



**EMHA** European  
Migraine &  
Headache  
Alliance



# The Missing Lesson

22 September 2020

Webinar organised by EMHA  
& hosted by Aldo Patriciello, MEP

On 22 September 2020, the European Migraine & Headache Alliance organised **'The Missing Lesson'** webinar to raise awareness about migraine at EU level and kick-start its EU policy advocacy campaign to make migraine a European health priority.

The webinar focussed on the medical curriculum deficit when it comes to migraine. This leads to under-diagnosis and under-treatment of migraine. This creates an unnecessary burden on the people, their family and society as a whole.

The webinar marked **'EU Migraine Action Day'** (12 September), a yearly EU event organised by EMHA to raise awareness about migraine.

## Introduction



Aldo Patriciello, Italian Member of the European Parliament (MEP), kindly hosted the webinar. In his introduction, Mr Patriciello indicated he was very happy to participate in this webinar as it raises awareness about migraine, a neurological disease that is often underestimated and treated as a simple headache, with poor interest from the institutions. Mr Patriciello stressed that migraine was the third most common disease in the world. It affects some 136 million EU citizens and over a billion people in the world. Migraine presents a gender bias: migraine is three times more common in women and affects them differently.

Migraine has a strong impact on individuals and society. As a consequence, migraine is a huge social burden in terms of healthcare and loss of productivity, with direct and indirect costs. Mr Patriciello referred to recent studies that indicate that the disease costs around € 27 billion in visits, medicines and lost workdays. Treatment options are much needed.

EU pharmaceutical standards ensure that medicines marketed in the EU are of high quality and safe for patients. In addition, specific rules exist for certain types of medicines such as advanced therapeutic medicines. These new technologies based on genes and cells offer new opportunities for neurological diseases, including potential drugs for migraine under development.

The EU has financed brain research for many years, including migraine projects. Horizon 2020, the current EU Research and Innovation Programme, has allocated over € 3 billion to better understand the brain, prevention and treatment of disease and care. A therapeutic revolution is now under way based on the prevention of attacks based on monoclonal antibodies.

It is for all these reasons that Mr Patriciello has joined the European Parliament Migraine Alliance, an informal group of MEPs who will focus on migraine. Mr Patriciello welcomed the idea of stimulating the European debate on migraine in order to increase its visibility within the EU public health agenda.

*Migraine has a strong impact on the individuals and society. It is a huge burden in terms of healthcare costs and loss of productivity. This is why I am joining the European Parliament Migraine Alliance to stimulate the European debate on migraine in order to increase its visibility within the EU public health agenda.*  
**Aldo Patriciello, MEP**

## The Missing Lesson

Three experts then took the floor to illustrate the webinar's theme.

### The professional experience with migraine



Peter Goadsby, Prof., MD, Director of NIHR Clinical Research Facility & Professor of Neurology, introduced the audience to migraine using a Norwegian definition that suggests that migraine attacks can last between 4 to 72 hours, are one-sided, with throbs that can be moderate to severe in intensity, movement making it worse. Nausea, vomiting, sensitivity to light and sound are other characteristics.

Prof. Goadsby stressed that migraine was much more than a simple headache. It is a disorder with repeated attacks: it can be episodic (< 15 days per month) or chronic ( $\geq$  15 days/month), it has a family history and responds to a number of biological factors (sleep, food, hormones, sensory triggers (light, smells...), alcohol, stress...). Migraine attacks have a range of manifestations: they start with premonitory (prodromal) symptoms with cognitive manifestations, yawning, food craving, passing urine..., moving on to canonical symptoms (pain, nausea, vomiting...) and ending-up in postdrome symptoms (tiredness, concentration problems...) and aura.

All this explains why migraine is a broadly disabling and a global problem. Nevertheless, Prof. Goadsby shared that the EU was a hotspot for migraine. This can be explained by the excellent work of the EU clinicians and investigators looking at the frequency of migraine.

Prof. Goadsby then looked at migraine across ages. Migraine is a disorder of people in their 'tax paying years', between the start of their working life and its end. Although people over 60 are also affected, this is much less than the peak which is at 40.

Migraine is more of a problem in women with 3 females for every male having migraine. Prof Goadsby remarked that one in three women in the EU has had a migraine attack in any year. The lifetime cumulative incidence of migraine is close to 43% for women and 10% for men.

Prof. Goadsby then explained that a one third prevalence at age 40 had quite an influence on primary care. The 'Landmark Study', a study that looks at patients turning up at primary care and keeping a diary to track their attacks, showed that 9 out of 10 people went to the doctors for a headache.

Despite migraine having been considered as the second most common cause of disability of people under 50 in the world in 1990, 2006 and 2015, Prof. Goadsby regretted more attention was not paid to this disorder.

Prof. Goadsby added we had tools to understand brain disorders such as migraine thanks to brain imaging that shows the different phases of migraine.

To conclude, Prof. Goadsby gave an insight into what is needed to better tackle migraine: we need more treatments and better ways to deploy the medicine that we currently have. His 'missing lesson' is that we need to invest to better understand the disease. The returns will be enormous because the cost of the burden affects a very large group of society.

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**Peter Goadsby, Prof., MD**



Then, Pablo Irimia, Prof, MD, Chair of the Headache Special Panel at European Academy of Neurology, talked about the professional experience.

To start, Prof. Irimia talked about the frequency of migraine: migraine and headaches are a frequent reason for consultation. Patients with headache constitute approximately 2 to 4% of emergency department visits. Headache accounts for 1 in 10 of the General Practitioners consultations, 1 in 3 neurology referrals and 1 in 5 of all acute medical admissions in neurology departments. In the end, migraine is the most common diagnosis between general practitioner and neurology consultations for headache.

Prof. Irimia then stressed that the lack of knowledge about migraine among the healthcare providers was 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.

*Only 4 hours of undergraduate medical education and 10 hours in specialist training are dedicated to headache disorders.*  
**Pablo Irimia, Prof., MD**

The consequences of this lack of knowledge was presented: in Spain, for instance, the delay to have a migraine diagnosis is 6 years. Surveys carried out in Europe have revealed that professional care is unavailable, fragmented or difficult to access for many patients, in particular when it comes to specialised care units. Specialised headache units in Europe are insufficient.

Other consequences are that Europeans patients are left in the dark: they do not receive adequate treatment and auto-medicate themselves with pain killers. Population-based studies show that less than 20% of people with migraine had seen a GP and less than 15% had seen a specialist. This is substantiated by the fact that healthcare providers do not know how to treat migraine: only 22% of patients were prescribed triptans (migraine medication) and only 13% of those eligible received preventive medication.

As the implementation of good headache healthcare is cost-saving, Prof. Irimia provided some recommendations for redressing the situation: undergraduate medical education on migraine must be improved, primary care physician have a key role to play provided they receive training to improve their migraine skills, more specialised head care units are needed to treat complex patients and lead clinical research, post-gradual teaching on headache disorders.

Prof. Irimia delivered some key messages to improve the situation: the lack of education is the key issue impeding the good management of migraine. It is therefore essential to improve undergraduate medical training to better apprehend the frequency of migraine and differentiate headaches from migraine. In Europe, the development of under-graduate and post-graduate curricula on migraine is badly needed.

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**Pablo Irimia, Prof., MD**

## Patient experience with migraine



Elena Ruiz de la Torre, Executive Director European Migraine and Headache Alliance (EMHA) illustrated the two previous presentations by talking about patients' experience of living with migraine. She first mentioned a recent EMHA survey looking at how long it took the survey participants to get a good diagnosis. For close to 38% of them, it took more than 5 years, long enough for the migraine to become chronified. For close to 29% of the participants, it took more than 5 years to get an efficient treatment while 55% had not received a treatment yet. 27% of the participants had to visit between 5 to 10 practitioners, which is rather challenging considering migraine is a common disease. That also demonstrates that quite a number of people are still needing a diagnosis and treatment. The survey also highlighted a clear lack of information with 76% of the participants declaring having resorted to consult other sources of information beyond their doctor or specialist. This presents a high risk for the patients having access to unreliable information.

To illustrate how difficult it is for migraine patients to receive a diagnosis and treatment, Ms Ruiz de la Torre showed [The truth behind migraine](#) video where people with migraine from different EU countries present their own experience.

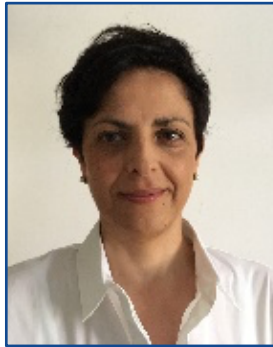
Then Ms Ruiz de la Torre spoke about her personal experience to show how migraine had impacted her life. Migraine hit her when she was 12 years old. Migraine was a condition running in the family: her mother was affected and knew what her daughter would have to put up with. Since then, Ms Ruiz de la Torre's life has been conditioned by migraine. When the migraine attacks started, one would have expected that such a common disease would lead to receiving a diagnosis and treatment, good healthcare and follow-up to control the disease. This was not the case and the condition deteriorated. Migraine became severe. Ms Ruiz de la Torre had to trail through the diagnosis and treatment labyrinth: she visited a number of doctors, was misdiagnosed, developed Parkinson's disease as a side-effect of a preventive therapy and consequently moved on to chronified migraine. The intervention of a new doctor and Ms Ruiz de la Torre going through the menopause succeeded in migraine reverting to episodic before the condition deteriorated again. Eventually, the specialist that Ms Ruiz de la Torre consulted could prescribe a treatment (a new CGRP) that is unfortunately not easily accessible.

Ms Ruiz de la Torre then made a striking summary of how migraine had affected her life. Since her first attack when she was 12, Ms Ruiz de la Torre, now 59, has lost 104 days/year due to the frequency of her migraine attacks. This amounts to 4,888 days during her 47 years of life with migraine. In the end, Ms Ruiz de la Torre will have lost 13.4 years of her life (an eternity to her) due to migraine and will have really lived 45.6 years.

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**Elena Ruiz de la Torre**

Nevertheless, thanks to the diagnosis and support Ms Ruiz de la Torre received and despite ups and downs, she has been able to fully engage in migraine patient advocacy.

## How can the European Commission help redress the situation?



Monica Ensini, European Commission, DG Research & Innovation, Policy and Programme Officer 'Combatting diseases', presented the current activities in brain research under Horizon 2020 and gave an overview of what Horizon Europe, the next programme for 2021/2027, will hold for brain research.

Based on all our knowledge about the burden of migraine, Ms Ensini stated that brain and mental health will be central to EU research in the next years.

She then showed that brain research was gaining importance: the funding allocated to research across the whole spectrum amounts to over € 3 billion

in Horizon 2020. She particularly mentioned Neuron, a European Research Area Networks project, that coordinates national research activities and will develop a strategic research agenda. She also mentioned IMI (Innovation Medicines Initiative), a public-private partnership that looks at speeding-up the development of innovative medicines that are much needed, as is the case for migraine. Moreover, EBRA (European Brain Research Area) is an EU-funded Coordination and Support Action project led by the European Brain Council. The focus is to develop a shared brain research agenda by mapping the brain research landscape, identifying priorities, actions and gaps in brain research. The agenda should feed the development of a possible 'European Partnership on Brain Health'. EMHA is invited to bring the migraine perspective to both EBRA and the Partnership if it finally materialises.

*Based on all our knowledge about the burden of migraine, brain and mental health will be central to EU research in the next years.*

**Monica Ensini, European Commission, DG Research**

Ms Ensini then presented Horizon Europe, the next research and innovation programme that will build on the achievements of Horizon 2020 and maintain its three-pillars structure. In particular, Pillar 2 will contain the Health Cluster while Pillar 3 will focus on facilitating innovations entering the market. Ms Ensini added that there was a new player, the European Innovation Council, which will facilitate the translation of research into real life. Horizon Europe will strengthen open collaboration, at EU and international level.

Ms Ensini then went into more details about the Health Cluster where one of the priorities identified is to tackle diseases and reduce disease burden. Emphasis is being put on better understanding diseases, their drivers and consequences (including pain and the causative links between health determinants and diseases), therefore migraine is included. Moreover, emphasis is also given to better methodologies and diagnostics that allow timely and accurate diagnosis, identification of personalised treatment options, innovative health technologies developed and tested in clinical practice. This includes personalised medicine approaches and use of digital tools, new and advanced therapies for non-communicable diseases, developed in particular for those without approved options.

## The way forward

As heard during the presentations, migraine is still an overlooked disease at EU and national level that calls for immediate action to relieve the burden. This gave Ms Ruiz de la Torre the opportunity to launch EMHA's [Call to Action](#), a policy advocacy document listing EMHA's different policy calls towards the European Commission, the European Parliament (EP) and the national governments.

As migraine has many facets, it must be mainstreamed in all EU policies and significant research funding must be allocated for migraine and brain research. The implementation of relevant EU

legislation (like the Work Life Balance Directive) or the European Pillar of Social Rights must pay due attention to migraine. EMHA wishes to count on the support of the EP to help raise awareness and drive the EU health policy agenda ensuring that migraine is featured in all EP work. EMHA particularly calls on the setting-up of an EP Migraine Alliance to support the migraine community. As NGOs play a significant role in shaping their national health agenda, EMHA calls on the national governments to support migraine NGOs in raising awareness about migraine, consult them to prepare and implement national migraine strategies and policies that will reduce the burden of migraine. EMHA also calls upon national governments to dedicate sufficient funding to migraine research.



Ms Nathalie Colin-Oesterlé (MEP – France) concurred that migraine was still an overlooked disease and consequently not taken seriously enough. She regretted we do not know the real number of people affected.

During her professional life, Ms Colin-Oesterlé came across a number of people who were affected by migraine. This is why she fully understands how this disabling disease affects their personal and professional life.

*It is important to recognise the disease, raise awareness about it in order to increase research and respond to the needs of people affected by migraine. This is why I am happy to join the EP Migraine Alliance.*

**Nathalie Colin-Oesterlé, MEP**

Ms Colin-Oesterlé pleaded it was important to recognise the disease, raise awareness about it in order to increase research and respond to the needs of people affected by migraine. These are the reasons why she was happy to join the EP Migraine Alliance, alongside her MEP colleague, A. Patriciello and support EMHA's work. She officially launched the EP Migraine Alliance.

Too many people with migraine are still left aside. The Question and Answer session that followed confirmed that urgent action needs to be taken to profile migraine onto the EU and national agenda. The webinar participants all agreed to support EMHA in doing so. EMHA will now propose some actions and count on the EP Migraine Alliance as a key EU ally.

Over 40 people registered to the webinar, spanning a large audience: EU representatives, migraine associations representatives, brain and neurological diseases NGOs, health and women NGOs, pharmaceutical industry representatives. The webinar outcomes will also be shared with all those who expressed an interest in the event but could not participate.

#### **More on migraine and EMHA's work**

The Missing Lesson on Instagram :

<https://www.instagram.com/themissinglesson/>

The Migraine Movement <https://themigrainemovement.com/>

EMHA on Twitter : @EMHAlliance

Facebook : <https://www.facebook.com/EMHAlliance/>

<https://www.emhalliance.org/>



European Migraine Action Day (12 September) is an opportunity to raise awareness about migraine. This year's theme is 'The Missing Lesson'. This webinar will highlight the evidence that the medical education must be improved across the European Union to better diagnose and treat migraine.

Migraine is not just a bad headache: it is a serious, distinct and complex neurological disease. It is a common and invisible life-span disease that affects over 41 million Europeans. Migraine often begins at puberty and mostly affects people aged between 35 and 45 years, during their most productive years. It is also common in children: about 10% of school-age children and up to 28% of adolescents between 15-19 years.

Migraine is a costly disease and a cause of temporary incapacity during the attacks. It continues to be under-diagnosed and under-treated. Today, the medical education still dedicates too little time to migraine.

**22 September 2020**

**12h00 / 13h30**

**Webinar organised by EMHA  
and hosted by Aldo Patriciello, MEP**

**Introduction and welcome**

**Aldo Patriciello**, Member of the European Parliament

**The Missing Lesson**

**Introduction**

**Peter Goadsby**, Prof., MD, Director of NIHR Clinical Research Facility & Professor of Neurology

**Professional experience**

**Pablo Irimia**, Prof, MD, Chair of the Headache Special Panel at European Academy of Neurology

**Patient testimony**

**Elena Ruiz de la Torre**, Executive Director European Migraine and Headache Alliance

**How can the European Commission help redress the situation?**

**Monica Ensini**, DG Research & Innovation, Policy and Programme Officer 'Combatting diseases'

**The way forward**

**Launch of EMHA Call to Action**

**Elena Ruiz de la Torre**

**Launch of the EP Migraine Alliance**

**Aldo Patriciello, MEP  
Nathalie Colin-Oesterlé, MEP**

**Question and answers  
Close of the meeting**



## *Migraine in Europe: Time to Act Now!*

### Call to Action for a comprehensive EU action on migraine

#### EUROPEAN COMMISSION

- Make migraine a EU health, social and research priority
- Ensure neurological disorders like migraine receive due attention in the Commission's current and future work (gender equality, demographic change, pharmaceutical strategy, disability, education, social affairs)
- Include a 'Brain Mission' In Horizon Europe that also looks at migraine
- Dedicate a significant and long-term funding in neurological disorders medical and social research (Horizon Europe, IMI) to fill the migraine knowledge gap
- Ensure all Artificial Intelligence developments at EU level respond to the needs of people with migraine
- Ensure the implementation of the Work-Life Balance Directive positively affects the migraine community
- Ensure migraine is included in the delivery of the European Pillar of Social Rights and the European Semester

#### EUROPEAN PARLIAMENT

- Support the setting-up of a Migraine Alliance in the EP to raise awareness, influence policies and develop migraine initiatives
- Ensure migraine is enshrined in the EP work on disability, gender equality, demographic change, the pharmaceutical strategy
- Include migraine in the EP work on health (depression, pain, women's health)
- Steer initiatives to better understand migraine, its development, how it affects society as a whole and how to improve the situation
- Help join forces to fight stigma associated with migraine
- Invite MEPs to be migraine ambassadors at EU and national level

#### NATIONAL GOVERNMENT

- Support migraine awareness campaigns to educate the public about the differences between migraine and headache
- Develop national migraine strategies with the involvement of migraine patient associations
- 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
- Help break the stigma associated with migraine to empower people with migraine and society to be fully inclusive of people with migraine
- Adapt school and work-place legislation to give people with migraine equal opportunities to contribute to society
- Increase migraine research funding to better understand how the disease develops and affects patients and develop treatments
- Support migraine associations as key partners in awareness-raising, professional education, social support and drug development