

**Contribution to the discussion paper  
of the Intersectoral Global Action Plan  
on epilepsy and other neurological disorders.**

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

The European Migraine & Headache Alliance (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.

Migraine, a disease that is mentioned a few times in the discussion paper, is the second leading cause of disability in the world and the first among young women. (Steiner, T.J., Stovner, L.J., Jensen, R. et al. Migraine remains second among the world's causes of disability, and first among young women: findings from GBD2019. *J Headache Pain* 21, 137 (2020). <https://doi.org/10.1186/s10194-020-01208-0>).

EMHA launched a policy advocacy campaign in 2020 to make migraine a EU and national health priority through its [Call To Action](#).

- The Intersectoral Global Action Plan (IGAP) should refer to [WHO's definition of neurological disorders](#) to allow all stakeholders be on the same line. Possibly a list of all neurological disorders could be included to reflect the broadness of these disorders and the will to leave no-one behind.
- The emphasis of the IGAP is on '*preventing neurological disorders and promoting brain health and development*'. Living a healthy lifestyle can be an effective way to try to keep migraines and headaches at bay. They can be reduced by avoiding identified triggers (nutrition, environment), engaging in healthy habits and resorting to medication. Nevertheless, it is important to remember that there are neurological diseases like migraine that cannot be avoided due to their nature.
- The IGAP must strike a balance between health promotion/prevention and disease management. The actions that will be proposed must offer answers to all neurological disorders, based on their very specificities, without leaving anyone on the side of the road.
- The existing data on neurological disorders, and migraine in our case, must be refined to give a clear picture of the scope of the disease at region and country level (prevalence, access to diagnosis, treatment and care, best practices). The IGAP must identify concrete deliverables accompanied by measurable outcomes, a dedicated budget and a timeframe for implementation.
- People with neurological disorders must be equal actors in the implementation of the IGAP alongside 'member states', 'secretariat' and 'international partners'. This must be made clear by adding a section '**Actions for patients**' under each objective.

- A stronger reference to gender must be included in the IGAP. Migraine is three times more common in women and influenced by sex factors. EMHA's [Women and Migraine: Bringing women out of the shadows](#) paper that was launched in march 2021 presents how migraine impacts women's lives and provides policy recommendations.
- The life-course nature of neurological diseases like migraine is important: migraine is most troublesome during people's productive years (late teens to 50s). Before puberty, more boys than girls suffer from migraine. The mean age of onset is 11 for girls and 23% of young girls will have experienced a migraine by the time they turn 17 (<https://www.globalpaininitiative.org/migraine-treatment-for-teens-approved/>). The impact of migraine on education and career opportunities, and work life, as well as its personal, financial and societal impact cannot be dismissed.
- The impact of neurological disorders on family patterns is important and need to be addressed in the IGAP. 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 relationship. Parents with migraine are caregivers that must not be forgotten.

## 2. Do you have any comments on the vision?

- The vision of the Plan to prevent neurological disorders should be expanded to their management and refer to the quality of life. As stated previously, some neurological conditions like migraine and headache attacks can be prevented by a good management of the disease (nutrition, environment, medication). This is why the wording of 20. i. should read : '*neurological disorders are prevented **and/or** appropriately managed to reduce risks and improve patients' and their families' quality of life*'.
- Some points are missing from the vision
  - **Eliminating disparities in care** (access to timely diagnosis, available treatments, quality care services) can improve the quality of life, reduce disease chronification or severity).
  - **Removing stigma and misconceptions** associated with neurological diseases. This is particularly the case for neurological diseases like migraine. EMHA's [Women and Migraine: Bringing women out of the shadows](#) paper gives an insight into the stigma and misconceptions linked with migraine ('migraine being a women's disease quickly relieved by a pill'). Reframing migraine can be a way forward to remove stigma.
  - **Improving our understanding of the brain**, both in its healthy and pathological aspects. This should lead to reducing the onset of neurological disorders and better management of the diseases.

### 3. Do you have any comments on the goals?

The wording 'reducing the impact and burden of neurological disorders' is somewhat limiting. The goal include raising awareness about neurological diseases, their specificities (like migraine specificities in our case). This will help improve diagnosis, treatment and care and remove the stigma and misconceptions linked to the disease. This can consequently reduce the impact on the disease on the patient, the family and society as a whole (socio-economic costs of the disease linked to missed opportunities in the education system and workplace).

Leveraging epilepsy prevention as an entry point may be somewhat restrictive when one considers the specificities of the neurological disorders (risk factors, manifestations, impact on daily life, associated costs...). It may be advisable to adopt a disease-specific structure keeping in mind that an overarching system-based approach (diagnosis, access to treatment) may be relevant to all.

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

The Plan must be centred around the persons living with their specific neurological disorders. As mentioned previously, the IGAP must consider patients and their families are key partners to deliver Action Plan. Their empowerment and their involvement must be meaningful and well-defined from the outset.

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

### **General comments on objective 1:**

- It is time to single out neurological conditions and move them away from the WHO mental health portfolio. They must be clearly identified as a 5<sup>th</sup> NCD priority. This will facilitate policy and legislation development and improve the quality of life of patients and their families.
- Neurological disorders are the second leading cause of deaths globally. Until now, they have not been given the priority that matches their burden on the individual and on society. Neurological conditions have not been identified as a distinct disease group with overarching characteristics that could benefit from a the success of a collective approach (as, for example, cancer, cardiovascular or respiratory diseases). Neurological disorders must become more visible in WHO Non-Communicable Diseases department.
- The whole neurological spectrum must be considered, not just epilepsy as an entry point.

- Stigma, misconceptions and reframing of neurological disorders are key to overcome barriers and initiate management of these diseases.

## 1.1 ADVOCACY

### General comments:

Other EMHA's work provide knowledge for advocacy purposes such as EMHA's [Migraine at Work](#) survey in 2019: the objective of this study was to know the situation of migraine workers within the workplace and compare the situation in the different participating countries.

In 2021, EMHA will present the findings of its survey on 'Access to treatment and cost of treatment for migraineurs.

## 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, its [The Missing Lesson](#) webinar paper and its 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.

In a nutshell, EMHA calls on the European Commission, European Parliament and Member States to increase the visibility of migraine, gather intelligence to develop policies, dedicate adequate funding to support a series of actions:

- Raise awareness about migraine
- Reframe the disease to break stigma and misconceptions
- Develop migraine-friendly schools and work-places
- Increase social research to gather data that will inform policy making
- Increase medical research to understand what causes migraines and develop treatments
- Focus on the gender aspect of migraine to tailor social solutions and develop precision-medicine
- Develop and implement national plans to comprehensibly respond to the migraine challenges
- Benefit from EU financial support to improve medical education (life-long learning)

EMHA has also launched the [The Migraine Movement Manifesto](#) and [The Migraine Movement](#) involving four specific groups (family members, healthcare workers, employers and policy makers) that work together to change migraineurs' life.

### 1.3 FINANCING

#### General comments:

The IGAP must secure significant and well-identified funding streams to make sure the goals can be reached.

Balancing the cost of non-treatment and cost of treatment must be fully studied. 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)<sup>1</sup>. 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 Migraine<sup>2</sup>.

<sup>1</sup> 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>

<sup>2</sup> 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>

### 1.4 INTEGRATED RESPONSE WITHIN HEALTH AND SOCIAL CARE SYSTEMS

#### General comments:

EMHA has identified a number of priorities for the health and social care services:

- Ensure access to timely and quality diagnosis and access to available treatments
- Develop and support care pathways that fully address patients' needs
- Improve the medical curriculum to dedicate sufficient time to headache disorders and migraine in particular
- Engage healthcare professionals to better diagnose migraine, discourage self-medication and drug overuse and direct patients to headache services
- Remove all barriers to access to diagnosis, treatment (reimbursement) and improve the organisation and delivery of healthcare through long-term care pathways

Improvement in other areas are necessary too:

- Adapt the school system to give children with migraine an equal chance to education by implementing migraine-friendly schools

- Adapt the workplace to avoid absenteeism and presentism by implementing migraine-friendly work environments

Engaging patients and their families is a pre-requisite to ensure the responses are tailored to their needs. As a great number of patient organisations struggle with limited resources (staff and finances), it is important to find funding streams to empower them represent their community and participate fully in action definition and implementation.

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

### **General comments on objective 2**

- Diagnosis of migraine comes too late as patients testify in EMHA's [The truth behind migraine](#) video. Early detection of neurological disorders and early intervention are essential to reduce stigmatisation, discrimination, marginalisation and chronification of the disease.
- In the case of migraine, acting early can positively reduce the burden of the disease and improve the patient's capacity to carry out everyday activities. 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 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 undergraduate 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.

This is further supported by EMHA's [How much is migraine studied ?](#) survey carried out among healthcare professionals

## **2.2 MEDICINES, DIAGNOSTICS AND OTHER HEALTH PRODUCTS**

### **General comments:**

As mentioned previously, access to timely diagnosis, treatment and care is highly important to manage migraine. Administrative and cost barriers to access migraine treatments must be lifted. This is a government responsibility. Patient and carers must be fully involved in the regulatory and reimbursement processes of new technologies so that

decision on access to care are patient-centred. Patients and carers must be trained to be on equal footing with regulators.

## 2.3 HEALTH WORKERS' CAPACITY BUILDING, TRAINING AND SUPPORT

### General comments:

The significant shortage of neurologists combined with the poor medical education on migraine explain the timely diagnosis and treatment deficit. This has an impact on the quality of life of those affected and socio-economic consequences. More neurologists are needed to match the number of patients with neurological disorders. Besides, life-long learning on migraine must be made available to the medical profession. EU-funds should be planned to support such training.

The impact of public health emergencies (like the COVID-19 pandemic) calls for a unified strategy to leave nobody behind during these difficult times.

## 3.5 REDUCING ENVIRONMENTAL RISKS

### General comments:

Migraine triggers are different from one person to another. Besides genetic factors, environmental and sex related factors are likely to trigger migraine attacks. Identifying risk factors of migraine and maintaining a healthy lifestyle are key for managing migraine, starting from adolescence but it is usually not enough to control the disease.

A number of triggers have been identified:

- Environmental triggers
  - Situations causing anxiety, excitement, any form of tension and shock influenced by the environment (such as work, family life, bright sunlight, flickering lights)
  - Air quality and odours
  - Environmental aspects of indoor space and workplace
- Migraine and screens
  - Use of a computer as a primary function of a job
  - Time spent looking at a computer screen (especially if light is a trigger and/or if photophobia are prominent symptoms)
- Weather, high temperature and air pollution
  - Possible association between higher relative humidity and onset of migraine headache, especially in warm season.
  - Higher levels of ambient O<sub>3</sub> may be associated with higher risk of having migraine, particularly in the cold season.

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, for instance).

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

### **General comments on objective 4:**

A number of priorities need to be addressed to achieve progress in the field of neurological disorders like migraine:

- Brain research support to better understand the brain function and the development of neurological diseases to improve diagnosis techniques and speed-up access to treatment
- Collaboration in brain research will avoid duplication and waste of resources
- Gender mainstreaming in brain research is most needed in the case of migraine (a disease that affects women three times more than men)
- Precision medicine must be developed as a response to the gender-related manifestations of the disease
- In recent years, there has been some evidence on potential biomarkers associated with migraine: a number of biomarkers have been proposed as diagnostic or therapeutic tools in migraine. Nevertheless, their detection is still a challenge for the scientific community. The identification of migraine-specific biomarkers could prove to be fundamental in a perspective of precision medicine, enabling risk assessment and tailored treatments. (Circulating Biomarkers in Migraine: New Opportunities for Precision Medicine - Patrizia Ferroni, Piero Barbanti, Antonella Spila, Federica Fratangeli, Cinzia Aurilia, Luisa Fofi, Gabriella Egeo, Fiorella Guadagni - DOI: 10.2174/0929867325666180622122938
- Ethical considerations around innovation must be looked at when necessary
- Involve people with neurological disorders in research planning, participation and funding (including appropriate training to feel confident and participate fully)

### **5. Please provide any general comments on the discussion paper of the intersectoral global action plan on epilepsy and other neurological disorders in the field below.**

This is a very comprehensive document that opens new doors for neurological conditions. Neurological disorders must be singled out as a priority in their own right. There are great expectations from the migraine community who offers its support to ensure the Action Plan identifies and delivers concrete solution to improve their life.



## About EMHA

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