

# WHEN YOUR LIFE TURNS INTO A WAITING ROOM

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EXPERT SEMINAR  
IMPROVING ACCESS TO MIGRAINE CARE  
IN CZECHIA

13. 9. 2022, SNĚMOVNÍ 7

**EMHA** European  
Migraine &  
Headache  
Alliance



# FOREWORD



Migraine is one of the **most common neurological diseases**. Nevertheless, it is underestimated and still **underdiagnosed and undertreated** throughout Europe. Patients who struggle with this disease are subsequently limited in their personal and professional lives, which has, among other things, a secondary social and economic impact on them.

We decided to contribute to changing this situation. Patient organization Migréna-help in cooperation with the European Migraine & Headache Alliance (EMHA), the Czech Headache Society and the pharmaceutical industry organized a professional seminar "Improving Access to Migraine Care in Czechia", which took place on September 13, 2022, in the event centre Sněmovní 7 in Prague 1.

During the seminar, the participants were introduced to both the issue of migraine and the experiences of Czech patients; together they also discussed the possibilities of ensuring early access to diagnosis and effective treatment for migraine patients. As part of the event, the **results of an extensive study prepared by KPMG, which mapped in detail the availability of migraine treatment across the European Union**, were also presented, as well as subsequent national studies focused specifically on the experiences of Czech patients.

The seminar was attended by representatives of the state administration, health insurance companies, patient organizations, and the professional public. The seminar was held **under the auspices of MUDr. Roman Kraus, MBA**, Chairman of the Senate Health Committee of Parliament of the Czech Republic.



## Tip:

*The entire document is interactive.  
Underlined items will redirect you  
to more information.*



# WHAT WAS SAID AT THE SEMINAR?

## Greetings from the European Parliament

The opening speech was given by the chairwoman of Migrena-help, Mgr. Rýza Blažejovská, DiS. and EMHA Director Elena Ruiz de la Torre. Greetings were sent by MEP Dott. Martina Dlabajová, who spoke about the stigmatization of migraine, her own experience with this disease, and the working group in the European Parliament that deals with migraine:



The video can be played [here](#).

*"I have a lot of respect for the Migrena-help patient organization for being so involved in this issue. I appreciate its efforts to spread awareness and destigmatize migraine and I am very happy that thanks to this we are gradually moving forward. But we are undoubtedly moving forward also because there is more talk about the need for early diagnosis of migraine, which is key to its successful treatment. Also, because this disease is being emphasized, there is a working group in the European Parliament that deals with it and points to it, for example, on the health committees."*

Dott. Martina Dlabajová



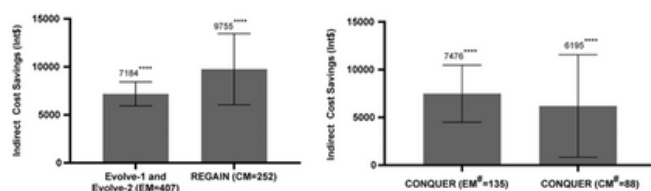


# A BILLION PEOPLE WORLDWIDE ARE STRUGGLING WITH MIGRAINE

Professional presentations followed - the first speaker was the chairman of the Czech Headache Society MUDr. Tomáš Nežádal, PhD. on the subject of **Migraine and its treatment in the Czech Republic:**

- Migraine affects women more often, it is the **second most disabling diagnosis worldwide**, and nearly one billion people worldwide suffer from the disease. In total, this is 17% of women and almost 6% of men.
- Up to 1% of the population suffers from so-called chronic migraine, due to which they are "out of action" for more than half a month.
- 33% of patients report that headaches have affected their career; 3% of patients reported that they chose not to have children, delayed conception, or had fewer children because of migraine.
- We are currently in a **new era of prophylactic (i.e. preventive) migraine treatment** - the so-called anti-CGRP treatment is now available. Treatment significantly reduces the indirect costs of migraine to society.
- According to MUDr. Nežádal, one of the problems in the Czech Republic is the limited financial budget of the Headache Center and the lack of personnel capacity.

## Redukce nepřímých nákladů při CGRP terapii



Tobin J, Ford JH, Tackenberg-Henderson A, Nichols RM, Ye W, Shandell R, Ma K, Sharma K, Lipton RB. Annual indirect cost savings in patients with episodic or chronic migraine: post hoc analyses from multiple placebo-controlled clinical trials. J Med Econ. 2022 Jan Dec;27(1):430-439.



# HEADACHE CENTERS HAVE LIMITED BUDGETS

MUDr. Jolana Marková, FEAN, head of the Center for Diagnosis and Treatment of Headaches at the Thomayer Hospital, took the floor as the second and focused on the way of **organizing care for migraine patients in the Czech Republic**:

- The so-called "**recommended patient path**" is the procedure that a patient should follow if they suspect they have a migraine: first contact a general practitioner, in case of more frequent attacks, seek a neurologist, and, after unsuccessful treatment attempts, visit a specialized centre. There is currently a total of 31 centres for the treatment and diagnosis of headaches in the Czech Republic.
- The survey, which mapped the views of the doctors from the Centres on their functioning, showed that the frequent reason for not using anti-CGRP treatment was for 26% of doctors the fact that the centre **does not have a contract with the given insurance company**.
- According to MUDr. Marková, FEAN, a limitation to the full functioning centres is also the fact that some have a limited budget contracted with health insurance companies, which **does not allow them to treat all patients indicated for treatment**, and burdens doctors with the administration of repeated applications for new patients.
- The most frequently mentioned methods of improving the availability of anti-CGRP treatment in the survey among doctors were mainly an increase in staff capacity and more time for migraine patients, or office hours reserved only for patients with this diagnosis (both mentioned by 26% of doctors).

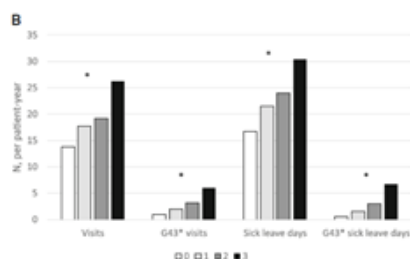


# THE SOCIETAL COST OF MIGRAINE IS HIGH

Another presenter was the founder of the Institute for Health Economics MUDr. Tomáš Doležal, PhD., who focused on the **socioeconomic impacts of migraine** and presented the newly established national **information registry ReMig**, which collects information on patients treated with anti-CGRP therapy:

- Patients affected by chronic migraine in particular feel the **economic impact**, especially in connection with their inability to fully function in their work and personal life.
- One of the biggest problems is the **huge number of patients outside the treatment system**, i.e. patients who do not deal with the disease or do not know that they suffer from the disease and that it can be treated. However, the trend is improving - last year about two hundred patients were added to the register, and this year already eight hundred.
- Using data from the ReMig registry, MUDr. Doležal, PhD. illustrated the concrete benefits of the innovative treatments: Thanks to it, up to 15% of patients can function without acute treatment. Only a small part of patients ends the therapy prematurely due to insufficient results or side effects.

Se závažností migrény roste zátěž zdravotního systému i ekonomické dopady



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# INNOVATIVE TREATMENT IS USELESS IF WE DO NOT HAVE ACCESS TO IT

In the next part, the executive director of the European Migraine Alliance, Elena Ruiz de la Torre, took the floor, presenting the results of **a European study on the availability of migraine treatment**, as well as an engaging illustrative video:

- On average, a European patient must visit 4 to 8 specialists before receiving adequate medical help. The problem is the **enormously long time it takes to diagnose the disease** - from 3 to 8 years.
- Europe-wide, health insurance companies do not have sufficient funds to provide innovative treatment for all patients, with **25% of patients having to pay for this expensive treatment out of pocket**.
- The majority of those not taking the new anti-CGRP treatment stated that the main barriers to their access were: their doctor did not mention the treatment (26%), the treatment was not covered by their health insurance (25%), they were not eligible for the treatment (25 %), for 10% treatment is not available in the country.



The video can be played [here](#).

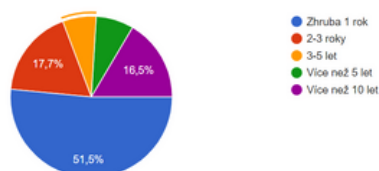


# 87% OF PATIENTS WOULD LIKE TO GET AN EFFECTIVE MIGRAINE TREATMENT

The results of a follow-up **Czech study on the availability of migraine treatment**, including specific experiences of Czech patients, were presented by Migrena-help chairwoman Mgr. Rýza Blažejovská, DiS.:

- In 43% of cases, a **Czech patient must visit 2 to 3 specialists** before getting a correct diagnosis of his illness: usually, it is years of waiting.
- Approximately **a quarter of people in the Czech Republic wait for 2 to 5 years for the first treatment**, and another quarter even longer than 5 years.
- A big problem is also the **overuse of often inappropriately chosen medicines**, which then cause headaches; the patient, therefore, suffers from two problems at once.
- **Innovative treatment is cited by Czech patients as the most difficult form of migraine treatment to access.** The main reason is the stigmatization of the disease when the doctor does not take the patient's problems seriously, the insufficient number of centres/their insufficient capacity, and the long waiting time to see a specialist.
- 19% of respondents changed migraine treatment at some point in their life because it was too financially demanding for them. For 34%, the cost of all migraine treatments has a **significant impact on their finances**.

Jak dlouho trvalo, než Vám po stanovení diagnózy migréna byla poskytnuta první léčba tohoto onemocnění?  
491 odpovědí





# INNOVATIVE TREATMENT CHANGED MY LIFE, BUT THE ROAD TO IT WAS ALMOST ENDLESS

Mgr. Rýza Blažejovská, DiS. also mentioned the **specific experiences of patients** who shared them in the survey [Access to Migraine Care in Czechia](#). The survey took place in the first half of 2022 and a total of 521 respondents took part in it.

- "Living with chronic headaches is not easy. Thank God for innovative treatment. I have only been on treatment for a month and already I **have less pain**. I wish someone had **informed me sooner about what was happening to me**. All I heard from neurologists was that I have a headache because I do not move much and sit at the computer. So, I lived thinking that **it was my own fault**. It went too far, and then **I brought myself to the worst possible condition** by taking too many painkillers. For half a year I was in pain every day. I was not living life, I was surviving. The worst part was that there was nothing I could do about it, there was no way to speed up getting a new treatment. **I did not have enough money** to pay for the innovative treatment myself. So, there was nothing else left, then **just waiting and hoping**. I would not wish that on anyone. Thank you for what you are doing."

Respondent of the survey Access to Migraine Care in Czechia, 25-44 years old, with chronic migraine, South Moravian region

- "There is a big difference in the numbers before the innovative treatment when I was in **constant pain and over 20 migraine days a month** - and I had to overuse analgesics and all the physiotherapy, psychotherapy, nutritional supplements, etc., and it **cost me a lot of money** - and the situation now, when I have innovative treatment: **Seizure frequency is lower** and budget costs are not so high anymore. I learned about innovative treatment from you, **so you changed my life**. Thank you!"

Respondent of the survey Access to Migraine Care in Czechia, Petr, 25-44 years old, with chronic migraine, Prague



# RECOMMENDATIONS TO IMPROVE THE ACCESS TO MIGRAINE CARE IN CZECHIA

At the end of the seminar, several recommendations and concrete steps were presented to improve the access to migraine treatment in the Czech Republic:

- **Well-organized care**
- **Treatment based on the lege artis principle**
- **Political support for the availability of effective treatment**
- **Education of healthcare workers**
- **Improving patient and public awareness**
- **Migraine-map: a map of care availability**

## Specific steps:

- The general practitioner **correctly diagnoses** migraine and **does not underestimate** the patient's problems.
- The neurologist **indicates relevant preventive treatment**.
- The neurologist **warns of the danger of overuse** of triptans and analgesics.
- The neurologist **will refer** the patient to the centre **in time**.
- Centres are **available equally** in all regions of the Czech Republic.
- The centres have sufficient **personnel capacities**.
- The centres have **sufficient budgets** for both existing and new patients.
- The centres have contracts **with all health insurance companies**.
- Patients are **informed** and adhere to the treatment.
- For discussion: **Easing the indication criteria** for innovative treatment.





# SEMINAR RECORDING

You can find a recording of the entire seminar in both Czech and English on the [YouTube channel](#) of the Migrena-help organization:



The video can be played [here](#).



The video can be played [here](#).





# ORGANIZATIONS MIGRENA-HELP AND EMHA

**Migrena-help** is the 1st patient organization in the Czech Republic that helps people with migraines. They are trying to make people with migraines more informed, more resilient, and able to work and live better with their disease. It spreads awareness about migraine, provides information service and advice, mediates psychotherapy, coordinates sharing circles in which people with migraine support each other, and carries out its own surveys or the Migraine festival brings us together. It has also been involved in the development of a mobile app and much more. Migraine-help is a non-profit organization, that provides most services for a nominal fee or completely free of charge.

**Contact:** [www.migrena-help.cz](http://www.migrena-help.cz), e-mail: [migrena.hep.zs@gmail.com](mailto:migrena.hep.zs@gmail.com), FB, IG: Migréna-help, tel: +420 777 776 056

**European Migraine & Headache Alliance (EMHA)** is a non-profit organization that brings together more than 33 associations of patients with migraine, cluster headaches, trigeminal neuralgia, and other headaches across Europe.

## SPONSORS

The seminar took place thanks to the kind support of the following partners:

