



# Migraine: a political, health and social priority.





# Introduction

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Undervalued, **underdiagnosed** and **undertreated**. These words aptly describe the reality of a disabling neurological disease that affects over five million people in Spain: **migraine**. This type of primary headache causes recurring bouts of moderate or intense pain that may be accompanied by nausea, vomiting or extreme sensitivity to light, sound and smells.

Migraine significantly deteriorate the quality of life of those who

suffer them, due to their adverse impact on professional, familial and social aspects.

On average, it takes six to seven years to diagnose migraine<sup>1</sup>, and it is estimated that 40% of cases remain undiagnosed<sup>2</sup>. Migraine is considered to be **the leading cause of disability among adults under 50 years of age**. Despite this, society continues to trivialise the subject by considering migraine to be simple headache, which only serves to stigmatise migraine sufferers.



# Introduction

In Spain, migraine is usually treated by primary-care professionals, not all of whom are aware of the correct treatment of this disease. Only the most severe cases are sent to neurologists, and not all such cases are sent to headache units. It comes as no surprise, then, that migraine treatment can be improved. In this sense, experts have pointed out the **insufficient use of triptans and the difficulty of access to preventive treatments** (currently received by less than 15% of candidates).

In view of this, Spanish patient organization, AEMICE has urged the Government of Spain to implement a **Nationwide Strategy regarding migraine** and other types of headaches as a means of:

- 1 addressing all relevant healthcare and social needs
- 2 **minimising** existing regional disparities
- 3 ensuring the **highest possible quality of the care** received

// Access to care

# Access to care event

Madrid, 6 October 2022





# Access to care event

On 6 October 2022, AEMICE and the European Migraine and Headache Alliance (EMHA) held an event to debate and discuss migraine. Targeting institutions and political leaders, the event was held at **Spain's Congress of Deputies** and was attended by healthcare professionals, patients and deputies of the Healthcare Commission.

**Adolfo Suárez**, 4<sup>th</sup> Secretary of Mesa del Congreso of the Spanish Congress of Deputies, presided over the institutional opening ceremony along with **Rosa Romero**, president of the Healthcare Commission, and AEMICE President **Isabel Colomina**.







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Only **14%** of migraine  
patients pursue  
treatment with the  
most **innovative** drugs.



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# Access to care study

EMHA Executive Director, **Elena Ruiz de la Torre** presented the results of the Access to Care initiative, a survey organised by EMHA and performed by KPMG Life Sciences Consulting, to study **migraine sufferers' access to healthcare**.

The study involved 3,397 migraine patients from 14 countries, 439 (13%) of whom were born in Spain, mostly women between 25 and 59 years of age who were employed at the time (72%). The greater part of the participants had suffered chronic migraines for over 10 years.

The most noteworthy results of the study are the following:

**37%**

4 or 5 specialists before migraine's **diagnosis**

**14%**

receive preventive treatment with **anti-CGRP** medication

**36%**

had to **pay** for the treatment themselves





# Over 5 years

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It takes migraine sufferers in Spain over five years to receive migraine treatment.

*Access to care study, 2022*



“ Despite the breakthroughs we are seeing in the knowledge and treatment of migraines, the fact is that healthcare for migraine sufferers in Spain has not undergone the same change. In 2009, an EMHA study identified the same needs that were now. ”

—Elena Ruíz de la Torre **EMHA**



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# Challenges in accessing migraine-related healthcare in Spain





The proceedings continued with a multi-disciplinary panel discussion with different experts.

The panellists offered their opinions regarding the potential improvement of healthcare for migraine sufferers in Spain.



**MODERATOR**  
**Iñaki Gutierrez-Ibarluzea**  
*IHT Scan Chairman*



**Verónica Sáez**  
*Chronic migraine Patient*



**Pablo Baz, PhD**  
*Primary care physician and coordinating member of the neurology task force of the SEMERGEN.*



**Pablo Irimia, PhD**  
*Neurologist and coordinating member of GECSN (Spanish Society of Neurology).*



**José Mª Sierra**  
*Pharmacists and member of the pharmaceutical-attention task force for neurological patients of SEFH.*



# Primary care

A patient's first contact with the healthcare system usually takes place at the primary-care stage.

Nonetheless, the healthcare received can be improved. Some professionals are unable to detect migraine symptoms, which causes delays in:



Proper  
diagnosis



Transfer to  
a specialist



Access to  
treatment

The main reasons for these deficiencies are the lack of **specialised training** of many doctors and the **lack of human and technical resources** at the healthcare level.



*"At the primary-care stage, migraine is often misdiagnosed as simple headaches."*

Pablo Baz, PhD



*"In the six years of studies required for a degree in medicine, only two hours are spent studying migraine."*

Pablo Irimia, PhD



# Poor coordination and communication among healthcare levels

The experts also spoke of problems of coordination and communication observed among different healthcare levels - primary care and specialised care. The creation of **direct channels of communication among professionals** working in primary care and specialised care would **improve diagnoses and treatment of migraine**.

*“Considering that primary-care doctors must deal with different illnesses and are unable to be experts in all of them, direct channels of communication with specialists would facilitate patients’ diagnoses”.*

Pablo Baz, PhD





# Heterogeneity and disparity in the patient journey

The patient journey of migraine sufferers may be heterogeneous, depending on where the patient lives. Not all patients have access to headache units or specialists near their places of residence.

Differences are observed among hospitals regarding access to preventive treatments. Some healthcare centres are not supplied with all available treatments (authorised and subsidised by the National Health Service). The panellists also commented on the need to raise awareness of monoclonal antibody treatments among neurologists who do not specialise in headaches.

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*“Some hospitals have only one monoclonal antibody treatment, and others have up to three different treatments”.*

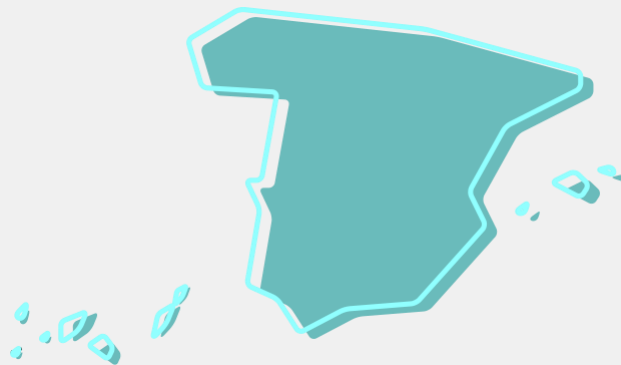
**Pablo Irimia, PhD**



## Dearth of headache units

Preventive treatments such as Botox and anti-CGRP medication must be administered or prescribed by specialists (neurologists). However, the existing dearth of headache units compounds regional disparities insofar as access to specialists and to treatments that are available only through specialists.

**Creating new headache units would offset this disparity.**





# Person-centred medicine

Despite the existence of clinical handbooks that establish treatment journeys, these guidelines are not always followed.

Furthermore, limited, vaguely defined and generic information on available treatments may lead to the prescribing of inefficient drugs, undesirable side effects, abandonment of treatment and self-medication.

In order to prevent this, we must not only follow clinical handbooks but provide each patient with personalised treatment. This is known as **person-centred medicine**.

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## National migraine strategy

The panellists stated that, in order to overcome the challenges of providing healthcare to migraine sufferers in Spain, a **nationwide strategy** must be implemented for the treatment of migraines and other headaches.

Such a plan must lay the groundwork necessary to **ensure equitable healthcare throughout in terms of access to healthcare and pharmacological treatments**, and, at the same time, **consider the taking of actions to raise awareness of the disease**.

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# Making migraine part of Spain's political agenda







The next panel discussion targeted the role of institutions. Among the panellists were representatives of patients' organizations, healthcare professionals and parliamentary spokespersons who are members of the Healthcare and Consumer Commission of Spain's Congress of Deputies.

The panellists discussed the following keynotes:

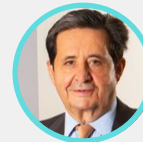
- Nationwide migraine **strategy**.
- Official recognition of **disability** associated with migraine.
- Access to therapeutic **innovation**.



**MODERATOR**  
**Iñaki Gutierrez-Ibarluzea**  
*IHT Scan Chairman*



**Isabel Colomina**  
*AEMICE's President*



**J. Miguel Láinez, PhD**  
*Spanish Neurology Society President*



**Juan A. Callejas**  
*Deputy Spokesperson of the Healthcare and Consumer Commission. PP Parliamentary Group*



**Juan Luis Steegmann**  
*Deputy spokesperson of the Healthcare and Consumer Commission. VOX parliamentary group*



**Agustín Zamarrón**  
*Member of the Healthcare and Consumer Commission of the PSOE parliamentary group*





# What should the nationwide strategy include?

On behalf of patients, Isabel Colomina urged the members of the Healthcare and Consumer Commission of the Congress of Deputies to submit to the government a proposal on the development of a **nationwide migraine strategy** that addresses all aspects of the subject -healthcare and social aspects- and all stages of the disease: diagnosis, treatment, social care, etc.

*“This strategy should ensure healthcare that is characterised by accessibility, specificity and continuity, without failing to address social care. Professional training is another matter that the strategy should address”.*

José Miguel Láinez, PhD



*“The Nationwide Strategy should include healthcare and social care, in all stages of migraine”.*

Isabel Colomina



Deputy **Juan A. Callejas**, representing the PP parliamentary group, spoke of the parliamentary initiatives that his party has backed in relation to migraine. He explained that, in response to a request made by AEMICE, in April 2022, his party submitted a non-legislative proposal urging the government to draft a nationwide migraine plan to facilitate a better approach to

relevant healthcare and social aspects, to bolster R+D+I and to facilitate access to state-of-the-art diagnostic testing, equipment and treatments. The deputies of VOX and PSOE expressed their interest in backing such initiatives, which **ensure the equity and quality of healthcare and higher quality of life for patients.**



# Migraine is a disabling disease



Data appearing in Spain's 2018 "Migraine Atlas" survey and study suggest that over half of migraine sufferers are affected by severe or very severe disability and that the proportion reaches 70% in cases of chronic migraines. Nonetheless, most patients are denied disability status, chiefly *"due to the lack of testing that would allow quantitative and objective calculation of the degree of disability associated with the disease"*, explained José Miguel Láinez, PhD.

Láinez proposed the **use of pain scales to gauge the impact of the disease**. In this regard, Juan A. Callejas suggested that it was necessary to invest in research for the development of tools for objective and effective measurement of degrees of disability of migraine patients.

*"Patients who do not respond to treatments should be given disability status, due to the significant impact of migraine on their lives".*

Isabel Colomina

50%\*

Moderate or severe disability

70%\*

Moderate or severe disability in chronic migraine



## Equity and Access to innovation



Juan L. Steegmann, deputy of the VOX parliamentary group, commented on the importance of access to therapeutic innovation as a means of taking a better approach to the disease, without failing to consider the importance of using cost-effective treatments.



The economic impact of therapeutic innovation must be studied in detail for the purpose of sound economic management of available resources.

Agustín Zamarrón, deputy of the PSOE parliamentary group, stressed the importance of ensuring compliance with pertinent legislation regarding cohesion and quality of Spain's National Health Service, which promotes equitable access of the country's citizens to healthcare. Spain's government recently submitted to Congress a so-called "Equity Act", although it failed to pass due to lack of consensus.

*"The cost of the most innovative drugs is less than the €12,000 cost of providing healthcare to a chronic migraine sufferer". JM Láinez, PhD*



*"I am very proud to act on behalf of many patients, and I hope and am confident that this will be the first of many steps.*

*Our National Health Service should meet the healthcare and social needs of over five million migraine sufferers in Spain. In this sense, **the Migraine's Nationwide Strategy is a means to that end**. For this reason, I urge all parliamentary groups to continue supporting such a necessary initiative".*

Isabel Colomina

95

Attendees



50

Hits in the press



8,111,210

Stimated Audience





# Summary video

You can view the video by  
clicking to image



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**AEMICE** ASOCIACIÓN ESPAÑOLA  
DE MIGRANA Y CEFALÉA

**EMHA** European  
Migraine &  
Headache  
Alliance

