



## PRESS RELEASE

### **Migraine in the European Union: EMHA's 'Access to Care' survey reveals shocking hurdles for patients to overcome and disparities in the EU**

**29 September 2021, Brussels, Belgium.** The European Migraine & Headache Alliance (EMHA) organised a webinar to present the results of a survey looking into the migraine patients' journey to have a diagnosis and treatment for their disease in the European Union (EU). The survey was conducted in 2021, with close to 3,400 participants from 10 countries.

The survey shed light on the impact of migraine attacks on the migraineurs' daily life and the shocking number of hurdles they have to overcome to get a diagnosis and treatment.

During migraine attacks, patients find it difficult to perform tasks they usually perform easily when free from the attacks: cooking, eating, taking care of the family or a child, working, getting medicines at the pharmacy, driving.

#### **It takes too long before a diagnosis of migraine is made.**

General Practitioners are usually the entry point to the patient journey and a neurologist will make a diagnosis. Nevertheless, it takes a number of specialist visits before a diagnosis is made: 19% of the participants had to see 4 to 5 specialists, 6 to 7 specialists (7%) and over 8 specialists (8%).

#### **It takes too long between diagnosis and access to treatment**

49% of the survey participants had to wait over 3 years to get a treatment. The first treatments received are general analgesics. Then, triptans (78%) are prescribed. Botox is the least prescribed treatment (11%). Poly-medication is frequent and multiple drug combinations have been reported. Patients' main barriers to new treatments like anti-CGRP access is that doctors do not mention them (26%), they are not covered by the health system (25%) or the patients are not eligible for the treatment yet (25%). 25% reported paying for the new anti-CGRP out of their pocket.

#### **Access to diagnosis and treatment is unequal in the EU**

In the EU, access to a professional for diagnosis and treatment varies. For instance, the survey showed that Finland and Greece were the two countries where the participants consulted a neurologist in the first place. Access to a neurologist for treatment and treatment follow-up, organisation of the healthcare systems, limited access to specialised migraine centres, access to treatment (including new treatments) also show differences between countries

#### **No more time to waste**

European migraineurs cannot wait any longer. EMHA presented a Statement calling 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. This Statement has already been supported by a number of key stakeholders. It

will be posted on EMHA's website to gather as much support as possible from the migraine community, professionals, policy makers... to reflect the magnitude of the problem and the urgency to act.

The webinar of 29 September 2021 was hosted by Deirdre Clune, Member of the European Parliament (Ireland) and member of the European Parliament Migraine Alliance.

*'Having such a number of hurdles to overcome before having a diagnosis and treatment is totally unnecessary and unacceptable. This has huge repercussions on the migraineurs' quality of life and society as a whole. EMHA and the migraine patient community call on the EU and national policy makers to commit to make migraine a priority health action, said Elena Ruiz de la Torre, EMHA Executive Director.*

*'Since EMHA's Call to Action' to make migraine a EU and national health priority, very little has been done. Today's Statement already endorsed by a large number of supporters and the survey's results must be wake-up call for the policy makers', said Patrick Little, President EMHA*

*'People with migraine should not be left in the dark any longer. EMHA's survey results go deep into what needs to be urgently addressed to improve migraineurs quality of life and full inclusion in society. Now we know, let's act. No time to lose,' said Deirdre Clune, Member of the European Parliament, EPP, Ireland.*

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

### **Countries participating in the survey**

Finland, France, Germany, Greece, Ireland, Italy, Latvia, Norway, Spain and United Kingdom.

### **A deeper look into the survey findings**

Closed to 3,400 patients from a total of 41 countries participated in the survey: EU countries (Germany – 17%, Spain – 13%, Italy – 12%, Greece and France – 9%, Latvia – 8%, Ireland – 7%, Finland – 5%), the UK (7%), Norway (6%), Brazil (3%) and a mix of other countries (3%).

Majority of responders are women between 25 and 59 years old, actively working, from urban areas and with low family incomes. 49% of the participants had chronic migraine. 83% of the respondents have been suffering from migraine between 10 and 20 years (26%) to over 30 years (32%). 57% of the respondents endured between 4 and 14 days of migraine a month (26%), to over 14 days a month (18%) while 13% suffered from migraine daily. 27% had migraine between 4 to 4 days month.

First visited specialist is the G.P (58%). The main specialist who made the diagnosis and the current follow up is the neurologist (48% and 54% respectively). It is worth noting that a third of responders visited more than 4 specialists until being diagnosed, and a quarter reported not being followed by any healthcare professional.

The 3 salient needs in relation to quality of life expressed by the participants were to have less migraine days per month (46%), having less severe attacks and having an effective treatment

(37% respectively). This would consequently improve their quality of life, help them be more productive at work and be more included in society.

### **What is migraine?**

Migraine is not just a bad headache. It is a serious, distinct and complex neurological disease. It is the third most common disease worldwide and a cause for incapacity. This generates a huge clinical and economic burden for both individuals and society.

Migraine is a common and invisible life-span disease affecting 41 million adult Europeans. It often begins at puberty and mostly affects people aged between 35 and 45 years. It is also common in children.

Migraine is a costly disease: it is most troublesome during people's productive years (late teens to 50s). In the EU, the total annual cost of migraine was estimated at € 111 billion (64% of all headache costs). The annual per person cost for migraine amounts to € 1,177, 93% being attributed to indirect costs.

Lost working hours and reduced productivity due to migraine are a driver of huge economic losses in the EU: an estimate of the total cost of migraine in Europe is €27 billion per year.

### **About The European Migraine & Headache Alliance**

The European Migraine & Headache Alliance (EMHA) is a non-profit umbrella organization that was launched in 2006. It includes over 33 patient associations for migraine, cluster headache, trigeminal neuralgia and other headache diseases, across Europe. Its head office is in Brussels.

EMHA's aim is to speak on behalf of and to advocate for the rights and needs of the 138 million people in Europe living with headache disorders.

EMHA is an active member of the European Federation of Neurological Alliances (EFNA), the International Association of Patient Organizations (IAPO), the European Patients Forum (EPF) and also works closely with organizations such as the European Headache Federation (EHF), International Headache Society (IHS), European Brain Council (EBC) and others.

[www.emhalliance.org/](http://www.emhalliance.org/)

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