JOINT STATEMENT

Migraine:
Time to act comprehensively to improve the life of European citizens with migraine

The signatories of this Statement jointly call for a comprehensive EU policy action that addresses the overlooked burden of migraine on individuals and society. This includes the elimination of existing barriers to diagnosis and treatment inequalities people with migraine have to overcome and a response to their exacerbated vulnerability in relation to school, access to work and during pandemics (like the COVID-19 pandemic).

The specific needs and concerns of people with migraine must be fully embraced through a targeted and coordinated approach that will improve their quality of life, enable them to be full part of society and contribute to the economy.

Migraineurs must be considered by policy makers as equal partners in their response to the burden the disease inflicts upon them and society.

The burden of migraine on individuals and society

Migraine is not just a bad headache: it is a **serious, distinct and complex neurological disease**. It is a **common**, yet **invisible life-span** disease.

41 million people in Europe live with migraine and the disease is three times **more common in women**[i-ii]. Migraine often begins at puberty and mostly affects people aged between 35 and 55 years.

Migraine is the **second leading cause of disability** in the world and the first among young women[ii-iii].

- Migraine itself is the second largest contributor of neurological DALYs in 2016 (16.3%) after stroke (42·2%)[iv].

The disease generates **stigma** due to the invisible nature of the pain, can co-exist with anxiety and depression and lead to withdrawal from society.

It has an **impact on children at school** and is **most troublesome during people's most productive years** (late teens to 50s).

- **Loss of school days**: children with migraine are absent from school twice as often as those who do not[v].
- **Lost work time due to migraine**: over 10 days during a 3-month period and on average a week of work per month for 60% of employed people with severe migraine[vi].

- **Impact on career advancement and earnings**: careers negatively influenced, reduced lifetime earnings, job losses, missed job opportunities. [vii-viii-ix]

Migraine is **under-diagnosed** and **under-treated** due to lack of awareness and stigma, clinical and social barriers, and poor access to treatment. The lack of knowledge about headache among healthcare providers is the principal clinical barrier (only 4 hours being dedicated to headache disorders in formal undergraduate medical training and 10 hours in specialist training)[x].

- **Impact of under-diagnosis and treatment**: about 50% of people with headache disorders are primarily self-treating, without guidance by health professionals; 10% are professionally diagnosed. This has major adverse health and economic consequences[xi].
- **Barriers to diagnosis and treatment**: EMHA's 'Access to Care survey' carried out in 2021 clearly shows that 34% of migraineurs had to visit between 4 to 5 and 8 specialists before obtaining a proper diagnosis. This can be explained by the lack of knowledge about headache among healthcare providers. Disparities within EU countries regarding the number of specialists visited before getting a diagnosis are also put forward. It is for example 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.

Migraine is a **costly disease**: in 2011, the cost of migraine to the European economies was € 50 billion a year. The mean per-person annual costs were € 1,222 for migraine (93% being indirect costs)[xii]. This generates a **huge clinical and economic burden for both individuals and society**.

Despite its widespread and debilitating nature,
migraine is still misunderstood, ignored, and stigmatised.

Reasons why it is Time to Act!

Raise awareness to remove stigma and discrimination

Raising awareness among the public and policy makers will help remove the stigma associated with the disease. Ending discrimination, improving inclusion of migraineurs in society (school, workplace) and respecting their basic human rights will help improve their quality of life of people.

There is an economic value in addressing migraine

Data from Spain show that 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[xiii].

Implementing coordinated care pathways that improve the diagnosis and access to treatments that reduce the number of attacks and their severity will also contribute to the sustainability of the healthcare and social systems by removing costs associated to late or inaccurate diagnosis and inefficient treatment.

Promoting migraine prevention and treatment to improve patients' quality of life

The medical education deficit on migraine needs to be redressed to fill the diagnostic gaps. The medical curriculum needs to be improved to match the stakes. EU education programmes must support life-long learning programmes for clinicians. An EU on-line Migraine University could be set-up and accessible for all GPs and neurologists to be kept abreast of migraine research and medical developments.

New migraine treatments that reduce the number of attacks and their severity must be made available to migraineurs in all EU countries. The results of EMHA's 'Access to Care' survey carried out in 2021 among migraine patients clearly show that a significant number of migraine patients do not have access to these treatments still.

To allow people with migraine better access to work, EMHA launched in 2021 a 'Migraine Friendly Workplace Label' that will be awarded to employers who adapt the workplace to the specific needs of migraineurs (light, noise, quiet rooms…).

The added value of involving patients at all stages

The added value of patients as experts with their disease needs to be fully considered when carrying awareness campaigns and all policy advocacy activities.

Concerted and intersectoral efforts to achieve Universal Health Coverage (UHC) and deliver on the UN Sustainable Development Goals must include those who know the disease best: patients and patient organisations.

'Health budget literacy' is also critical for patients to be in a position to influence decision-making on the allocation and use of public resources for health. For civil society representatives to be contributors on equal footing with others, available tools such as the toolkit[xiv] developed by UHC2030 and PMNCH to understand public financing must be largely deployed. This will empower them be in a better position to support the implementation of UHC and participate in HTA discussions.

EU and global programmes and plans can support actions to tackle migraine

The EU4Health programme[xv] that looks at addressing important long-term challenges for health systems (burden of non-communicable diseases, health status inequalities, access to affordable, preventive and curative health care of good quality) must serve to deliver solutions for migraineurs and their families.

Within Horizon Europe[xvi], the EU's key funding programme for research and innovation, the Health Cluster under Pillar II (Global challenges and industrial competitiveness) must reflect the importance and urgency for improved recognition of brain research, and migraine in particular.

WHO has recognised the high global burden of neurological conditions and the insufficient access to both services and support for these conditions. This has led to the development of an 'Intersectoral global action plan on epilepsy and other neurological disorders'[xvii]. The action plan will address the challenges and gaps in providing care and services for people with epilepsy and other neurological disorders that exist worldwide and ensure a comprehensive, coordinated response across sectors. EMHA has provided comments to the two WHO public consultations WHO[xviii]-[xix] to ensure migraine patients fully benefit from the Plan.

The signatories below call upon the European Commission, the European Parliament and national governments to set-up an ambitious **European Migraine Action Plan** to **overcome the burden of migraine on individuals and society** that will:

- Profile migraine as a stand-alone disease in all EU and national health and social policy developments to consider duly the number of people affected and the weight the disease has on society
- Raise awareness to increase the visibility of migraine to overcome stigma and improve the quality of life of people with migraine
- Develop coordinated care strategies that encompass prevention, diagnosis, access to treatment and care
- Take stock of the gender aspect of migraine to support gender mainstreaming in all policies and personalised medicine activities that will benefit migraineurs
- Dedicate significant medical and social research funding to tackle the disease from all angles (sex, age, different sorts of migraines, impact on quality of life…)
- Ensure the EU digital agenda propose online consultations for people are not able to access healthcare facilities physically during attacks or pandemics that reduce face to face consultations
- Drive concerted and intersectoral efforts that will achieve Universal Health Coverage and deliver the UN Sustainable Development Goals
- Involve patients as experts and equal partners in all decisions affecting their life (policy development, HTA…)
- Support the development of national migraine strategies
- Recognise the important and supportive role of European and national associations.

29 September 2021

To endorse EMHA's Statement, please visit:
https://www.emhalliance.org/for-policy-makers/#migraine-sufferers

This Statement calling for a European Migraine Action Plan is currently endorsed by

EU organisations

European Federation of Neurological Associations

European Brain Council

European Patients Forum

European Institute of Women's Health

National associations

La Voix des Migraineux (France)

MiGRA (Portugal)

Belgian Brain Council

Latvian Society of Headache Patients

AEMICE (Spain)

Migraine Ireland

EU policy makers

Nathalie Colin-Oesterlé
Member of the European Parliament

Deirdre Clune
Member of the European Parliament

International associations

International Headache Society

Women’s Brain Project

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 was launched in 2006 and advocates for the rights and needs of the 138 million people living with headache disorders in Europe. Its goal is to represent European migraine and headache associations, help them advocate for headache disorders and be recognised as key partners in the healthcare system. It also helps patients to be well informed and have equal access to appropriate diagnosis and treatment. EMHA is an active member of the European Federation of Neurological Associations (EFNA), the International Association of Patient Organizations (IAPO) and the European Patients Forum (EPF). It also works closely with organisations such as the European Headache Federation (EHF) and the European Brain Council (EBC).
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