) or social policies or initiatives (work-life balance, European Pillar of Social Rights) that will improve the management of diseases and improve the quality of life of patients and their families.

3.1 PROMOTION OF OPTIMAL BRAIN DEVELOPMENT IN CHILDREN AND ADOLESCENTS

General comments

Migraine is a life-span that often begins at puberty. It has an impact on children at school: it prevents them from functioning fully at work or school and they lose school days. Children who have migraine are absent from school twice as often as those who do not.

It is thus important that children with neurological diseases like migraine be a full part of the Action Plan. Children with migraine must have equal chances in the education system and consequently later in life.

OBJECTIVE 4: TO FOSTER RESEARCH AND INNOVATION AND STRENGTHEN INFORMATION SYSTEMS FOR NEUROLOGICAL DISORDERS

General comments

Fostering research and innovation is pivotal to understand the brain, develop diagnostic tools and preventive treatments.

Collaboration in research will avoid duplication and waste of precious resources.

Gender mainstreaming in brain research is most needed in the case of migraine (a disease that affects women three times more than men) and precision medicine (#4.1.195) must be developed as a response to the gender-related manifestations of the disease.

Ethical considerations around innovation must be looked at when necessary. Patients must be involved in all discussions about ethics.

People with neurological disorders must be involved in research planning and participation in research. This must be accompanied by appropriate training to feel confident and participate fully.

EMHA fully supports the Data and information systems Actions for the Secretariat (#4.2.214).

ANNEX: COMMENTS ON THE GLOBAL TARGETS AND INDICATORS FOR EACH OBJECTIVE

EMHA agrees with the setting of targets and monitoring indicators that were voted as another key action during the OneNeurology Global Advocacy Workshop of June 2021.

Yet, it is important to set intermediate targets, a specific process for on-going review and outcome measures to incentivise Member States to start implementing the Action Plan as early as possible.

Other targets must be included: neurological workforce increase, patient involvement (public and private research, reimbursement, legislation), quality of life improvement, integration of neurology in NCD-related global programs.

Neurology and brain health should have stand-alone national plans or be explicitly covered by wider strategies. This does not exclude the development of national disease specific plans that can significantly tackle disease burden (like migraine).

Please provide any general comments on the first draft of the intersectoral global action plan on epilepsy and other neurological disorders

Neurological disorders must be singled out as a priority in their own right as non-communicable diseases (NCDs). Significant resources really need to be given to brain disorders.

About EMHA

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