

The Migraine Movement

ACTIVITIES REPORT FOR 2021



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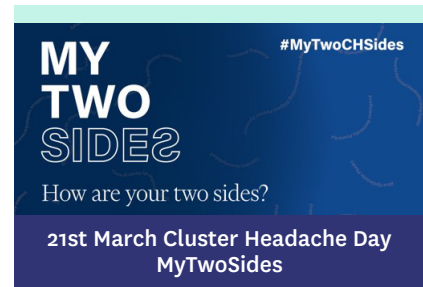
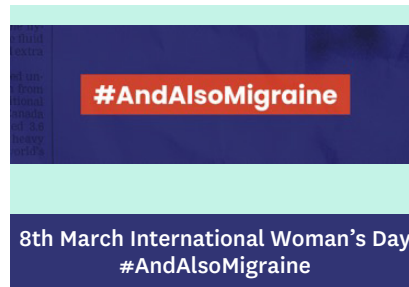
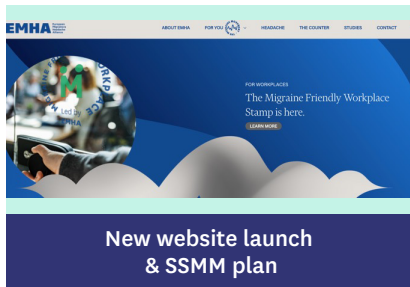
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1.The Migraine Movement



1.1 Activities Recap 2021

The Migraine Movement
as an umbrella.



1.2 Awards



EMHA
WINNER-EFNA ADVOCACY AWARDS
March 2021

Action Against Stigma
The truth behind Migraine



THE MISSING LESSON
SILVER-ASPID AWARDS
April 2021

Best educational programme
and scientific services to professionals.



THE MISSING LESSON
HONORABLE MENTION - WINA FESTIVAL
June 2021

Health & Pharma / Digital. Medications, Drugstores
The truth behind Migraine

2.EMHA activities for Cluster Headache 2021

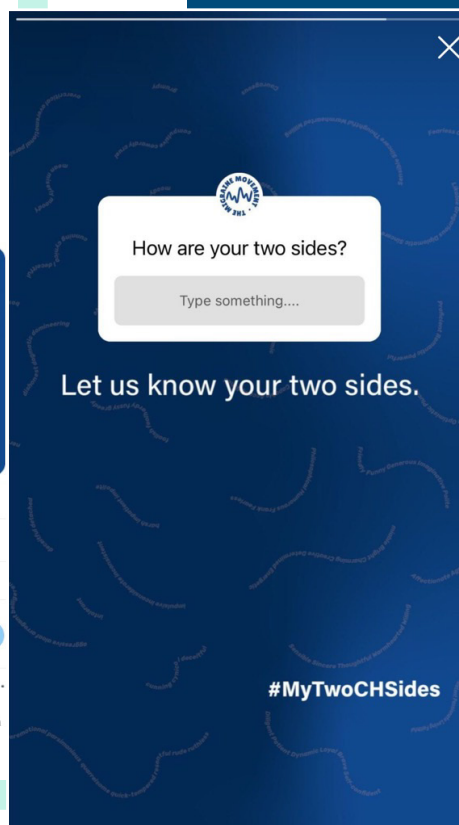
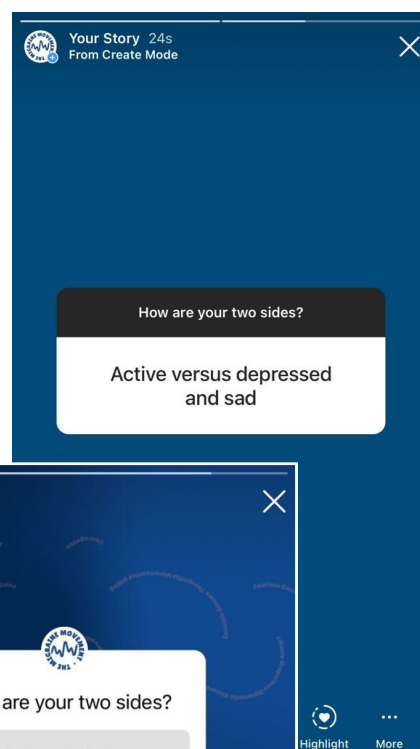


2.1 Cluster Headache Group

21st March- Cluster Headache Awareness Day CH: My Two Sides.

To portray how different CH sufferers' lives can be when they have a Cluster episode and when they are not under one.

Patients participated by describing with adjectives or short phrases, how their life was like during both, their cluster episodes and when they were not having them.



2.1 Cluster Headache Group

November 2021- Cluster Headache Webinar.

Webinar devoted to the EMHA Cluster Headache Group and all EMHA member's to inform about the "Latest news on CH"

Counting with the participation of experts like Prof. Pozo-Roschil or Prof. Goadsby.

The screenshot shows a webinar interface. On the left, a presentation slide titled "Classification" is displayed. It features a circular logo with the word "Clinical" and a list of Trigeminal autonomic cephalalgias (TACs) under the heading "3. Trigeminal autonomic cephalalgias (TACs)". The list includes:

- 3.1 Cluster headache
 - 3.1.1 Episodic cluster headache
 - 3.1.2 Chronic cluster headache
- 3.2 Paroxysmal hemicrania
 - 3.2.1 Episodic paroxysmal hemicrania
 - 3.2.2 Chronic paroxysmal hemicrania
- 3.3 Short-lasting unilateral neuralgiform headache attacks with conjunctival injection and tearing (SUNCT)
 - 3.3.1 Short-lasting unilateral neuralgiform headache attacks with conjunctival injection and tearing (SUNCT)
 - 3.3.1.1 Episodic SUNCT
 - 3.3.1.2 Chronic SUNCT
 - 3.3.2 Short-lasting unilateral neuralgiform headache attacks with cranial autonomic symptoms (SUNA)
 - 3.3.2.1 Episodic SUNA
 - 3.3.2.2 Chronic SUNA
- 3.4 Hemicrania continua
 - 3.4.1 Hemicrania continua, remitting subtype
 - 3.4.2 Hemicrania continua, unremitting subtype
- 3.5 Probable trigeminal autonomic cephalalgia
 - 3.5.1 Probable cluster headache
 - 3.5.2 Probable paroxysmal hemicrania
 - 3.5.3 Probable short-lasting unilateral neuralgiform headache attacks
 - 3.5.4 Probable hemicrania continua

On the right side of the interface, there is a search bar labeled "Buscar un participante" and a list of participants with their initials and names, along with icons indicating their status (e.g., microphone, video, chat).

3.Communication Plan 2021



3.1 Social Media Networks

Strategy: On 2020 we worked on building a community, As from 2021 onwards we will work on making that community stronger and increase the engagement. With more in depth knowledge of EMHA's audience needs, we adjusted the tone and message in each social network, with the aim of covering different audiences based on their knowledge of migraine and the EMHA. We named them "The Migraine Movers"

Campaign Actions 2021

- 01. #AndAlsoMigraine (Women's Day)
- 02. Together Talks
- 03. The Counter
- 04. Access to care Survey
- 05. 12th September

Content Lines by verticals

The Migraine Movement

- 01. Women and migraine
- 02. Migraine at work
- 03. European Parliament
Migraine Alliance
- 04. Dayketing

Migraine 101

- 04. The Impact of Migraine:
Data Content
- 05. Is it migraine?

The Dark Room

- 06. Smile! Migraine is watching
- 07. FOMO I have a migraine

Campaign Actions 2022

- 01. Women's Day
- 02. The Counter
- 03. Migraine Friendly Workplace
- 04. 12th September
- 05. The Migraine Movement branding
- 06. Boost actions

3.2 New website launch

& Social Media plan review.

Organise the information, improve the accessibility to it and keep working on a content-driven strategy which adds value to our audience.

With deeper knowledge on the audience's needs, the content and media strategy gained more relevance than ever.



3.3 Social Media Results

The EMHA's community gains strenght.

1.195.311

People reach on our social media channels thanks to the sum of the activities of The Migraine Movement.

+32,47%

Increase in the number of **followers** of social networks (4845)

209,83%

Engagement with our social media content.

82,38%

Decrease in rebound rate in EMHA's website.

*RESULTS FROM JANUARY TO DECEMBER 2021 COMPARED TO SAME PERIOD 2020.



4.EMHA activities and projects 2021



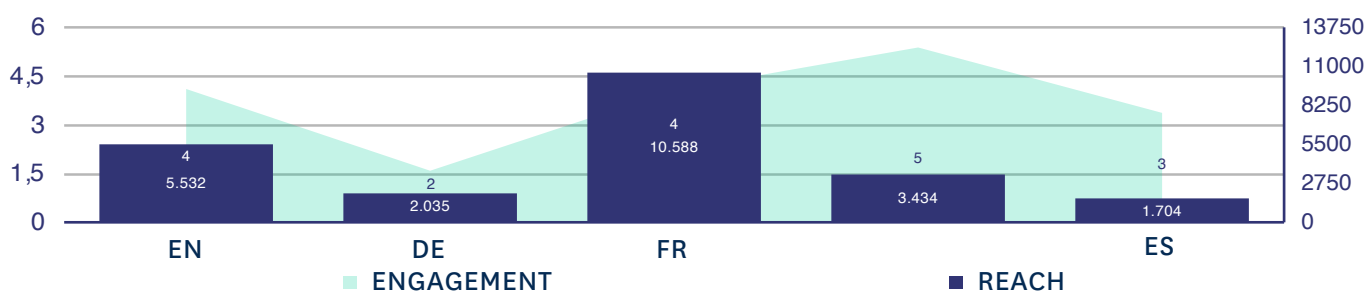
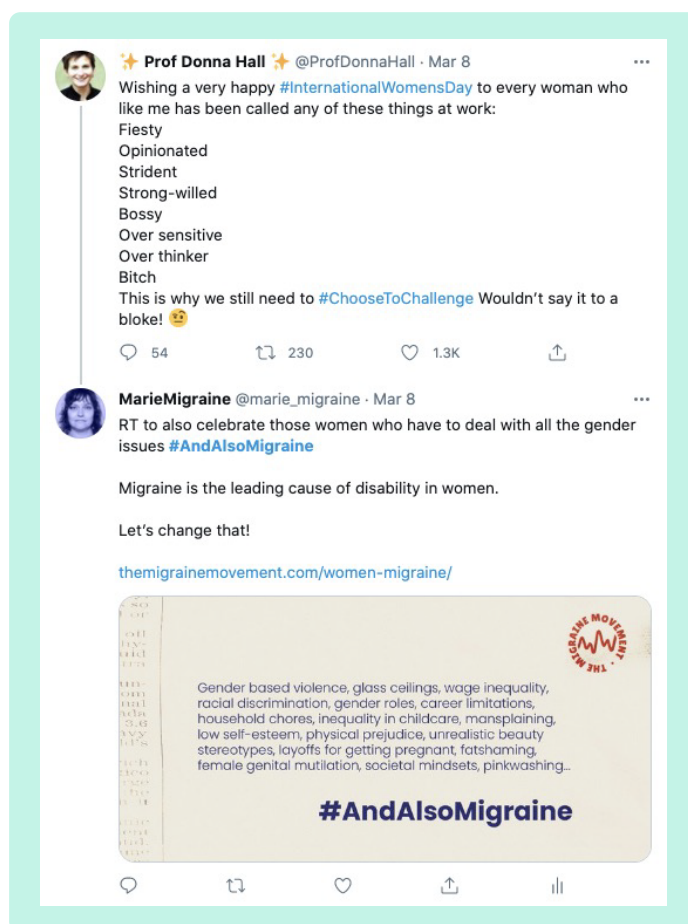
4.1 International Women's Day Activity

#AndAlsoMigraine

To raise awareness on migraine, give notoriety to the disease and put on the spotlight that women have to deal with all the gender issues as well as migraine.

Activity: Using a real time action on twitter, with 5 different profiles in 5 different languages, the action consisted of sharing/retweeting all the European campaigns and publications about Women's Day of other entities or people, following them by the hashtag **#AndAlsoMigraine**.

We reached a total of **23.293** twitter users, generating **938** interactions with our communications with a **4,03%** of engagement.



4.2 The Counter

The Counter is the tool which EMHA created to put on evidence **how many migraine sufferers are around the world**, to show society and Policy makers that there is a huge number of migraine sufferers around the world.

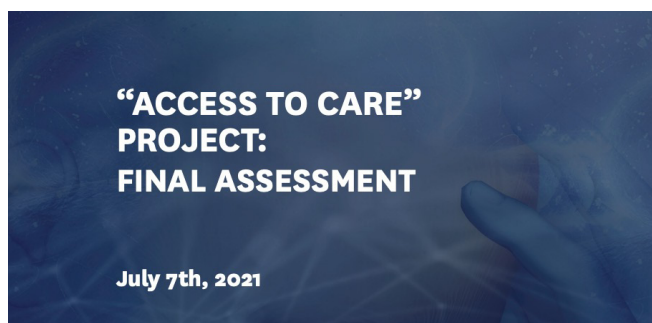
Users visiting the tool would be able to know how many patients have been diagnosed, the type of migraine more prevalent at each country, gender, age...etc



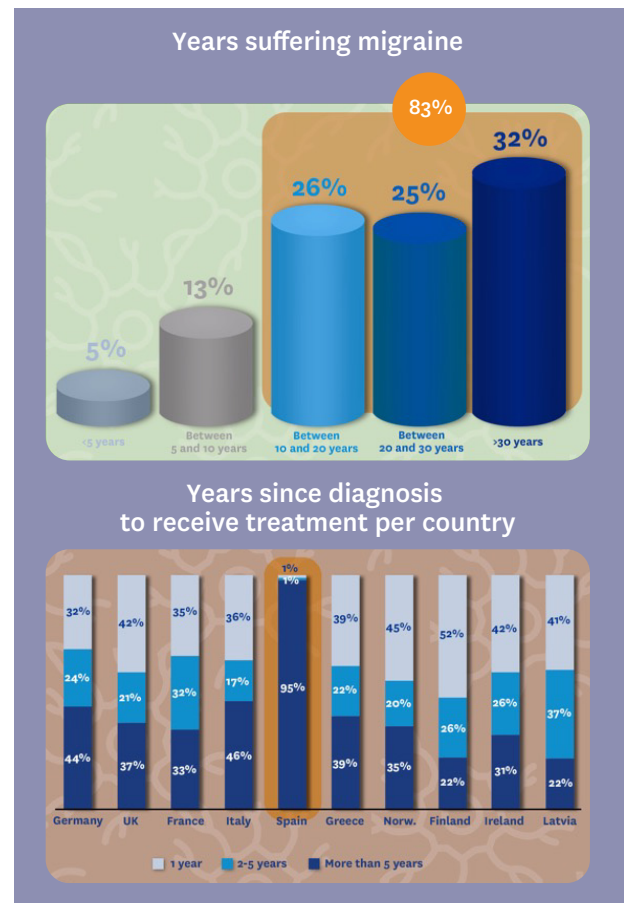
4.3 Access to Care

EMHA worked along with KPMG on a market research to understand the patient journey and burden of disease for migraine in 12 countries. The Access to care survey 2021 has shown insightful results on the patients' access to treatment and care in each of the countries. Read the full analysis here:

<https://www.emhalliance.org/project/access-to-care-survey-2021/>



Launch of Access to Care Survey: 29th Webinar.



To amplify the scope of the survey, the European Migraine & Headache Alliance (EMHA) organised a webinar “Migraine in the EU: Lifting the barriers to treatment” 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 webinar was hosted by MEP Deirdre Clune and included presentations from speakers such as Elena Ruiz de la Torre (EMHA’s executive director), Fiona Dubernet (La voix des Migraneux), Prof.MD. Peter Goadsby, Katarzyna Ptak-Bufkens (Policy Officer European Commission), Inaki Gutierrez-Ibarluzea (HTA International), Juan José Fernández Romero, (Policy Assistant, European Patients Forum) and Annette Dumas (EMHA’s policy affairs)

4.3 Access to Care

The Impatient Chair.

To create awareness for migraine, to spread the **Access to Care Survey** main insights and for all of the targets to sign a joint statement to be distributed among policy makers.

To sign the statement:

<https://www.emhalliance.org/for-policy-makers/#migraine-sufferers>

We rely on the data of the **“8 years of waiting”** to argue the message and impact the reader in a relevant way.

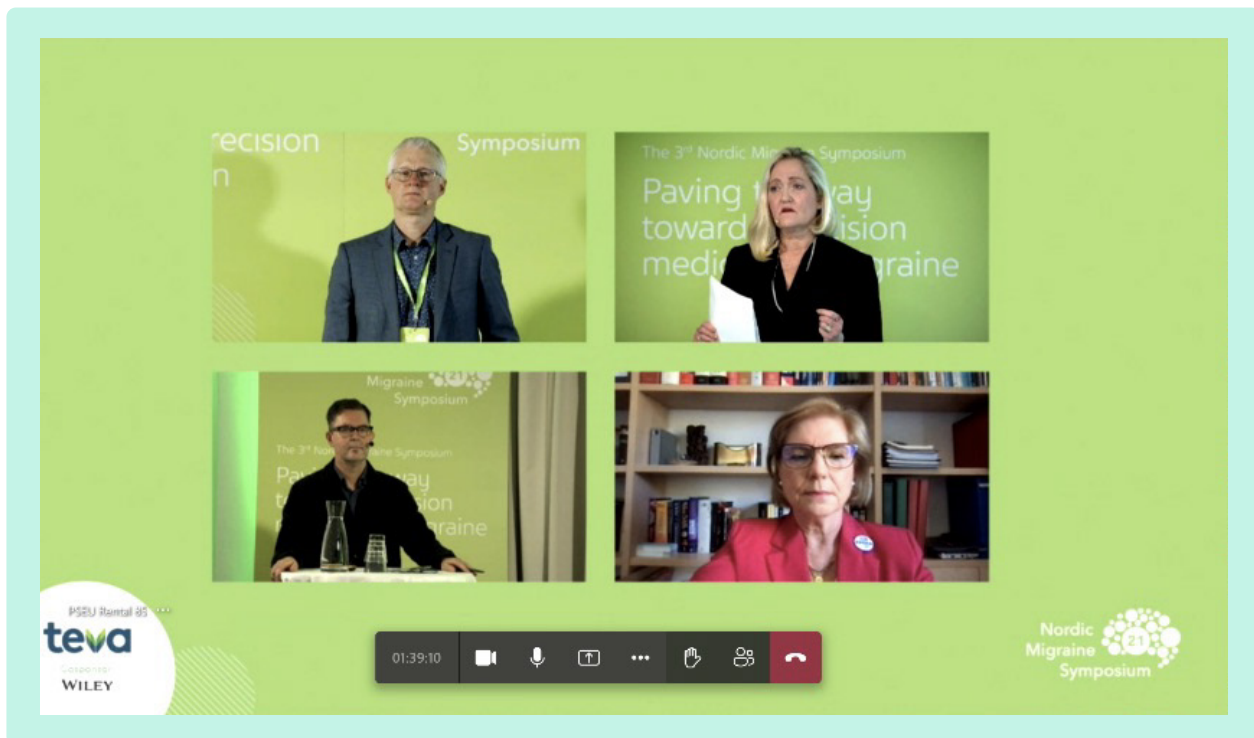
Moreover, the campaign included a video to portray the long wait patients have to go through to get an effective diagnosis and treatment.



4.3 Access to Care

At National Level: Nordic Countries.

Series of events in each of the **countries involved in the Access To Care study** to show the impressive **insights** of each of the countries to Policy Makers, Healthcare professionals, HTAIs and national media.



NOVEMBER 2021:
NORDIC MIGRAINE SYMPOSIUM FINISH AND NORWEGIAN RESULTS.

4.4 Together Talks

At National Level: Together Talks on Access to Care.

Activity

Discussing the different migraine treatments available in each country.

Goals

- To raise awareness and educate on migraine treatments and access to care around Europe.
- To give patients tools to get a good diagnosis and treatment, for them to cope with migraine in the best possible way.

UK: THE MIGRAINE TRUST



Prof. Peter Goadsby

GERMANY: MIGRÄNELIGA
AND STIFTUNG KOPFSCHMERZ



Veronika Bäcker

ROMANIA: HEADACHE SOCIETY ROMANIA



Dr. Adina Roceanu

IRELAND: MIGRAINE IRELAND



Jeff Smith MD

FRANCE: LA VOIX DES MIGRAINEUX



Docteur Lucas

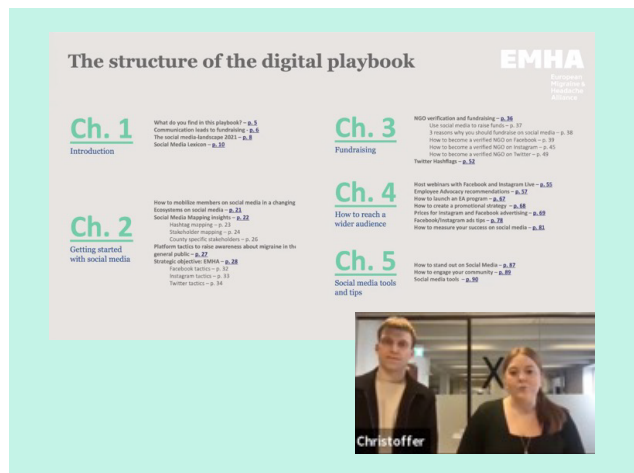
4.4 Together Talks

Capacity Building sessions.

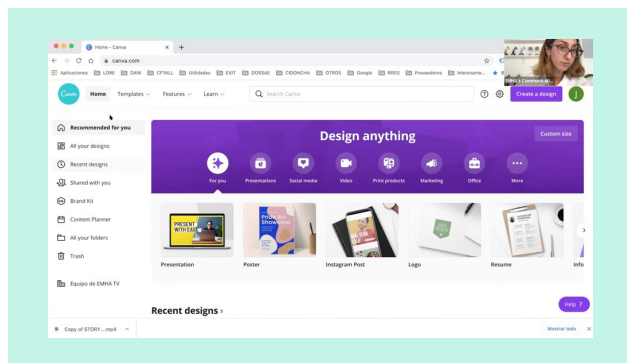
Goals

- To give new tools to local associations for improving their online communication as well as their local policy work.
- Members where able to attend the webinars, learn a new tool and have a Q&A with the speakers, as well as access to complimentary material that reinforces the lesson of the session.

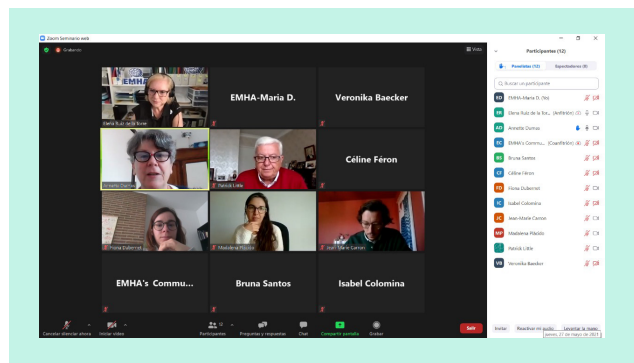
1. SOCIAL MEDIA: WHAT'S HOT AND WHAT'S NOT ON SOCIAL MEDIA.



2. CANVA: HOW TO USE CANVA TO CREATE EFFECTIVE ONLINE COMMUNICATIONS.



3. POLICY ADVOCACY TO MAKE MIGRAINE A EUROPEAN AND NATIONAL HEALTH PRIORITY.



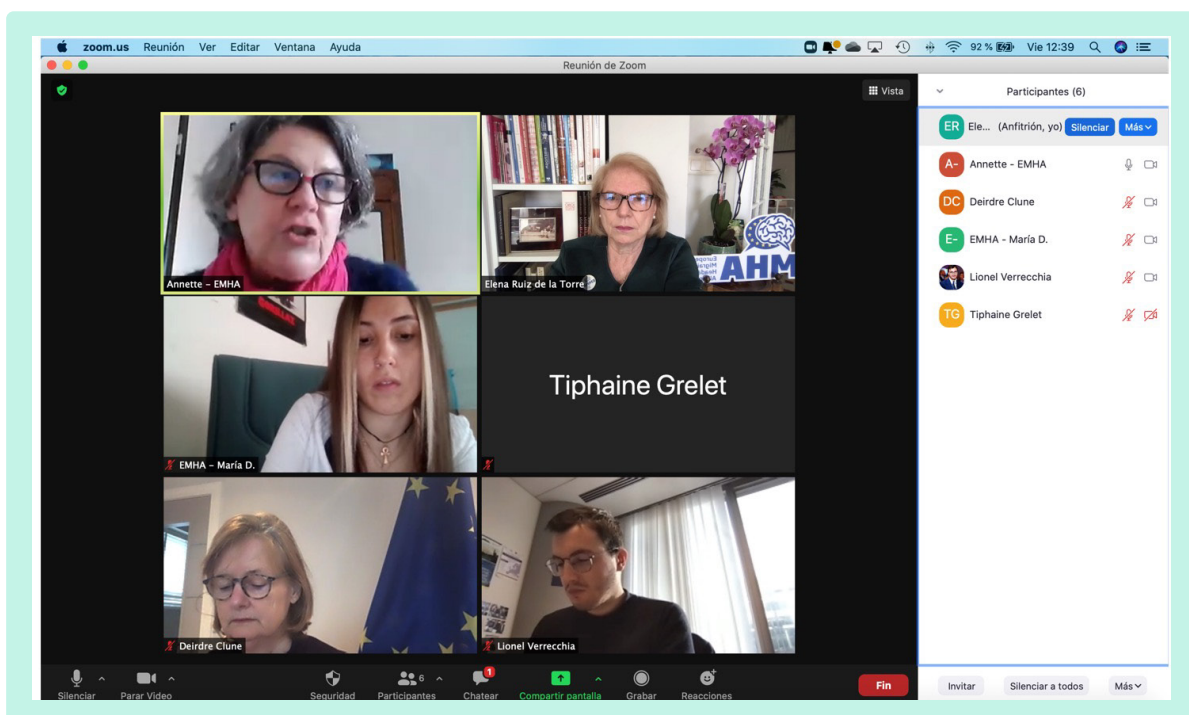
4.5 Policy Makers

Woman and Migraine Policy Paper.

EMHA's long-term EU policy advocacy strategy embedded in the organisation's Call To Action. The Call To Action highlights the gender bias around migraine and the need to look deeper into how women deal with migraine in their daily life.



MEP Migraine Alliance Meetings.



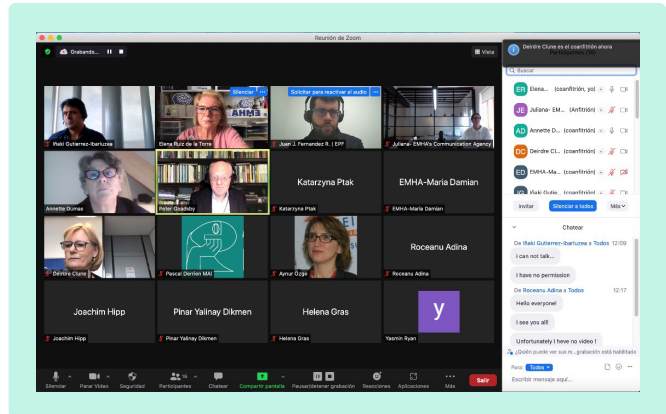
4.5 Policy Makers

2 Webinars at/with the EU Parliament.

29th SEPTEMBER

MIGRAINE IN THE EU: LIFTING THE BARRIERS TO TREATMENT

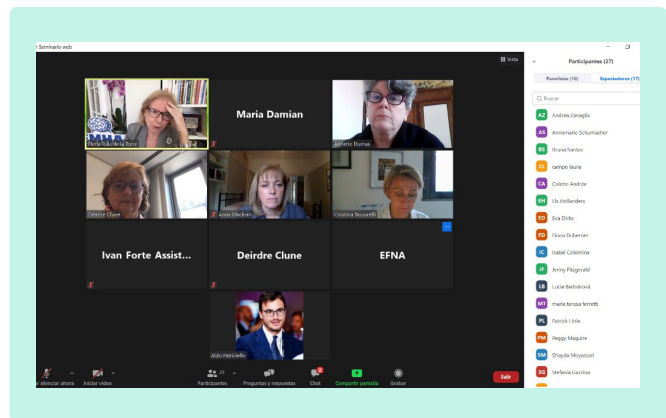
Launch of the Access To Care results during the EU Webinar, hosted by MEP. Deirdre Clune.



23rd MARCH

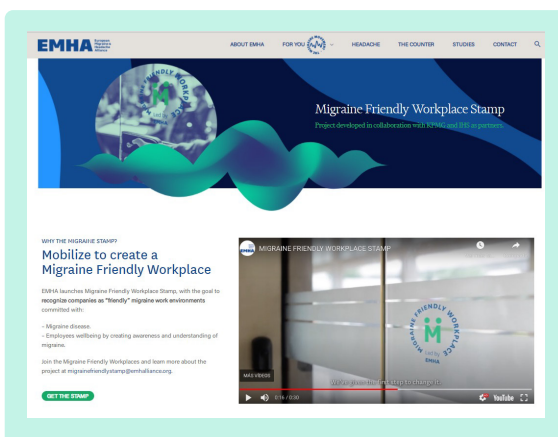
WOMEN & MIGRAINE IN THE EU: LIFTING WOMEN AND MIGRAINE OUT OF THE SHADOWS'

To mark International Women's Day (8 March) and complement its Call To Action to make migraine a EU and national health priority, EMHA presented a Policy Paper on 'Women and Migraine in the EU: Lifting Women and Migraine out of the Shadows'



4.6 Migraine Friendly Workplace Stamp

- Concept definition on the Stamp
STAR Categories
- Collaboration Agreement definition.
- Symbolic Fees Strategy.
- Webpage Specific site for the Stamp initiative.
- Initiatives Strategy.
- Detailed initiatives description.
- Initiatives Evidence.



Initiatives:

Migraine counsellor	Training: Ergonomic Awareness Courses	Anti-glare screen	Flexibility
Healthy lifestyle (information)	Offer fitness activities within the company	Access to medical care: screening	Teleworking
Non-discrimination inclusive programs	Light, noise and odours	Referral protocols to the specialist	
Training: Stress management	Prevent dehydration	Silent/rest rooms	

TOPIC 1: AWARENESS TOPIC 2: WORK ADAPTATIONS TOPIC 3: RISK FACTORS TOPIC 4: ERGONOMICS TOPIC 5: MEDICAL CARE TOPIC 6: INFO

4.6 Migraine Friendly Workplace Stamp

Definition on content for Marketing material.

ONE-SLIDE FOR PROJECT OVERVIEW

Goal
Recognize companies as "friendly" migraine work environments committed with:

- Migraine disease.
- Employees wellbeing by creating awareness and understanding of the disease.

Benefits for the Company
When the "Migraine Friendly Workplace Stamp" is implemented:

- Reduce absenteeism and productivity loss to enhance productivity from your employees.
- Improve the retention of current workers and create long term employee loyalty.
- Improve organization reputation as your company is sending the message that it cares about employees and is serious about safeguarding and preserving their health.
- Reduce health care costs by lowering health risks as workers are encouraged to implement healthier behaviours.
- Successful marketing tool when recruiting new employees.
- Get respect for all employees, including those who are affected by migraines.

How to obtain the Stamp
The Stamp is obtained when the company sends all its employees the Migraine specific EMHA course.

Stamp upgrade
The company can request an upgrade by implementing specific initiatives to help raise awareness for migraine.

Initiatives:

Migraine awareness	Support development	Anti-gone courses
Flexibility	Training: Stress Management	Access to mental care services
Networking	Offer breaks and time within the company	Adapted equipment for the workstation
Workplace changes	Healthy lifestyle (performance)	Anti-discrimination workplace programs
Light, noise and odors	Training: Management Awareness Courses	

5 initiatives
10 initiatives

Please note that upgrades are available for those companies that have already implemented (at least) one Migraine Friendly Workplace stamp by completing the migraine specific course.

EMHA logo

EMPLOYEE COMMUNICATION

Your company has mobilized to become a Migraine Friendly Workplace

KPMG
Project developed in collaboration with KPMG as a partner.

What is Migraine?
Serious neurological condition that can affect the ability to perform daily activities.

1 out of 7 workers suffer from migraine.

EMHA logo

DOSSIER

FURTHER DETAILS ON THE INITIATIVE

Goal for the Companies
To recognize companies that are committed with its employees wellbeing by understanding and promoting awareness and visibility for migraine

With the Migraine Friendly Workplace Stamp EMHA wants to contribute to migraine awareness and visibility at the workplace promoting a more **INCLUSIVE** work culture where ALL employees feel supported and respected.

Simple Stamp Process
Carefully designed to avoid unnecessary administrative work.

Inclusive
Developed to be inclusive with all kinds of companies regardless of its size or sector.

Endorsed
The stamp includes an annual communication plan and a specific online migraine course.

Symbolic Fees
Symbolic fees based on the number of employees at the workplace.

Do you receive support from your colleagues?

YES	62.60%
NO	37.40%

EMHA logo

How to obtain The Stamp

Requirement
The Stamp is obtained when the company sends all its employees the Migraine specific EMHA course.

Evidence
A confirmation e-mail from the company stating that the Migraine specific EMHA course has been sent to the employees. OR A screenshot of the intranet area where employees can access the specific training course.

Training Migraine specific EMHA course (video-quiz)
Short training with a quiz containing information about the disease, impact, disability and how to handle with other co-workers who suffer migraine.

EMHA logo

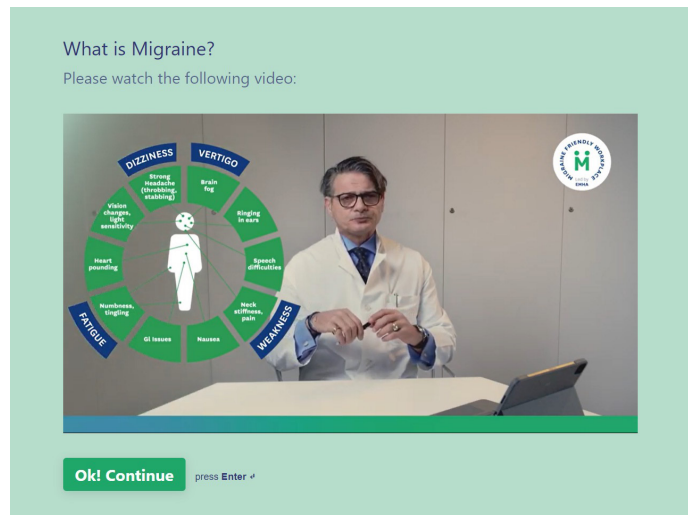
4.6 Migraine Friendly Workplace Stamp

EMHA Specific Migraine training Video for all Employees.

4 videos

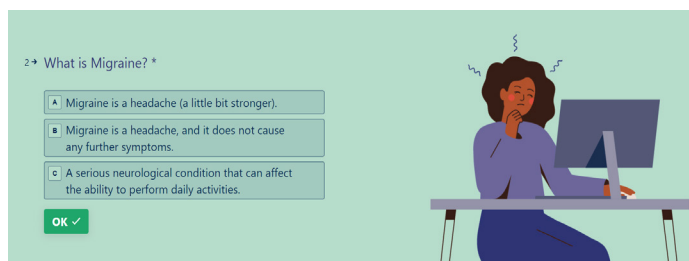
- Self - presentation
- What is migraine?
- Impact of Migraine (and at the workplace)
- How to better support colleagues that are migraine sufferers

+ INTERACTIVE VIDEO-QUIZ



5 Quiz questions

Relative to the information provided in the clips



4.6 Migraine Friendly Workplace Stamp

Concept for the additional EMHA videos:

- Video for Migraineurs
- Video for Managers

VIDEO 2: For migraineurs

Why do I have migraine? (+- 15 min)

- Why do I have Migraine?
- Diagnosis and possible treatments.
- What else can I do out of pharmaceutical treatments?
- Useful links and info
- Tips "How to speak about my migraine to my Employer and Colleagues"

Set indications:

- Ideally, the video will be recorded over a white background.
- The scene should be as clean and minimal decorated as possible. You can use a laptop on a table, but it should not distract the viewer from the speaker.
- The specialist will be sitting in a chair or in a couch talking directly to the camera in the middle of the frame.
- The video should be recorded on MP4, 4K and 16:9.
- The ideal shot of camera is middle shot (showing the specialist from the waist up).

Form to fill in once companies are onboard:

EMHA		EMHA															
INITIAL FORM FOR ORGANISATIONS <small>In order to implement the Migraine Friendly Workplace Stamp in Organizations, EMHA requires specific details. Please complete the form in order to get a good understanding of your needs and expectations.</small> <small>By filling and returning this questionnaire you are giving consent to EMHA to use and store your personal data on file with the sole aim of including specific details when there is a compromise for an agreement/contract on the implementation of the Stamp. The data included in this questionnaire is strictly confidential. Under no circumstances will it be used by EMHA for commercial purposes.</small> <small>Your data will be maintained on record until the information is no longer necessary to hold on file being compliant with the current applicable legislation. You have the right to request your personal data to be deleted from our database at any time. For this, please contact: migrainefriendlystamp@emhaliance.org</small> <small>*Compulsory fields</small>		Situation at the Workplace Workplace Adaptations / Wellbeing consciousness <small>Have any accommodations been adopted at the workplace? (Rest rooms, dimming lights, flexibility/teleworking, medical services etc.)</small> Geographic Area Recognition <small>The recognition can be at regional (all EUROPE) or national level (specific country/countries) or at both levels at the same time. Please describe geographic area implementation.</small> Other important information <small>Please state any questions or share any information that is important to you.</small>															
Organisation Details: <table border="1"> <tr><td>Organisation name*:</td><td></td></tr> <tr><td>Org. ID*:</td><td></td></tr> <tr><td>Number of employees*:</td><td></td></tr> <tr><td>Address*:</td><td></td></tr> <tr><td>Subsidiary or Parent company:</td><td></td></tr> <tr><td>Org. activity*:</td><td></td></tr> <tr><td>Social Media details (LinkedIn/Instagram/Facebook):</td><td></td></tr> </table>		Organisation name*:		Org. ID*:		Number of employees*:		Address*:		Subsidiary or Parent company:		Org. activity*:		Social Media details (LinkedIn/Instagram/Facebook):			
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Contact details for EMHA: <table border="1"> <tr><td>Contact name*:</td><td></td></tr> </table>		Contact name*:															
Contact name*:																	

4.6 Migraine Friendly Workplace Stamp

Launch at IHS + EHF Congress
12th September - Migraine Day of Action.

The 2021 Migraine Day of Action was marked by EMHA's presentation of the Stamp on the International Headache Congress, leading the patient's course.

During the event, professionals such as Prof. Z Katsarava, Prof. Goadsby, Prof. Irimia, Mr. Patrick Little, Prof. Dodick, Prof. Sakai, Mr. Arao Belitardo De Oliveira participated, as well as counting with testimonies of patients, healthcare professionals and company managers to launch the Migraine Friendly Workplace Stamp for the first time.

To supplement the launch during the congress, and to reach a broader audience, a video was created and distributed along with images reinforcing the importance of the Migraine Friendly Workplace Stamp launch.

Patient's Initiatives on Migraine

The **Patient's Initiatives on Migraine** will be livestreamed on 12 September 2021 from 11:00 to 13:00 (CEST) on this page.

PROGRAMME OF PATIENT'S INITIATIVES ON MIGRAINE



4.7 Online Migraine Academy

OMA: Online Migraine Academy.*

Main target

Healthcare professionals.

Goals

Educate and spread reliable knowledge on migraine.

Activity

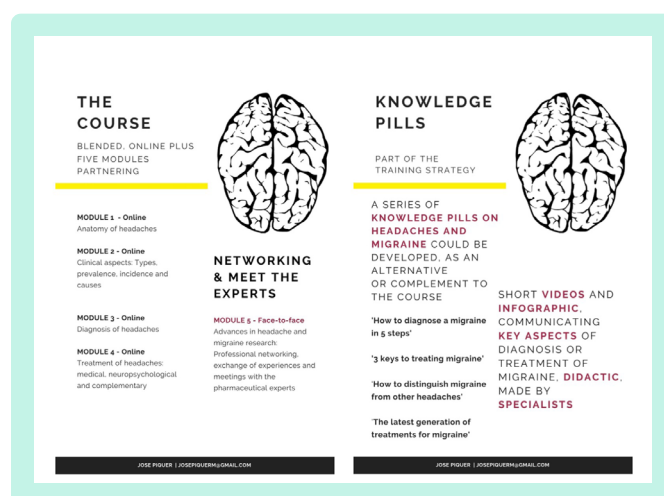
To create an online migraine academy for healthcare professionals willing to gain deeper knowledge on migraine.

The EMHA is currently working on:

- Creating a multi stakeholders steering committee to shape the project.
- Engaging an advisor specialist to work on legal, bureaucracy, etc.
- Engaging a technical expert to build the online University.
- Developing the best programme and teachers panel. Languages, is an issue to be considered too.

EMHA'S TO COORDINATE THE PROJECT

***THIS PROJECT IS CURRENTLY ON STANDBY DUE TO LACK OF BUDGET**



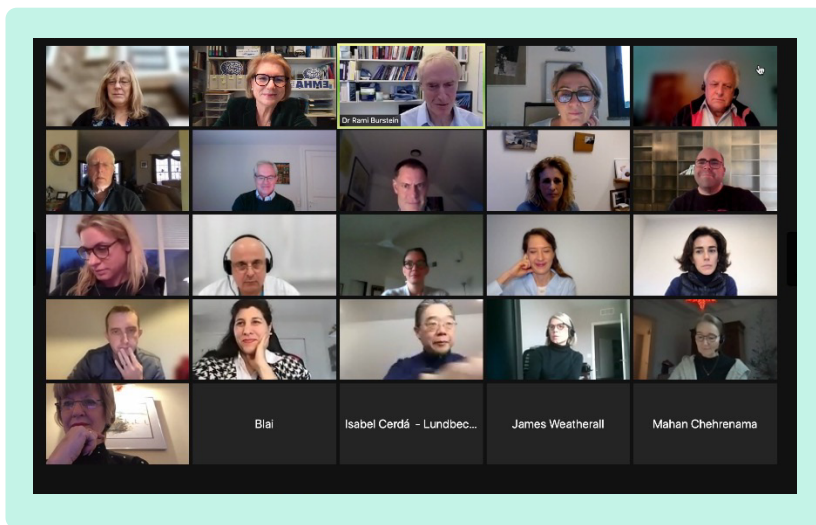
5.EMHA Activities with other Stakeholders



5.1 Science

IHS

CORPORATE MEETING



CORPORATE MEETING

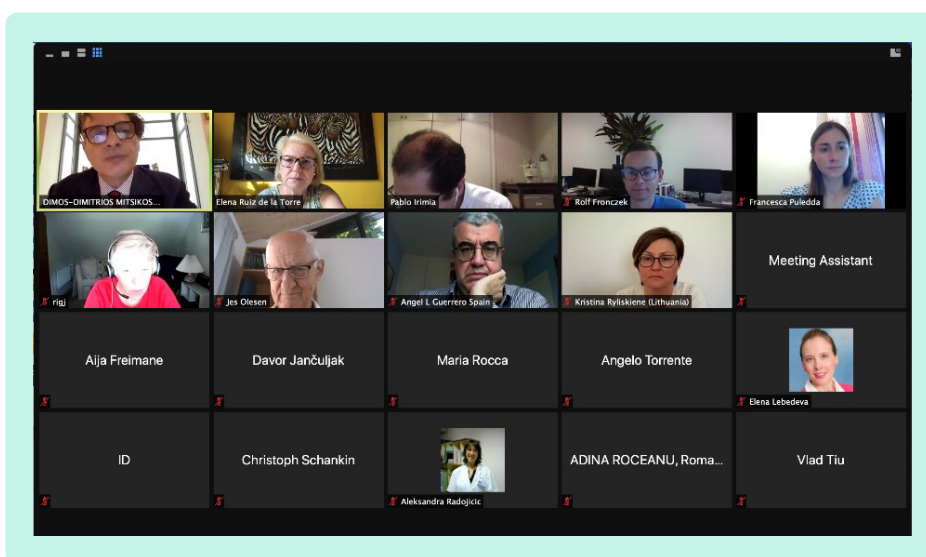


5.1 Science

National Pharmacists' Association Collaboration.



European Academy of Neurology
Scientific Pannel on Headache.



5.2 Other Organizations

GPAC

Module 1 – Intro to Migraine

Video 1: What is Migraine?

- Migraine is a disabling, neurological disease
- There are different types of migraine
 - with/without aura, chronic, menstrual, abdominal, hemiplegic, etc.
- Migraine phases - timeline of an attack (prodrome, aura, headache, postdrome)
- Triggers and symptoms
- Migraine treatment options are available
 - acute/preventive, OTC/migraine-specific, non-invasive/ non-pharmacological
- There are lifestyle changes and accommodations that can help manage migraine

Video 2: Who is affected and how does it impact people?

- Migraine affects 1 in 7 people, 1 billion globally
- Women are 3x more likely to have migraine than men / Children have migraine, too.
- Migraine exists on a spectrum: Episodic vs Chronic Migraine
- Beyond physical pain, there are personal and professional impacts
 - Personal: Missing out on family events, not being "fully present", etc.
 - Professional: absenteeism and presenteeism

Video 3: Common migraine triggers

- Everyone's triggers are different but a general guiding principle is that the migraine brain is very sensitive, doesn't respond well to changes in routine
- Overview of common triggers: environmental (loud sounds, bright lights, etc.) and lifestyle (diet, routine, etc.)
- The role of a headache journal - A headache journal can help to identify patterns and triggers and can help prevent attacks.

BONUS PDF Infographic: The Timeline of a Migraine attack

- Explains and illustrates the four phases of a migraine attack: Prodrome, Aura, Headache and Postdrome
- Lists the accompanying symptoms for each phase
- Provides advice for each phase and how to find relief

Sources

- <https://migraine.ie/what-is-a-migraine/types-of-migraine>
- <https://migrainecanada.org/posts/the-migraine-tree/trunk/core-skills/top-ten-facts-on-migraine-for-beginners/>
- <https://www.migrainetrust.org/about-migraine/types-of-migraine/>
- <https://americanmigrainefoundation.org/resource-library/timeline-migraine-attack/>
- <https://wfnepurology.org/world-brain-day-post-years/world-brain-day-2019>
- <https://www.migrainetrust.org/about-migraine/migraine-what-is-it/facts-figures/>
- <https://americanmigrainefoundation.org/resource-library/migraine-symptoms-between-attacks/>
- <https://americanmigrainefoundation.org/resource-library/migraine-facts/>

Charles Anclaje

American Migraine Foun...

Elena Ruiz de la Torre

Ashley Logan

Warren Legner

Debbi Lorenz

EFNA - G.A. Meeting

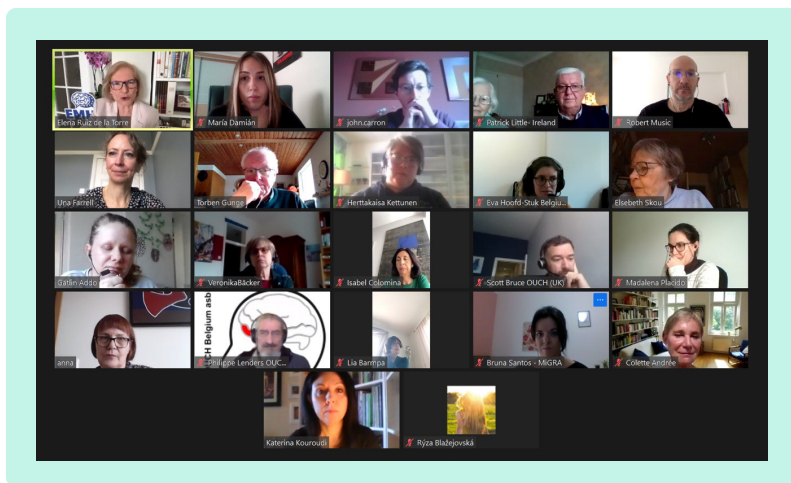
EPF

EBC

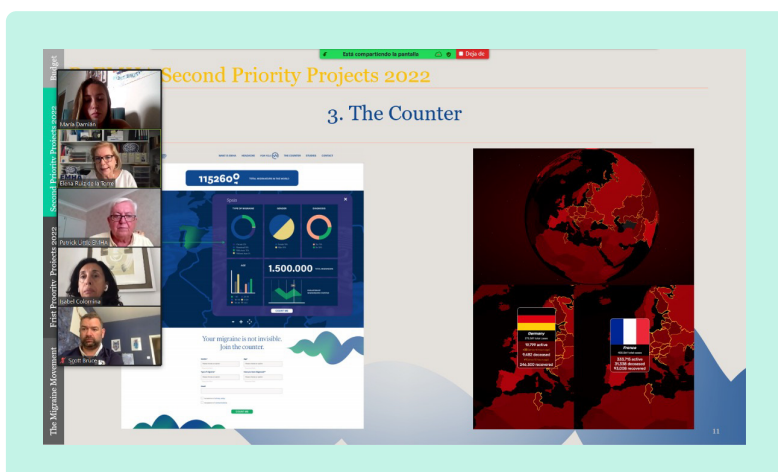
OneNeurology

5.3 EMHA Internal Meetings

Member's Meeting to present the annual Projects.



Board Meeting.



5.3 EMHA Internal Meetings

General Assembly.

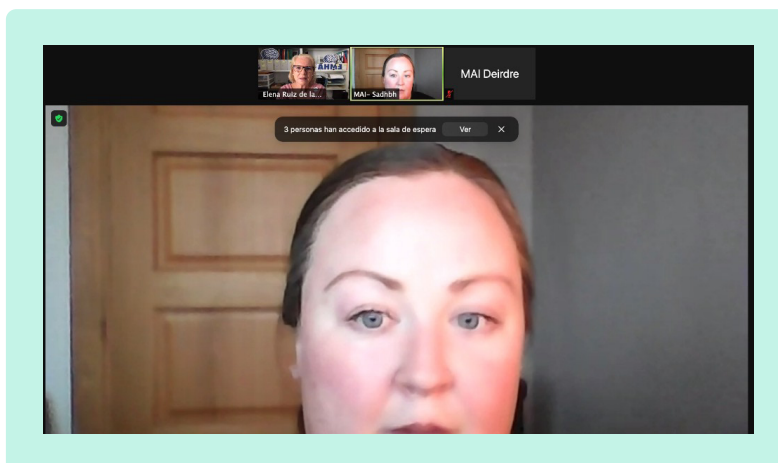


5.4 Activities with members

AEMICE - General Assembly.

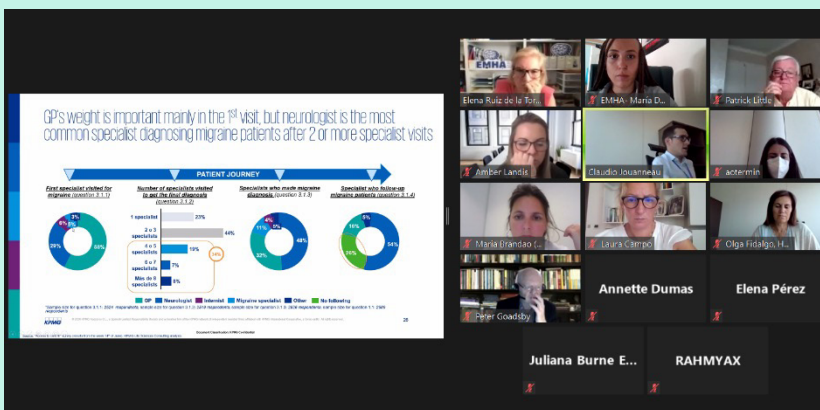


MAI - Migraine at the Workplace Webinar.



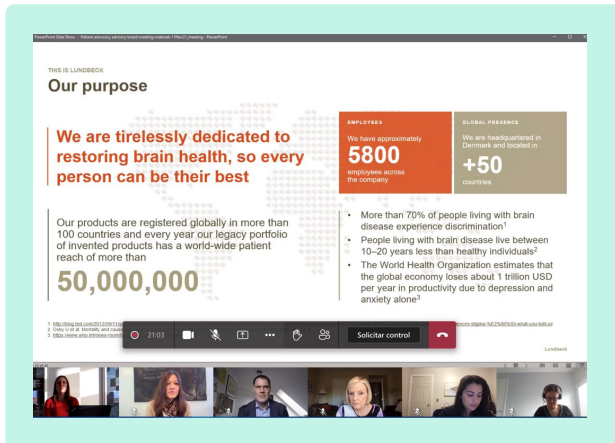
5.5 Industry

Corporate Meetings.

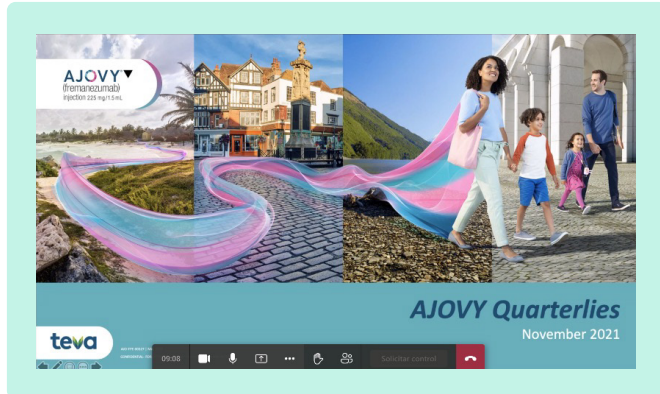


5.6 Sponsors

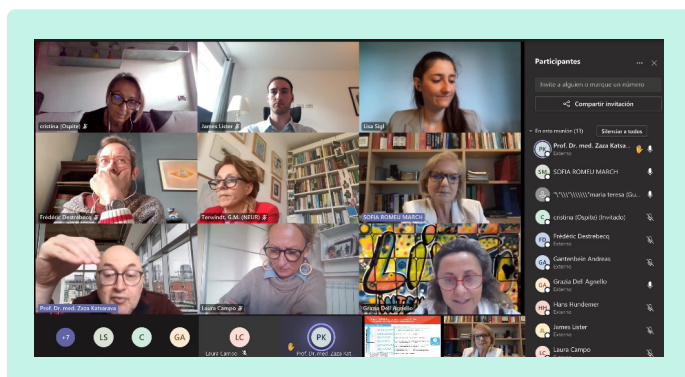
Lundbeck Advisory Board and more...



Teva Internal Workshop and more...



Eli Lilly Multidisciplinary Group and more...

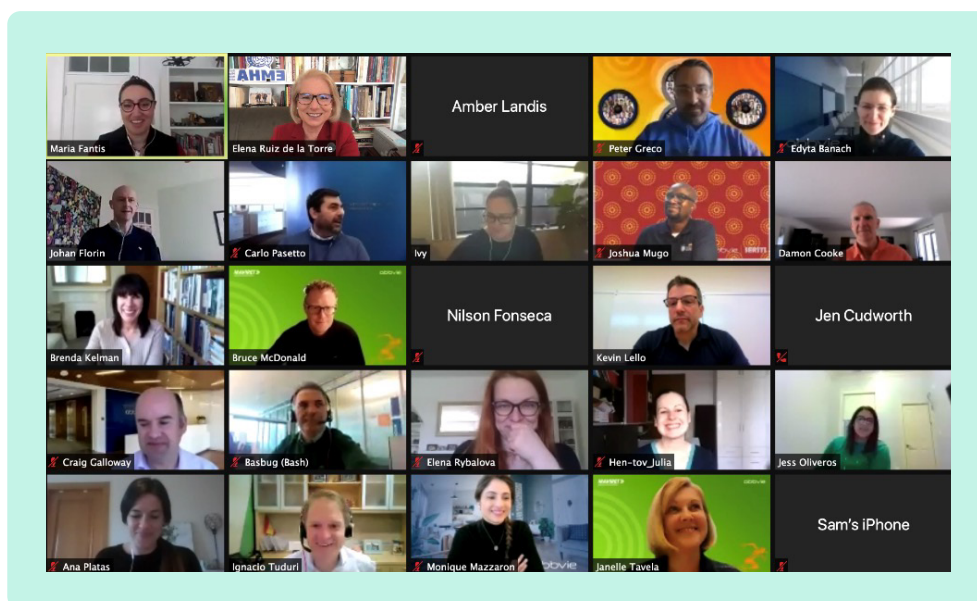


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