

EMHA

European
Migraine &
Headache
Alliance

EMHA Activities report for 2022



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Access To Care National Events

Access To Care Events and Comm. Campaign

The results of the “Access to Care” study per country were presented to policy makers, KOLs and general society in a series of events across Europe with an aligned message and Communication Campaign the same, in all the Countries:



ATC: Italy

The EMHA (European Migraine and Headache Alliance), with the support of Motore Sanità, launched in Rome, the “Access to Migraine Care Survey” on 16 March.

EMHA’s goal is to support migraine sufferers, as part of the pan-European “GetImpatientForMigraine” campaign.

Result: The event was attended by politicians, who quickly mobilised to provide concrete answers for these chronic patients.

- Creation of a Scientific advisory board to the Italian Health group at the Italian Congress.
- Approval of Migraine as a social disease by Italian law.

Lara Merighi’s, representing EMHA, delivered a speech to the audience which included Senator Paola Boldrini, the Hon, Celeste D’Arrando and Nicola Provenza.



Access To Care Events: Italy

★★★★★

*"In Italy lots of media coverage from the event.
Amazing success!!!! Brava!"*

L.C.

★★★★★

*"I've heard all very good things about the
Monitore Sanita event ! Fantastic engagement,
participation and visibility ! Congratulations and
well done ! A very positive precedent for hopefully
some other local events"*

E.T.

★★★★★

*"Firstly congrats for the event in Italy this week
– I received great feedback ! WELL DONE."*

A.A.

Salute&Benessere

Progetto Emicrania, confronto pazienti, clinici e istituzioni

Donna
in salute

Emicrania: al via la campagna "La mia vita: una sala d'attesa"



Tweet

FISC_Onlus
@FISC_Onlus

ANSA - Progetto #Emicrania 2022 - Live Streaming
oggi 16 Marzo 2022 ore 10:30 - 13:00. bit.ly/34OeDSA
motosanita.it/eventi/progett... #CristinaTassorelli
@P_Martelletti @EMHAlliance



Sbirca la notizia
#Migraine

EHMA in audizione presso l'intergruppo
parlamentare sulle Cronicità

iFattidiNapoli.it
il quotidiano online della terza metropoli italiana

**MOTORE
SANITA'**

EHMA IN AUDIZIONE PRESSO L'INTERGRUPPO PARLAMENTARE

Libero

**Emicrania, una campagna
europea per l'accesso a diagnosi
e cure**

**EMICRANIA: AL VIA LA CAMPAGNA PANEUROPEA DAL
TITOLO "MY LIFE: THE WAITING ROOM"**

16 Marzo 2022 12:03 — Otto anni per avere una diagnosi e ricevere cure adeguate, con gravi ripercussioni sulla qualità di vita di chi soffre. EMHA (European Migraine and Headache Alliance) promuove il "Progetto Emicrania Accesso alle Cure 2022" in difesa delle persone affette da tale patologia e lancia il hashtag #GetImpatientForMigraine.

IL TIRRENO

Emicrania, in Italia il 46% dei pazienti
attende 5 anni per un trattamento

ATC: Portugal

On 12 September, to mark the Migraine Day of Action, Migra Portugal and EMHA organized an event to showcase the results of the Portuguese survey on access to care.

The opening session was led by Madalena Plácido (MiGRA Portugal), Dr. Raquel Gil-Gouveia (Portuguese Medical Society of Headache) and Dr. Isabel Luzeiro (Neurology Portuguese Medical Society).

Result: The agenda included talks by members of Migra Portugal as well as representatives of the EMHA, closing with a round table in which different actors shared their perspective on "Migraine and headaches, what is the future?" including the previous mentioned as well as Dr. Maria de Belém (former Minister of Health) and Dr. Armando Alcobia (Pharmaceutical Services of the Garcia de Orta Hospital), moderated by the journalist Marina Caldas.



ATC: Czech Republic

The CR patient organization Migréna-help and EMHA, the Czech Headache Society and a group of several pharma companies, organized the seminar: "Improving access to migraine care in the Czech Republic", which took place on 13 September 2022 in Prague and presented the results on the Access to Care Survey in Czech Republic.

The keynote speech was given by the president of Migrena-help, Msgr. Rýza Blažejovská, DiS. and the E.D. of EMHA, Elena Ruiz de la Torre, to the attendees which included representatives of the state administration, HTA bodies, health insurance companies, patient organizations, and the professional public.

In addition, the panel featured MEP Martina Dlabajová, President of the Czech Headache Society Dr. Tomáš Nežádal, Dr. Jolana Marková, FEAN, Director of the Headache Diagnosis and Treatment Centre at Thomayer Hospital, and the founder of the Institute of Health Economics, Dr. Tomáš Doležal. The event was hosted by MUDr. Roman Kraus, MBA, Chairman of the Health Committee of the Senate of the Czech Republic.

Result: A commitment from the Ministry of Health to meet Migrena-Help To find out the unmet needs to be tackled To improve the access to the best and most innovative treatments.



ATC: Czech Republic



ATC: Spain

On October 7th at the Spanish Parliament in Madrid, Elena Ruiz de la Torre, E.D. of EMHA, presented the results of the "Access to Care survey". The event also included a multidisciplinary colloquium entitled 'Challenges in access to migraine care in Spain', with the participation of healthcare professionals, managers and patient representatives.

This was followed by the debate 'Let's put migraine on the political, health and social agenda of our country'. Among those present were also Adolfo Suárez, 4th Secretary of the Bureau of the Congress of Deputies and Rosa Romero, President of the Health and Consumer Affairs Commission of the Congress, who opened the conference together with Isabel Colomina, President of AEMICE.



Access To Care Events: Spain.



ATC: Spain

On the scientific panel, the conference was moderated by Iñaki Gutierrez-Ibarluzea, Director of Organisational Innovation and Management of the Basque Foundation for Health Innovation and Research, with speakers Dr. Pablo Irimia, (neurologist and coordinator of GECSN), with patient testimony from Verónica Sáez.

Dr. Pablo Baz. (Family doctor and coordinator of the Neurology working group in SEMERGEN),

Dr. José María Serra, (Member of the Coordinating Group for Neurological Patient Care of the Spanish Society of Hospitalary Pharmacy), who exchanged points of view and tried to find a better Access to treatments.

Result: Ministers and political party delegates agreed to meet with AEMICE to move forward a National Plan for Migraine



Climate change and Migraine

The EMHA was part of this year's 6th Recent advances in quantitative remote sensing, International symposium.



Netrpělivě čekej na snazší a rychlejší přístup k léčbě.

Netrpělivě čekej na správnou diagnózu a lepší podporu lékaře.

Netrpělivě čekej na zdravotní péči, která překlene regionální rozdíly.

#BudteNetrpeliviKvuliMigrene

Communication General Campaign for the
Access to Care Project:
#GetImpatientForMigraine

Access To Care Events: #GetImpatientForMigraine

In 2021, we launched the campaign "The impatient chair" in which we denounced the 8 years that a migraine patient has to wait on average to get an effective treatment.

For 2022, we have evolved the message to talk not only about what happens in the waiting room, but also about what life is like for migraine sufferers.

At the same time, we no longer have a single protagonist of the campaign, but three women and a man, to portray that 90% of the migraine sufferers in the Access to Care survey were women of different ages.

[GET IMPATIENT TO MIGRAINE VIDEO](#)



Would you spend eight years of your life
sitting in a waiting chair?

Access To Care Events: #GetImpatientForMigraine

We developed visual materials specially designed with local data for the hosting country, so they could share the results of the Access To Care local study.

These materials were launched to reach the general audience and create awareness of the events, as well as the issues and findings extracted from the study.





Migraine Friendly Workplace

Migraine Friendly Workplace

During 2022 11 global companies joined the project and the video-quiz training was released in more than 12 languages.

Material was delivered for the project such as commercial documentation, guideline on the initiatives that can mitigate or

eliminate the triggers for Migraine attacks at the workplace, documentation for the employee internal communication, video-quiz training about Migraine, a project-specific website page as well as an external communication plan to promote companies that are a Migraine Friendly Workplace.

RECOGNIZED AS A MIGRAINE FRIENDLY WORKPLACE

TEAM LEWIS



NOVARTIS
CZECH REPUBLIC

teva

abbvie



Curelator
Take back control¹

EXIT

Lilly

BODY
BACK-UP
HEALTHCARE

Promonity
marketing promocional

Migraine Friendly Workplace

Materials Delivered

Migraine Friendly Workplace Video-Quiz training

1 → Which disease is suffered by more than 1 billion people worldwide? *

☐ A Depression

☐ B Backpain

☐ C Migraine

☐ D Fibromyalgia

☐ E Other

Your company
has mobilized
to become a
**Migraine Friendly
Workplace**



KPMG

Project developed in collaboration
with KPMG as a partner.

EMHA



For more information send an email to
migrainefriendlystamp@emhaalliance.org



Under the auspices of the
International Headache Society

WORKPLACE ADAPTATIONS – INITIATIVES DETAILED DESCRIPTION

Initiatives:

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

TOPIC 1: AWARENESS

TOPIC 2: WORK ADAPTATIONS

TOPIC 3: RISK FACTORS

TOPIC 4: ERGONOMICS

TOPIC 5: MEDICAL CARE

TOPIC 6: INFO


Migraine Friendly Workplace

External communication plan to promote companies that are a Migraine Friendly Workplace.



EMHA- European Migraine and Headache Alliance

634 seguidores

5 meses • 

...

Thank you Eli Lilly and Company for becoming the first Migraine Friendly Workplace.

EMHA recognizes Eli Lilly and Company with the Migraine Friendly Workplace Stamp for their work done in raising awareness, within the company, for people living with migraine.

In addition, Eli Lilly and Company safeguards their employee's health, including those suffering from migraine, via capabilities and initiatives in place.

[#TeamWorkingForMigraine](#)

[#MigraineFriendlyWorkplace](#)

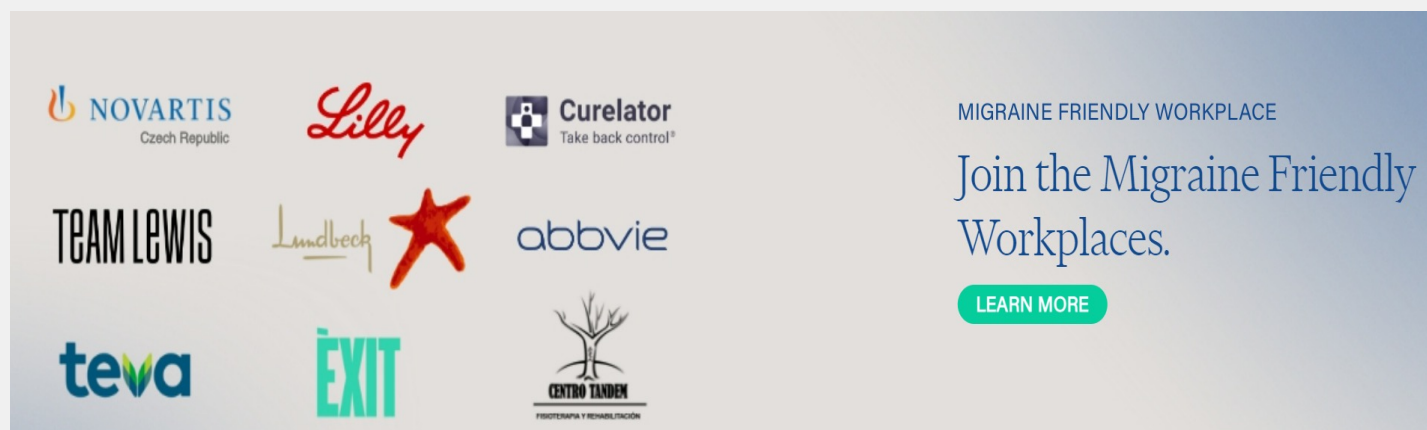
[Ver traducción](#)

Welcome *Lilly*



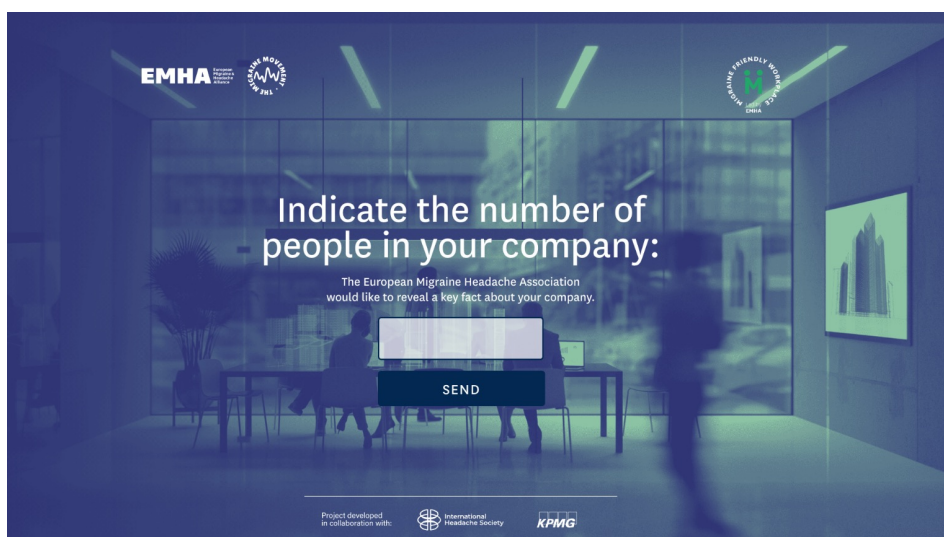
Migraine Friendly Workplace

For the 12th of September. Migraine Day of Action, we launched a communication campaign promoting the companies that had obtained the Stamp by adding a banner within EMHA's landing page and through social media.



Migraine Friendly Workplace

We also created a special action on social media for the 1st of May, international labor day. This campaign was shared on LinkedIn, where we encouraged users to visit a landing page in which by entering the number of employees in their company, they were able to estimate the approximate number of those suffering from migraine.



This is the approximate number of migraine sufferers working with you, although you probably may not have recognised them.

If you are concerned about absenteeism, be aware that presenteeism can be even worse. We would like to help you improve this situation and place your company as a leader in the integration of people with migraine.

[LEARN MORE →](#)[SHARE TO A COLLEAGUE](#) 

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Migraine Friendly Workplace

As the project began to grow, we also realized that it had to evolve. So, in order to attract more companies, the Migraine Friendly project is now more than just a stamp. It has become a project that distinguishes companies that take a step forward in corporate social responsibility policies. Within this new focus, we started to develop a new landing page as well as a variety of content to help spread awareness within the company.



Migraine Friendly Workplace

Companies that are part of the Migraine Friendly Workplace project.





Brain Awareness Week

Brain Awareness Week

To celebrate the #BrainAwarenessWeek the EMHA created and distributed 6 short videos of renowned neurologists and patients sharing their advice to keep a healthy brain.

The neurologists who participated in the campaign were:

Prof. Peter Goadsby, Prof. Cristina Tassorelli and Arao B. de Oliveira, PhD. The patients, supported by EMHA's member Hodepine Norge shared their main hobbies and tips for avoiding migraine attacks.

The campaign was created with the support of Lundbeck.



GLOBAL RESULTS OF THE CAMPAIGN

Total videos published	Impressions	Reach	Video Views	Engagement	Engagement rate
18	9412	6826	6220	326	4,8

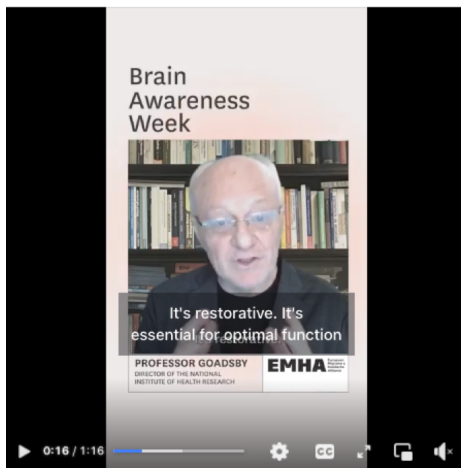
Brain Awareness Week

Healthcare professionals videos

For this year's [#BrainAwarenessWeek](#), Professor Goadsby shares some useful tips on how to keep your brain healthy. In order to do so, he suggests focusing on 3 main items:

- Sleep
- Diet
- Blood pressure

Watch the video to find out more!

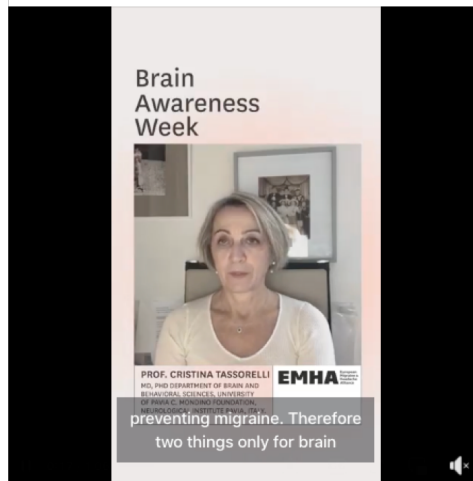


Prof. Cristina Tassorelli shares her advice on keeping a healthy brain and preventing migraine for this [#BrainAwarenessWeek](#).

The 2 main focus for her, beside adequate treatment, are:

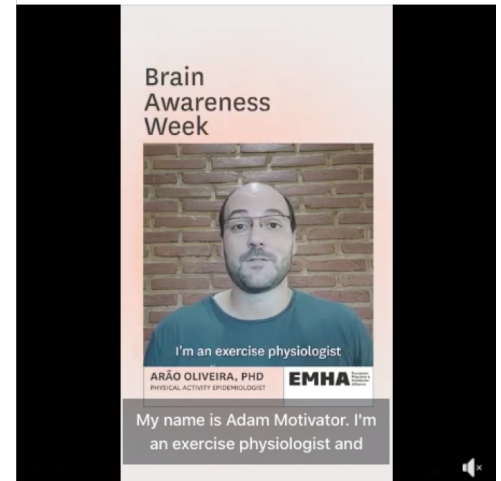
- Stress management
- Exercise

And you, how do you keep your brain healthy?



Physical activity epidemiologist Arao B. Oliveira reminds us of 3 tips to keep our brains healthy during this [#BrainAwarenessWeek](#).

1. Accumulate 150 to 300 minutes a week of moderate to vigorous exercise 🏃.
2. Perform 2 times a week muscle training exercise 🦵.
3. Avoid spending too much time in a seated position 🪑.

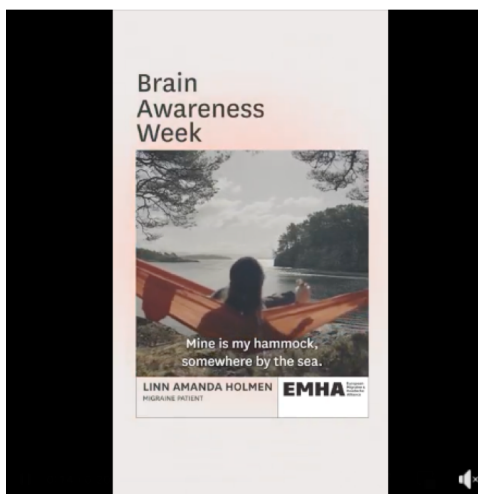


Patients videos

How to keep a healthy brain?

During this [#BrainAwarenessWeek](#) we asked migraine patient Linn Amanda Holmen to share some tips for managing migraine and maintaining a healthy brain 🧠.

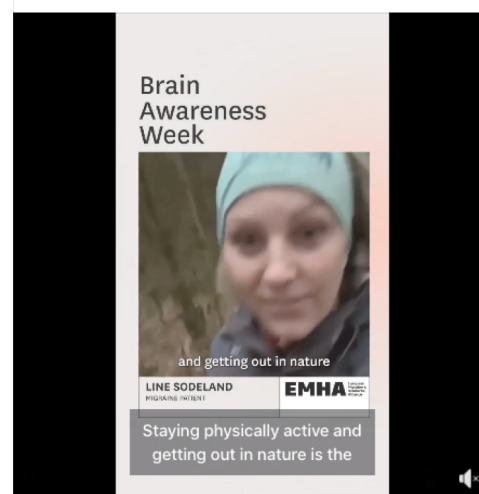
Watch the video to find out more!



How to keep a healthy brain?

For migraine patient Line Sodeland, staying physically active and enjoying time outdoors is a must 🌳.

What is your [#BrainAwarenessWeek](#) advice on keeping a healthy brain?

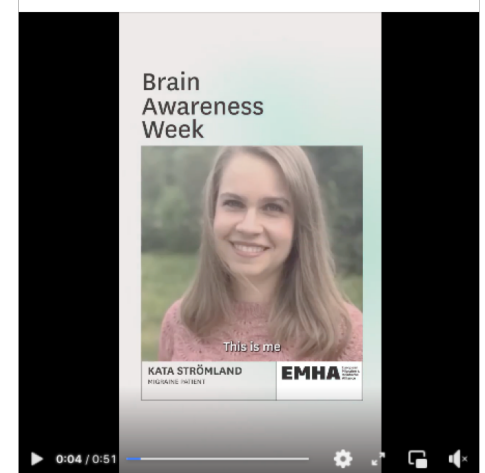


For this [#BrainAwarenessWeek](#), migraine patient Kata Strömmland shares the hobbies and activities that help her keep a healthy brain.

Can you guess them?

Watch the video to find out more.

[#BrainAwarenessWeek](#)

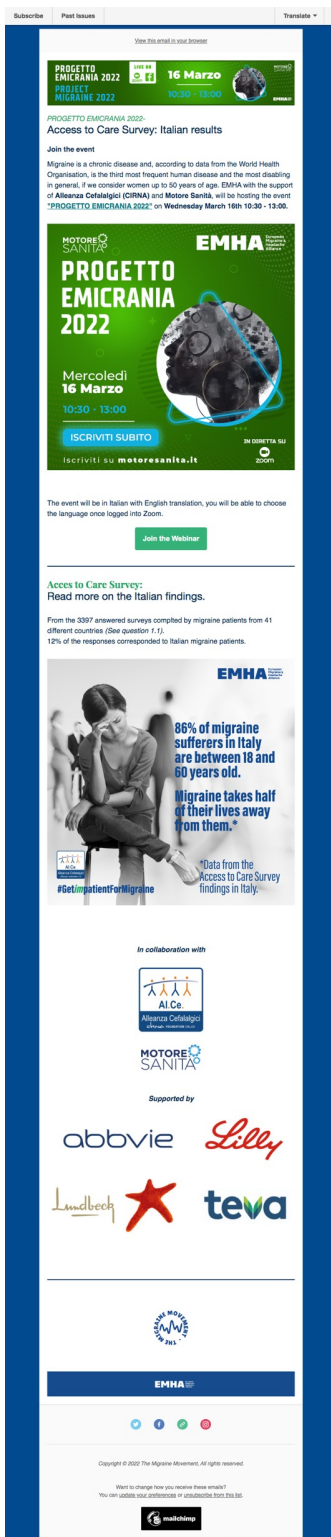


EMHA Newsletters

Newsletter

During 2022 we focused on creating regular email communications to our subscribers, mainly sharing EMHA's political activities and achievements.

Throughout the year, the opening rate was 41,7% and the click rate was 1,3%.



Newsletter

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MAY 2022 - ISSUE 07

The latest news on the EMHA:

PUBLIC AFFAIRS

MEP Jordi Cañas joins the European Parliament Migraine Alliance.

MEP Cañas joins the group of MEPs that are sensitive to helping and working to improve the lives of people with migraine and make migraine a European priority.

The European Parliament Migraine Alliance is now stronger thanks to its members: Aldo Patriciello, Christophe Hansen, Cindy Franssen, Daniele Cione, Elżbieta Kobylińska-Lasiecka, Jordi Cañas, Verónica Bächer-Ostendorf and Greta Perschke.

Working closely with the EU parliament

EMHA has presented to **Members of the European Parliament (MEPs)** a set of amendments to the initiative of the European Parliament: **"Towards a Common Action on Care"** taken focused to efforts on the inclusion of neurological disorders within the fields of care. The amendments take into account the challenges regarding gender equality, the elderly, and health services to achieve harmonised efforts within the European Union.

EMHA has also provided its input to the European Commission on the **Non-Communicable Diseases Initiative**. The document includes policy priorities regarding neurological disorders and a series of best practices gathered from our partners and members.

All these actions will be duly followed up in the upcoming months and followed by further steps to achieve EMHA's goals in the European Union framework.

[LEARN MORE ON EMHA'S PUBLIC AFFAIRS WORKS](#)

Welcome Lilly

Eli Lilly and Company becomes the first official organization to be recognized as a Migraine Friendly Workplace

It is our pleasure to announce that **Eli Lilly and Company** is the first company to be recognized as a **"Migraine Friendly Workplace"** a recognition from EMHA. 150+ workers suffer from migraine and most of them suffer in silence and hide their condition whilst at work.

The **Migraine Friendly Workplace Stamp** is awarded to inclusive workplaces that raise awareness and understanding about migraine within their workplace and have implemented a series of initiatives in their workplace to safeguard the health of all their employees, including those suffering from migraine.

[If you would like your organization to be recognized as a "Migraine Friendly Workplace",](#) as Eli Lilly and Company it can be done by signing business arrangement letters. Raising awareness and understanding can have the potential to significantly improve migraine patient's experience in the workplace. Visit our website: [www.emha.eu/healthcarepartners](#)

Activities report 2021

You can now read all about the activities EMHA worked on during the past year. Online events, communication campaigns, members meetings and more!

[Download the Finance Report](#)

Finance report 2021

Transparency is key, that's why last year's finance report is now available at our website.

[Download the Activities Report](#)

Migraine and Cluster Headache global partners

CHAMP calls for participants living with episodic **Cluster Headache** for the **Alliance Clinical research study**.

The **Alliance Study** will evaluate the effectiveness, safety, and tolerability of the study medicine, **epinephrine**, as a possible treatment for episodic **Cluster Headache**. **Epinephrine** is currently approved by the Food and Drug Administration (FDA) as a safe and effective preventive treatment of **migraine headaches**, but its use for cluster headache is investigational. The purpose of this clinical research study is to determine if the study medicine (**epinephrine**) helps to reduce the severity, frequency, and duration of episodic **Cluster Headache**.

[If you would like to learn more about the Alliance Study and find a participating site near you, please visit: \[www.clusterheadache.com\]\(#\)](#)

EMHA

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JULY 2022

It's time for migraine to be a European concern.

Migraine has finally been recognized as a serious neurological disease by the EU Commission

The EU Non-Communicable Diseases Initiative from the European Commission was presented at the end of June. In the final proposal, our efforts for the inclusion of migraine are showing results and **migraine has been included in the topic of the neurological diseases**, mentioning the EMHA as a stakeholder.

EMHA has also contributed with its inputs to the targeted consultation on the **"EU4Health programme 2021-2027 – a vision for a healthier European Union"**.

In this way, our Association is also focusing its efforts on defending the rights of the Europeans who suffer from migraine and headaches, with its contributions to the long-term health challenges by building stronger, more resilient and more accessible health systems with the EU.

Our policy work never stops

During the 8th of July, EMHA presented amendments to two initiatives for Mental Health in the Digital World of Work and Towards a Common European Action on Care, with the aim to **give visibility to migraine** as well as to support all the efforts that EMHA has been working for.

The amendments have finally been approved.

It is a milestone for EMHA's political efforts, as the adoption of these amendments adds value to all EMHA members, as well as strengthening its position as an umbrella organisation.

These initiatives will lay the foundation and guide future European policies. **They will be a strong political force for raising migraine awareness**, mobilising the interests of all migraine sufferers, overcoming barriers in access to treatment and migraine-friendly workplaces.

EMHA

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AUGUST 2022

After a long wait... we could finally meet face to face.

Together, we are stronger.

We were able to join some of our dearest members and share our mutual efforts to build a better future for all migraine sufferers.

As face to face events start to take place again, EMHA's trip to Leiden was the perfect opportunity to reunite with our European family of patient associations.

VERONIKA BÄCKER OF MIGRANELICA, EMHA'S MEMBER

DR. MELLE COOLS OF HOOPFANNET, EMHA'S MEMBER

Elena Ruiz de la Torre, EMHA's executive director, had the honour to attend the **IHS Roundtable** to represent all the voices of migraine patients and work along renowned scientific key opinion leaders.

The **International Headache Symposium** also took place during those days. The agenda grouped important neurologists who delivered their talk under the symposium's theme: **"Leiden Headache Center into a new era"**. The opening lecture was delivered by **Dr. Gisela Terwindt**, director of the **Leiden Headache Center** and deputy head of the **Neurology department**.

INTERNATIONAL HEADACHE SYMPOSIUM

ELINA RUIZ DE LA TORRE, EMHA'S MEMBER

1 Voice Summit: Patient advocacy summit.

During the 8th of June, the EMHA attended the 1 voice summit event by **Lundbeck**. This was a unique opportunity which brought together patient advocacy organizations from across the world to exchange ideas, collaborate and find ways to amplify the voices of people with lived experience of brain disease.

PATIENT ADVOCACY SUMMIT

EMHA

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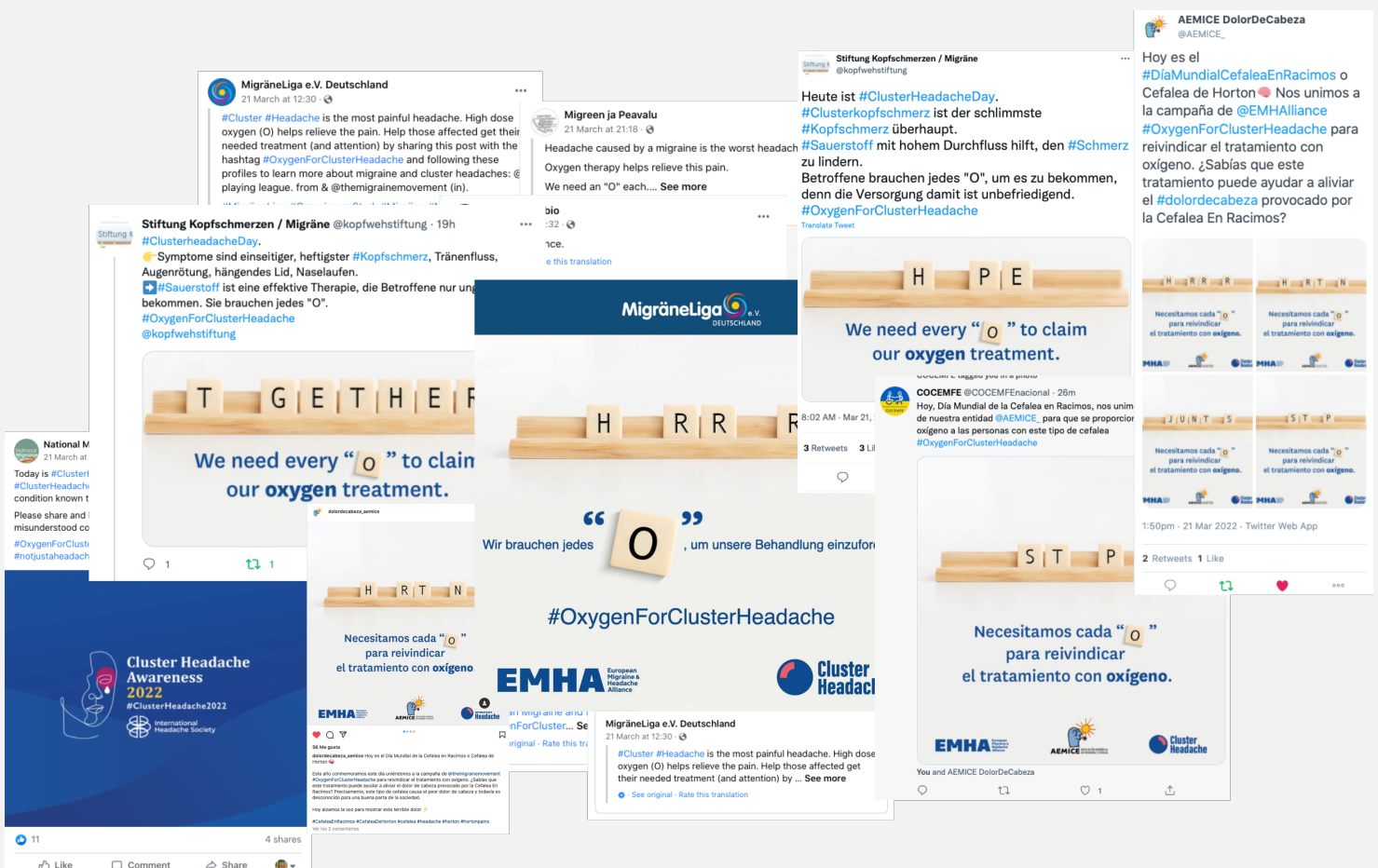


Cluster Headache Day

21st March- Cluster Headache Awareness Day “O is for Oxygen”

The goal of the campaign was to create awareness of Cluster Headache and the importance of having access to high flow oxygen treatments. In order to achieve this, we created an online campaign shared with the hashtag #OxygenForClusterHeadache.

The campaign was based on the Scrabble board game, but, all the words were related to the feeling CH sufferers have regarding their illness.



21st March- Cluster Headache Awareness Day “O is for Oxygen”

We created different images around this topic and encouraged all the CH associations to share them on their social media channels.

These images were also translated into Spanish, German and Portuguese, by request of the associations, to encourage the conversation in their own language.



We need every “O” to claim
our **oxygen** treatment.

EMHA European
Migraine &
Headache
Alliance

Precisamos de todos os “O” para reivindicar
o tratamento com **oxigénio**.

EMHA European
Migraine &
Headache
Alliance



Communication Plan

Communication Plan: Social Media 2022

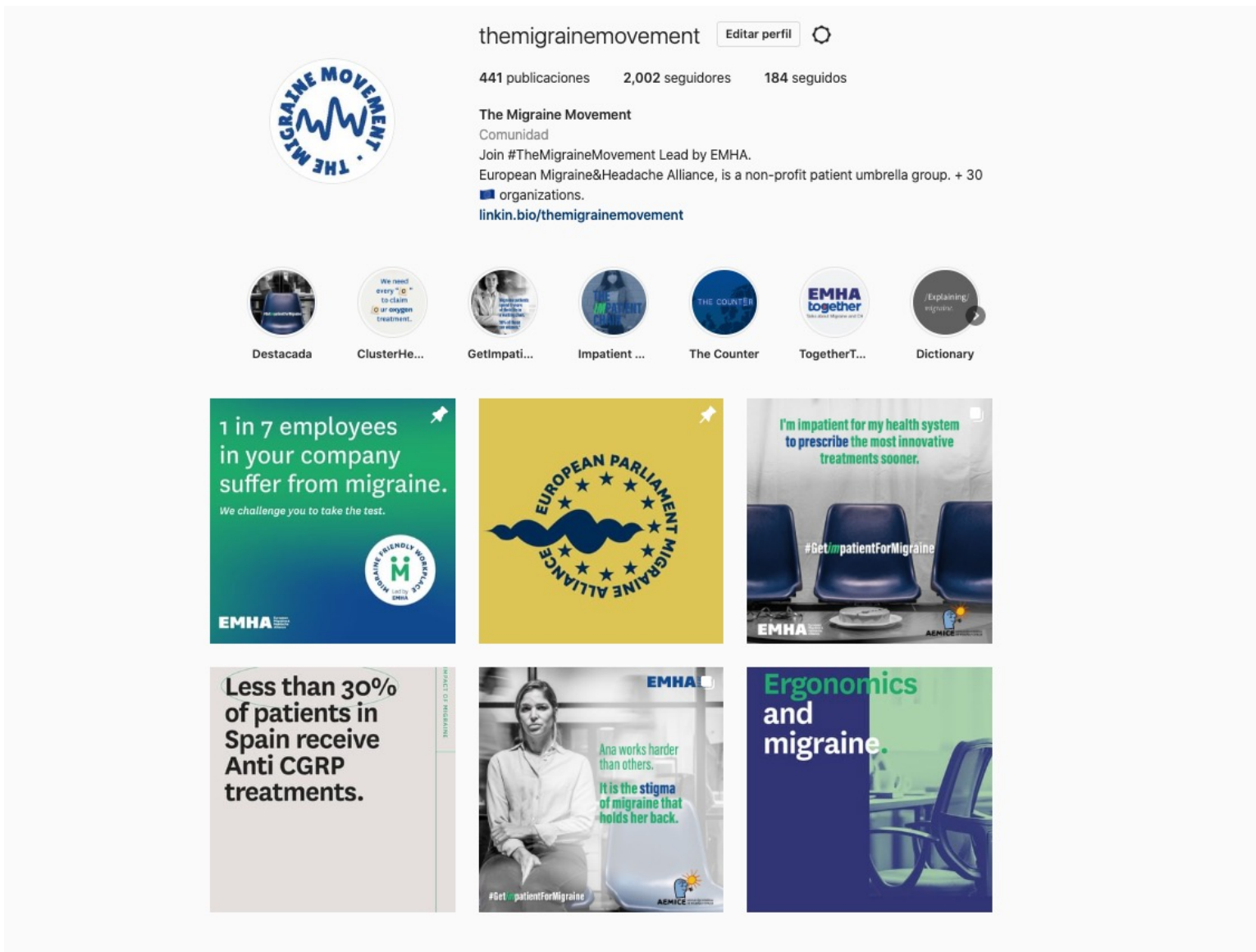
Strategy: In 2022 we focused on making our community stronger and increasing the engagement. With more in depth knowledge of EMHA's audience needs, we adjusted the content and message in each social network, with the aim of covering different audiences based on their knowledge of migraine and the EMHA.



Communication Plan: Social Media 2022

Content Lines by verticals:

- 01.** Women and Migraine
- 02.** Migraine at Work:
Migraine Friendly Workplace
- 03.** European Parliament Migraine
Alliance: Policy work activities.
- 04.** The Impact of Migraine:
Data Content
- 05.** Is it Migraine?
- 06.** Dayketing



Communication Plan: Social Media 2022

The EMHA's community gains strength.

People reach on our social media channels thanks to the sum of the activities by the EMHA during 2022

193032

Increase in the number of followers of social networks (6577).

+27,04%

Engagement with our social media content in 2022.

104,10%

Increase in time spent per session in the EMHA's website.

+51,85%

*RESULTS FROM JANUARY TO SEPTEMBER 2022 COMPARED TO SAME PERIOD 2021



Policy Affairs



EU Affairs Achievements 2022

Planned stamp implementations

Policy Achievements

- Proposal and inclusion of amendments for the “Towards a Common European Action on Care” Initiative
- First time inclusion of migraine in European documents: “Towards a Common European Action on Care” & “Mental Health in the Digital world of Work”



Position Achievements

- Regular contact with key MEPs such as Susana Solís Kira Marie Peter-Hansen and Sara Matthieu for the positioning of EMHA in the European health debate and for the submission of amendments and opinions on EU initiatives.
- Meeting with Rosa Estarás to discuss the submission EMHA’s proposed amendments to the initiatives and present the alliance projects to the MEP.
- Meeting with Jordi Cañas to discuss the proposed amendments for the initiatives and present EMHA’s projects.
- Meeting with Deirdre Clune to discuss the European Parliament Migraine Alliance, the future event and other EMHA projects.
- Coming up: 1-to-1 meetings with other key MEPs inside and outside the Alliance, e.g.: Sara Matthieu & Kira Marie Peter-Hansen

EU Affairs Achievements 2022

European Commission



- Provision of Stakeholder input for the EU.
- Non-Communicable Diseases initiative.



European Parliament Migraine Alliance



- One new member of the Alliance, Spanish MEP Jordi Cañas from Renew Group: 8 members in total.
- Coming up soon: On –Site Meeting with the Alliance in Brussels.



EMHA Projects



- Proposal of a new approach for the project more adequate for the EU institutions and key stakeholders inside them.
- Content creation on the topics of EU Affairs and Policy Makers for the monthly newsletter.
- Regular contact with key non-institutional stakeholders.
- Attendance to EFNA General Assembly.



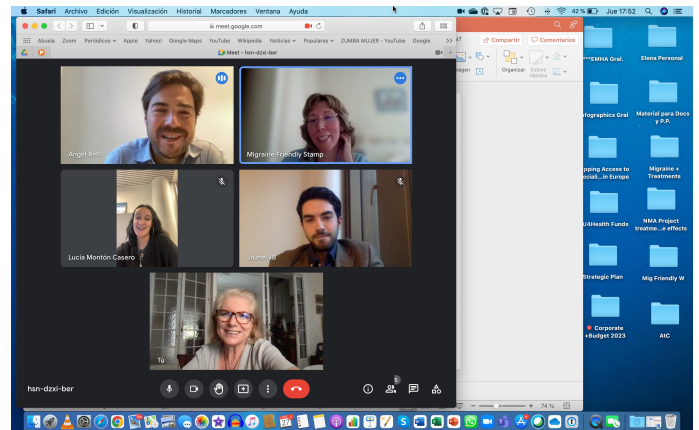
EU Affairs Achievements 2022

EU Funding Projects



- Introduce EMHA as a value-adding partner in the EU4Health call on Mental Health. Dialogues with different organizations and consortiums to position EMHA as part of the Project.

Ongoing: Management of EMHA's possibilities to Benefit from EU4Health Operating Grants



EU4health

European Events



- The Organization of an event under the theme “safety and health at work” with the support of OSHA.

Sponsorship of the event by MEP Pablo Arias.

Dates: Event scheduled for April 2023





EMHA Activities with other Stakeholders

Science

IHS Corporate Meeting



IHS Corporate Advisory Roundtable	
17 December 2021	
Virtual meeting	
Minutes	
Participants	
IHS	Cristina Tassorelli Ram Burstein Mesoud Adhina Patricia Pozo-Rosch Guido Terwindt Hans-Christoph Diener
Industry representatives	Abbvie – Laurent Delabaye, Mudra Kapoor Amgen – Mahan Chaitanya, Denise Chou, Bai Cai, An Rhoades, Gabriel Pava de Silva Lima Biogen – Courtney Cappelletti, Gil Fritallan electraCare – Eric Lebeux, Ian Brindland Lilly – Gracia Dell'Agnello, Lari Viskup Lundbeck – Isabel Carita Maroz, Lotte Nielsen, Ole Elvén, Rigmor Sperling, James Weatherall Novartis – Mafalda Ferraris, Marja Koch Teva – Lynda Rosenbaum, Verónica Ramirez Campos, Prior Kalkur, Andrew Alts
Patient groups	Elena Ruiz de la Torre (European Migraine & Headache Alliance) Audrey Croves (Migraine Association of Ireland)
Topic:	
Welcome and introductions	o Cristina Tassorelli welcomed participants and thanked them for attending the meeting
Cluster headache guidelines review	o Guidelines of the International Headache Society for Controlled Clinical Trials in Cluster Headache – sent for Roundtable review on 25 December o Last cluster headache (CH) guidelines published in 1995 o Working group for guidelines revision led by Jean Schoenen, Michel Ferrari and Agnès Jansen, along with young neurologists o Working group discussed with IHS leaders how to implement some recommendations on adolescents o Allow Roundtable members time to review – since the last guidelines were published many things have changed in the field of CH and there have been many trials. IHS appreciates industry colleagues have considerable experience with setting up clinical trials and their comments will be of great value to enrich the guidelines. Send comments by 15 January 2022 – if it's felt there is need for more discussion IHS can arrange another meeting o Next draft of guidelines will be sent to EMA and FDA for review
Discussion	o What constitutes a placebo group? The definition can be diverse from one trial to another. In some designs certain medications are excluded from the placebo arm; other medications are included. This creates challenges in defining a consistent placebo arm. Need to define what placebo patients can get in terms of treatments in a consistent way. In Europe a lot

IHS Corporate Roundtable minutes
Virtual meeting – 17 December 2021

1

International Headache Symposium



Please complete and return to:

EAN Head Office
Breite Gasse 4 / 7
1070 Vienna
AUSTRIA
Fax: 0043 1 889 05 03 13 or
Email: scientific@ean.org



EAN

The purpose of this form is to provide the EAN with information about your other interests that could influence how they receive and understand your work.

Name of the task force/guideline: guideline on migraine treatment

Section 1. Identifying Information

1. Your first name Elena 2. Your last name Ruiz de la Torre

3. Date of completion of form 11/04/2022(DD/MM/YY)

4. E-mail address: elena@emhalliance.org



Scientific Conferences

MTIS Opening Ceremony + EMHA booth

The EMHA was part of the MTIS event, organized by [The Migraine Trust](#), giving voice to all migraine sufferers around Europe.

Elena Ruiz de La Torre, Executive Director of the EMHA, (representing the EMHA) together with Professor Peter Goadsby, Chair of the Scientific Programme Committee, and Michelle Walder, President of the Migraine Trust all participated in the opening ceremony of the event.

To expose the painful truth about the delay in access to treatment and correct diagnosis of migraine, the speakers sat for 80 seconds in complete silence. The uncomfortable silence in the room was followed by an explanation of the activity, as well as a video thanking the scientific community and industry for their constant efforts to reduce waiting times for patients.



Scientific Conferences

MTIS Opening Ceremony + EMHA booth



Scientific Conferences

MTIS Opening Ceremony + EMHA booth



Scientific Conferences

MTIS Opening Ceremony + EMHA booth



Scientific Conferences

MTIS Opening Ceremony + EMHA booth



Scientific Conferences

MTIS Opening Ceremony + EMHA booth

Participation on the documentary for migraine with IHS and Ander Chattingius.



Scientific Conferences

EHC Vienna: Stigma Roundtable

EMHA's Executive Director Elena Ruiz de la Torre launches the Stigma Project at European Headache Federation Congress at a roundtable with Neurologist, Industry, Editors and Patients.



Scientific Projects

META ANALYSIS PROJECT –

MNA ON MIGRAINE PROTOCOL with Prof. Diener, Prof. Ashina et al.

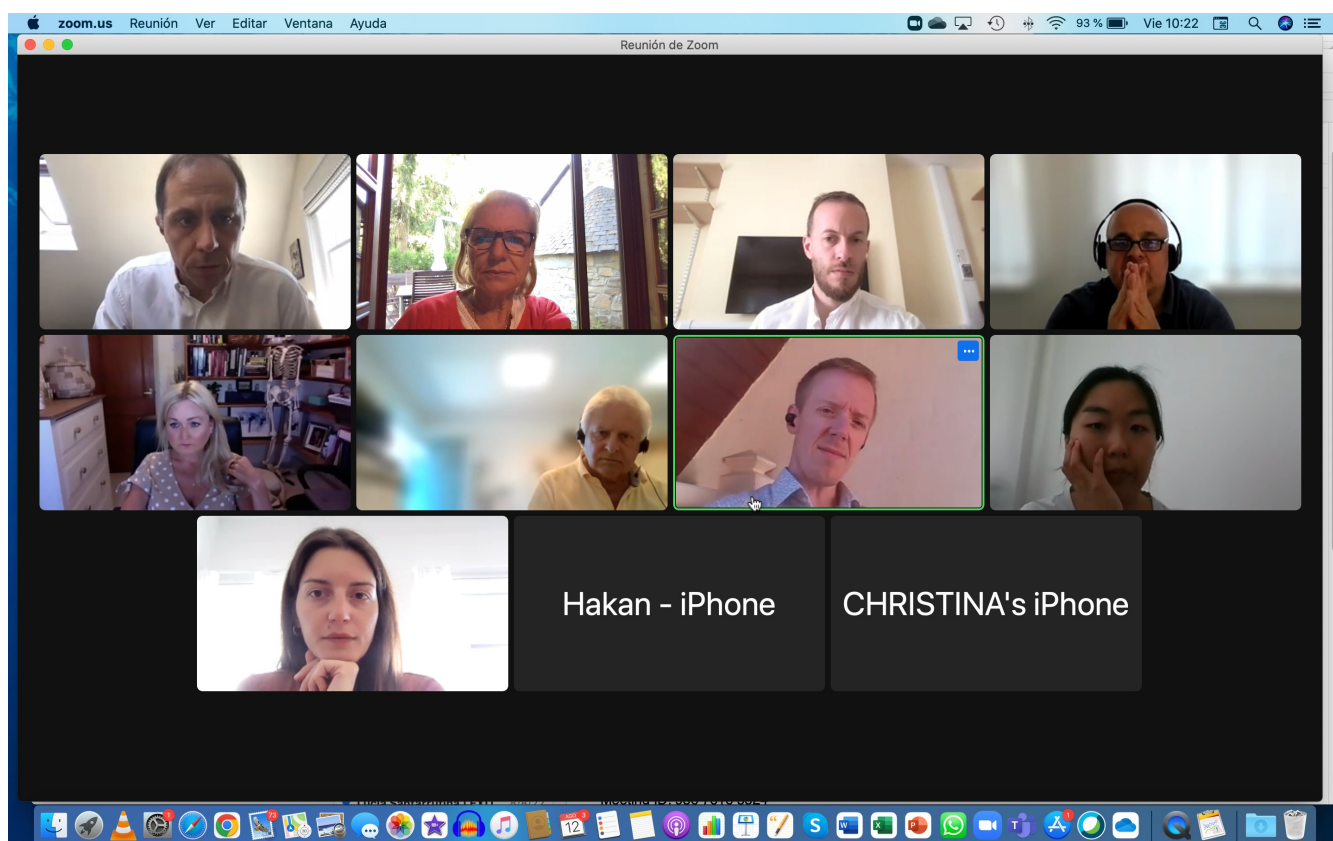
Office: Hufelandstrasse 26
45147 Essen, Germany
Tel. 0049 201 723 6540 Fax 0049 201 723 6918
E-Mail: hans.diener@uk-essen.de; hans.diener@uni-duisburg-essen.de
<https://www.uni-due.de/hc-diener/>

[Ver más de Andrea Cipriani](#)



NIHR | Oxford cognitive health
Clinical Research Facility

Meta Analysis projects on migraine medication side effects



EMHA Internal Meetings

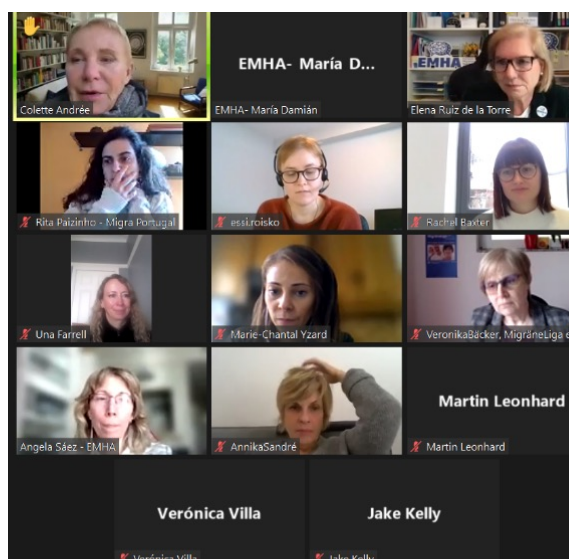
General Assembly

The top screenshot shows a Zoom meeting with 19 participants. The grid includes video feeds for Dietmar Krause, Richard, and Romania, ADINA RO... (highlighted in green). The participant list on the right includes: Elena Ruiz d... (Anfitrión, yo), Patrick Little EMHA, Vesselina Grozeva, Angela Sáez, Isabelle Andoulsi, Anna Maclean, Debbie The Migraine Trust, Dietmar Krause, EMHA - María Damián, GIORGIO SANDRINI, Isabel Colomina, lara merighi, Lia Barmpa, and Richard.

The bottom screenshot shows the same Zoom meeting with 20 participants. The grid includes video feeds for Dietmar Krause, Richard, and Romania, ADINA RO... (highlighted in green). The participant list on the right includes: Elena Ruiz d... (Anfitrión, yo), Patrick Little EMHA, Vesselina Grozeva, Angela Sáez, Isabelle Andoulsi, Anna Maclean, Debbie The Migraine Trust, Dietmar Krause, EMHA - María Damián, GIORGIO SANDRINI, Isabel Colomina, lara merighi, Lia Barmpa, and Richard.

EMHA Internal Meetings

Members' meeting



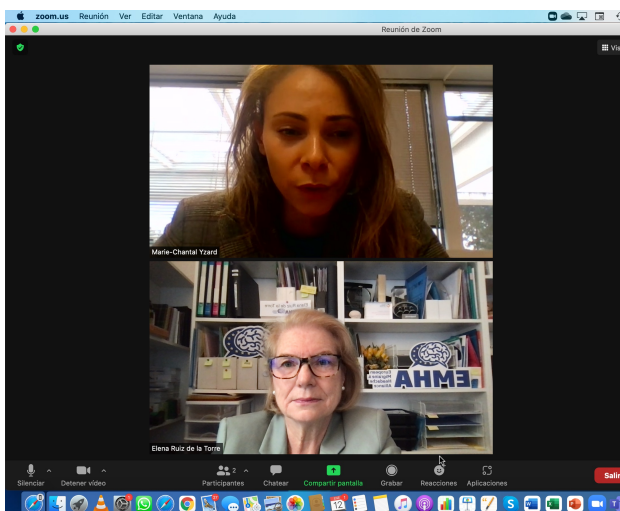
EMHA Internal Meetings

Board meetings

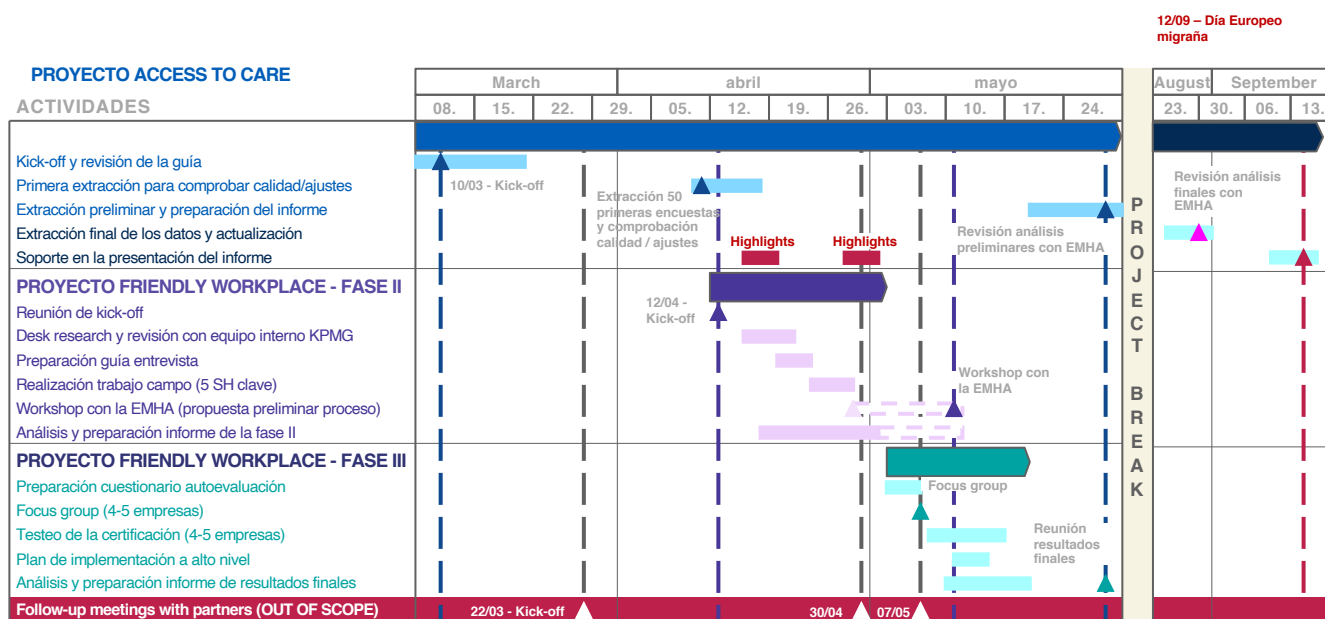


Meetings with Members

Migräneliga with Mrs. Veronika Bäcker

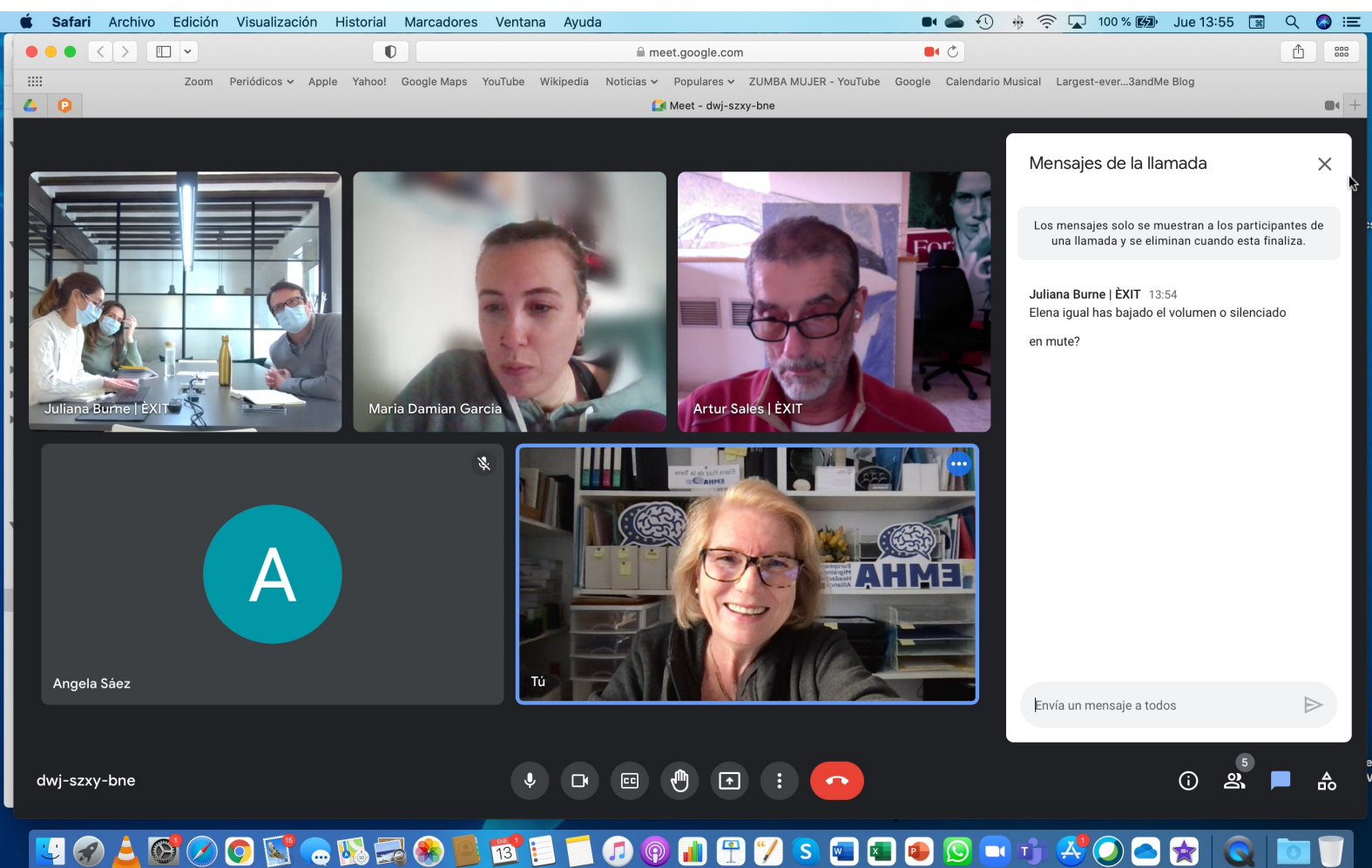


Dr. Nekelle Cools
from Hoofpijnnet



Meetings with the EMHA

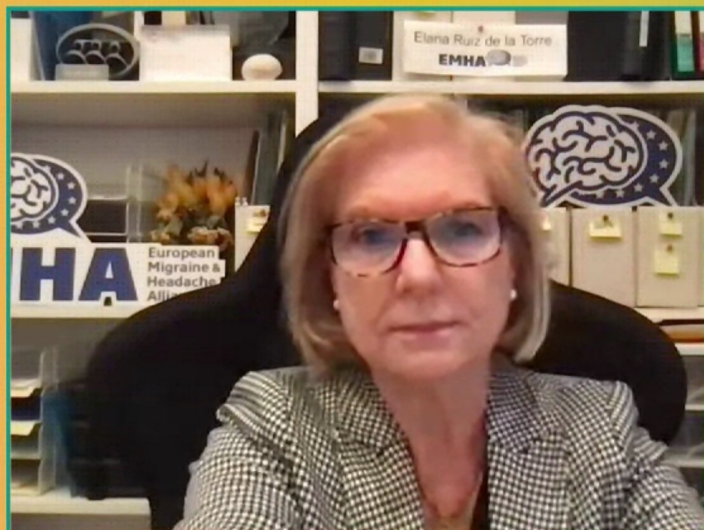
Communication Agency EXIT-UP



Meetings with the EMHA

Participating at national webinars

DESMONTANDO MITOS SOBRE MIGRAÑA



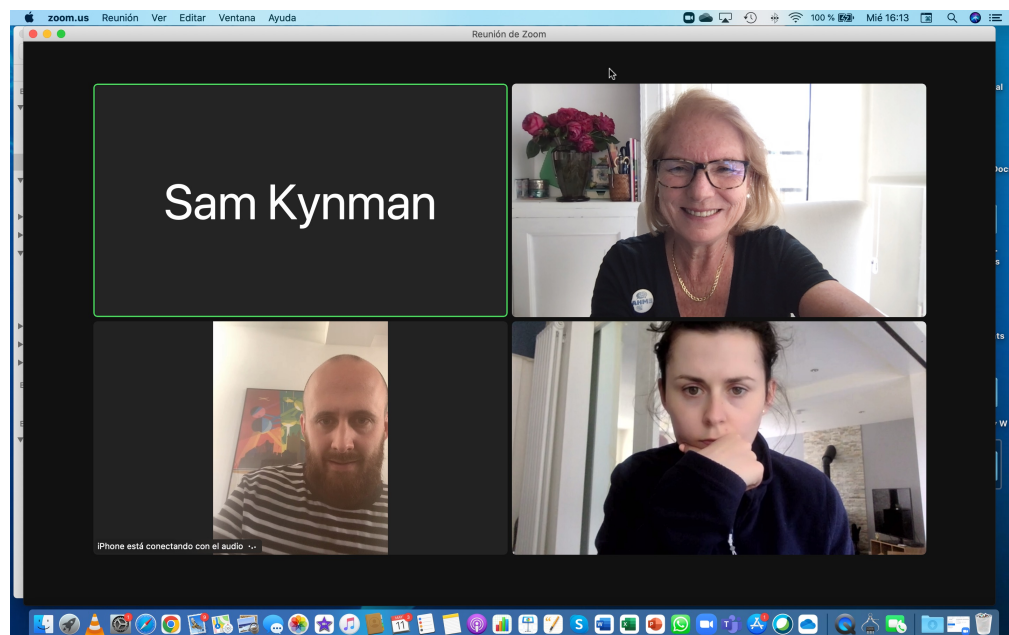
Elena Ruiz de la Torre, Vicepresidenta de AEMICE



Dr. Samuel Díaz Insa, Neurólogo

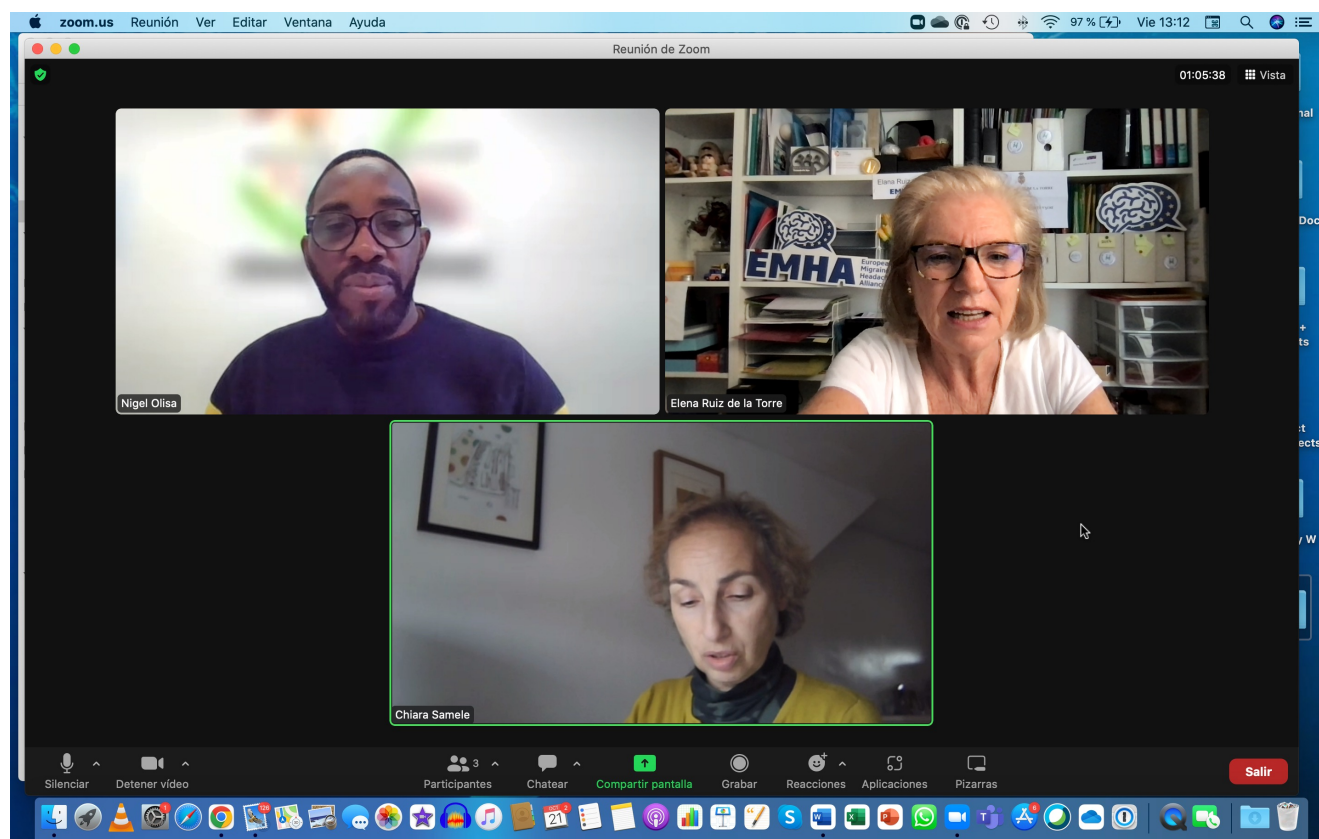
Meetings with the EMHA

MTG with EFIC



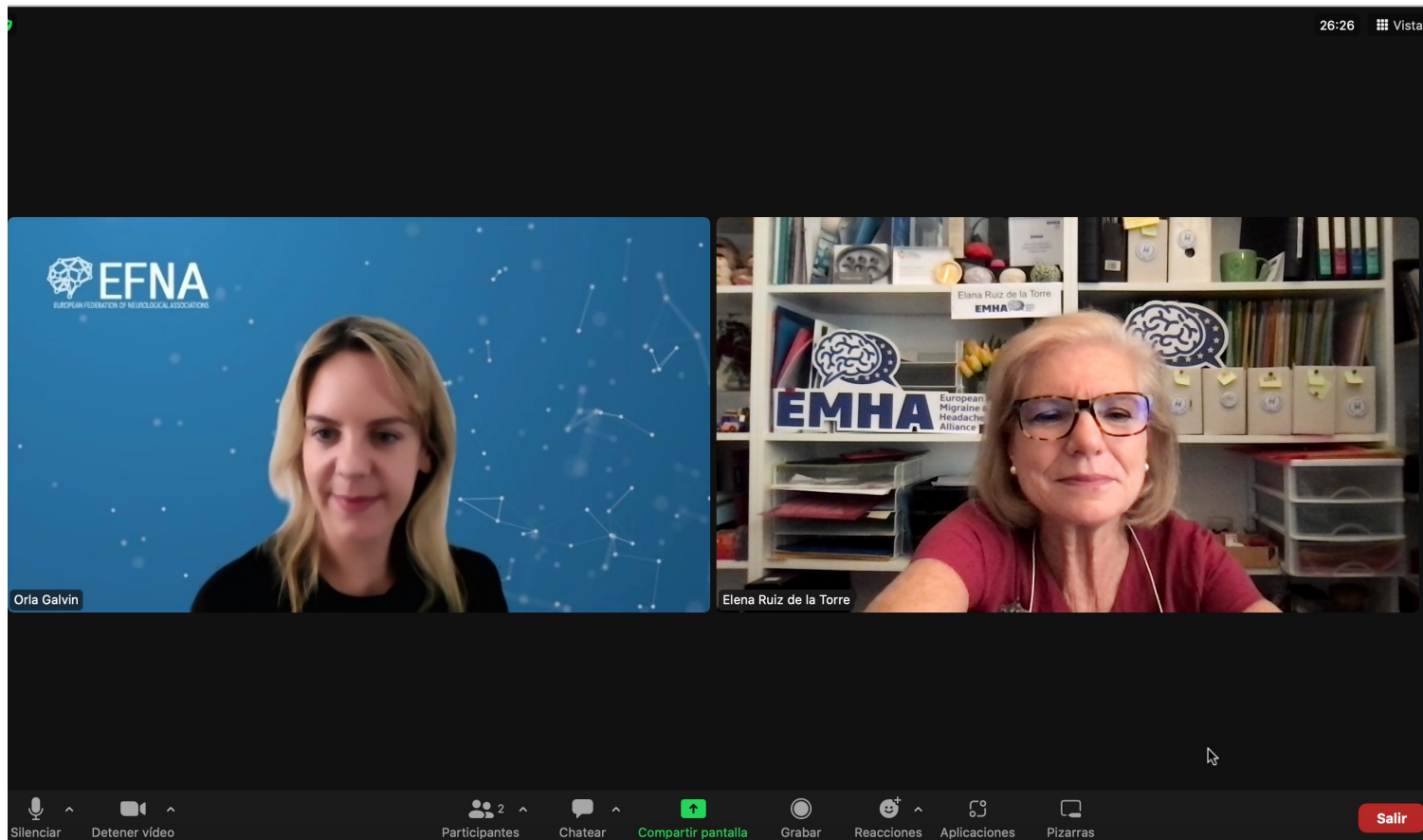
Gamian – Mental Health

Nov. 9th Migraine and MENTAL HEALTH WEBINAR



Other stakeholders

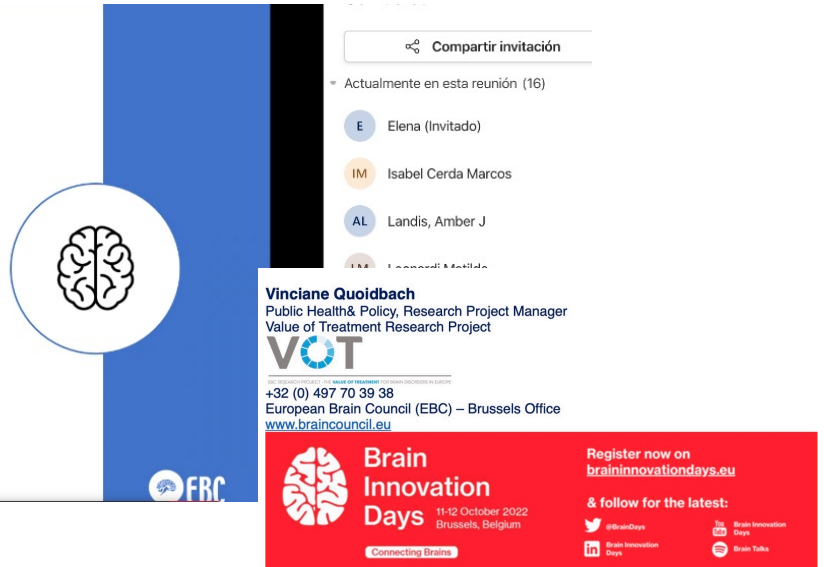
EFNA



Other stakeholders

Discussion

1. Discuss availability of key evidence and recent publications
2. Group leader with an economic background to lead the discussion
3. AOB

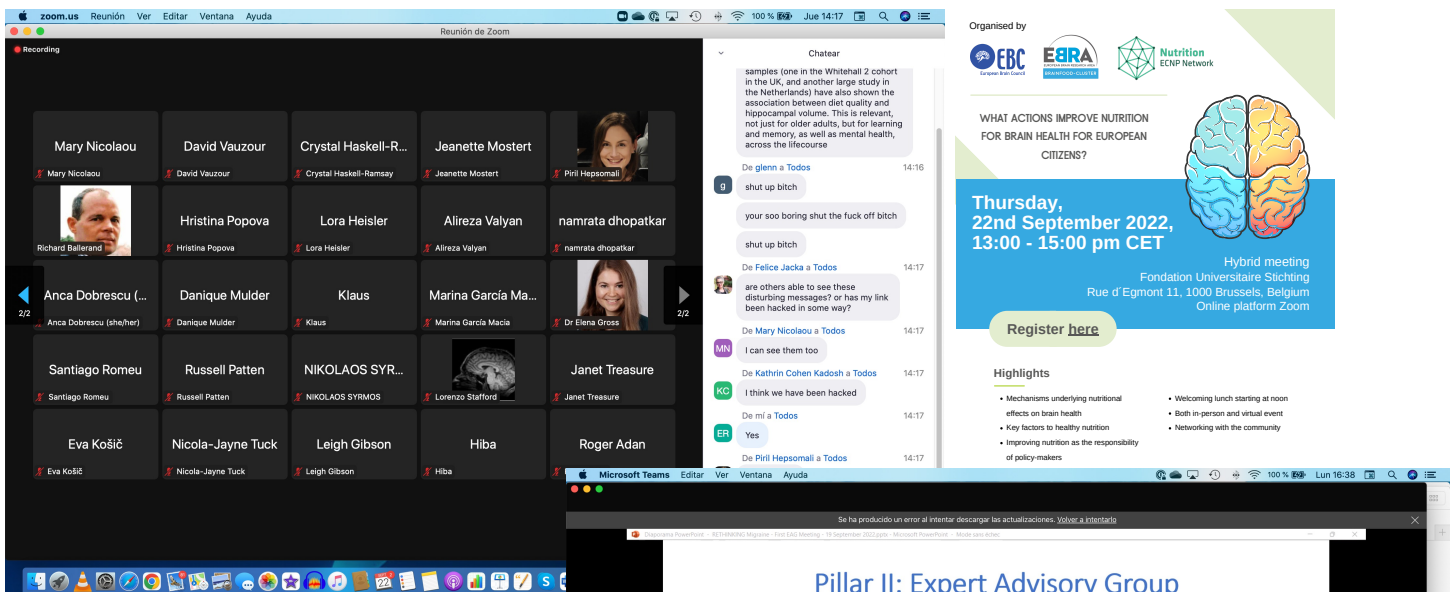


Vinciane Quoidbach
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Value of Treatment Research Project
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European Brain Council (EBC) – Brussels Office
www.braincouncil.eu

Brain Innovation Days
11-12 October 2022
Brussels, Belgium
Connecting Brains

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Brain Innovation Days
Brain Talks

Brain and Food Webinar



Organised by
EBC European Brain Council
EBRA European Brain Research Alliance
Nutrition ECNP Network

WHAT ACTIONS IMPROVE NUTRITION FOR BRAIN HEALTH FOR EUROPEAN CITIZENS?

Thursday, 22nd September 2022, 13:00 - 15:00 pm CET

Hybrid meeting
Fondation Universitaire Sclhting
Rue d'Egmont 11, 1000 Brussels, Belgium
Online platform Zoom

Register [here](#)

Highlights

- Mechanisms underlying nutritional effects on brain health
- Key factors to healthy nutrition
- Improving nutrition as the responsibility of policy-makers
- Welcoming lunch starting at noon
- Both in-person and virtual event
- Networking with the community

Cost of Migraine EBC. Re thinking Migraine



Pillar II: Expert Advisory Group

Name	Job title	Affiliation
Paul Derrien	CEO	Migraine Association of Ireland
Patricia Pozo-Rosich	Specialist in Neurology	International Headache Society
Simona Sacco	Professor of Neurology	University of L'Aquila, Italy/ European Headache Federation (EHF)
Maria Teresa Ferretti	Co-founder & Chief Scientific Officer	Women's Brain project
Christina Tassorelli	President	International Headache Society
Pablo Irimia Sieira	Co-chair	EAN Scientific Panel on Headache
Matilde Leonardi	Director Neurology, Public Health, Disability Unit & Coma Research centre	Fondazione IRCCS Istituto Neurologico Carlo Besta, Milan, Italy
Licia Grazi	Head	Institute's Headache Centre
Christian Lampi	Head of Department of Neurology	President of the European Headache Federation EHF
Elena Ruiz de la Torre	Executive Director, Immediate Past president	European Migraine and Headache Alliance (EMHA)
Paolo Martelletti	Director, Department of Clinical and Molecular Medicine	Emergency Medicine & Internal Medicine Residency Program Sapienza University of Rome
Rigmor Jensen	Med. Director	Danish Headache Center, Department of Neurology,
Tim Steiner		

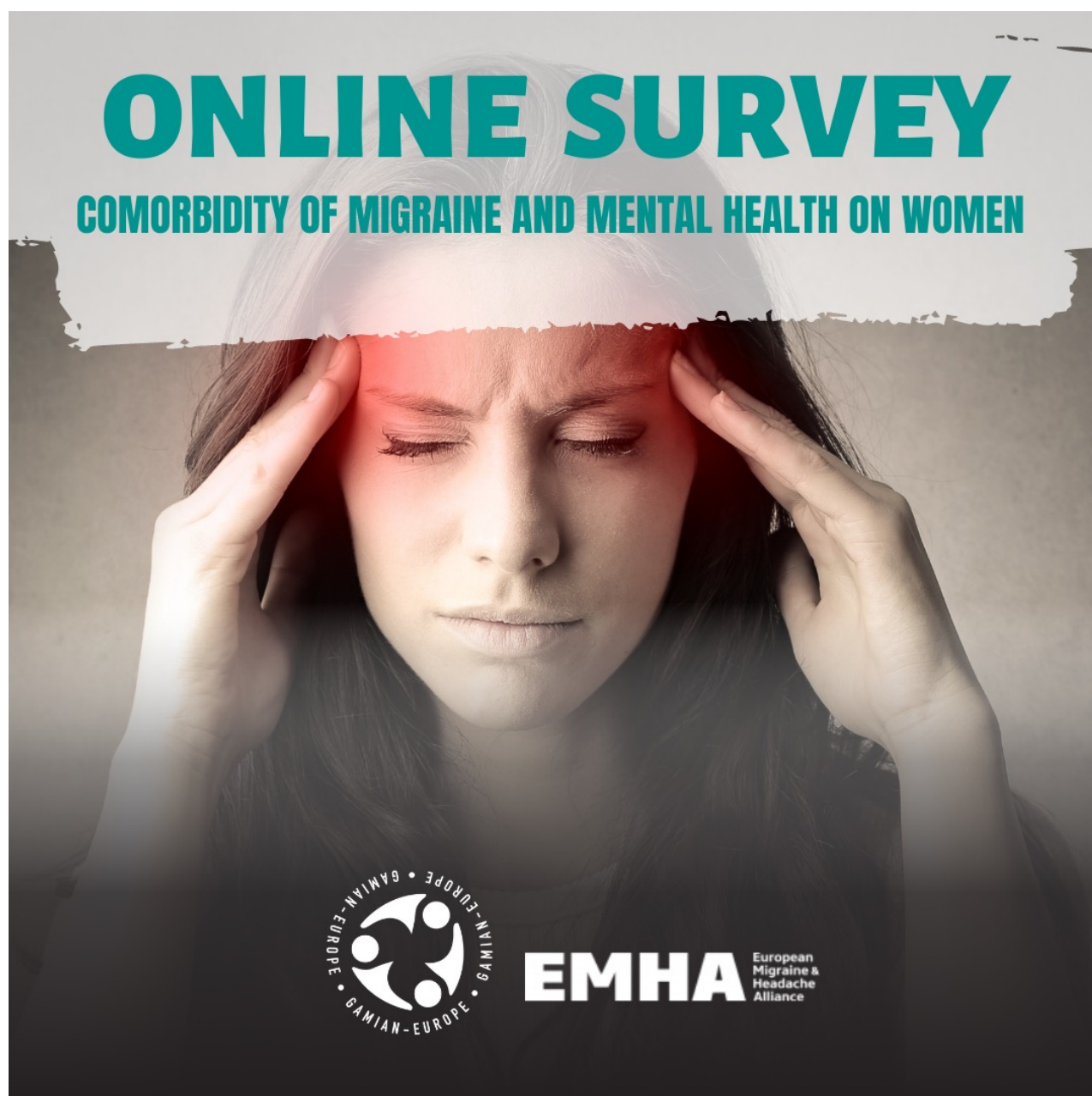
Other stakeholders

GAMIAN-Europe Next Webinar on Migraine and Mental Health in Women: 9th November 15.00 CET



Other stakeholders

Online survey with GAMIAN on Comorbidity of Migraine and mental health on women.



Industry

Lundbeck: #1VoiceSummitLundbeck



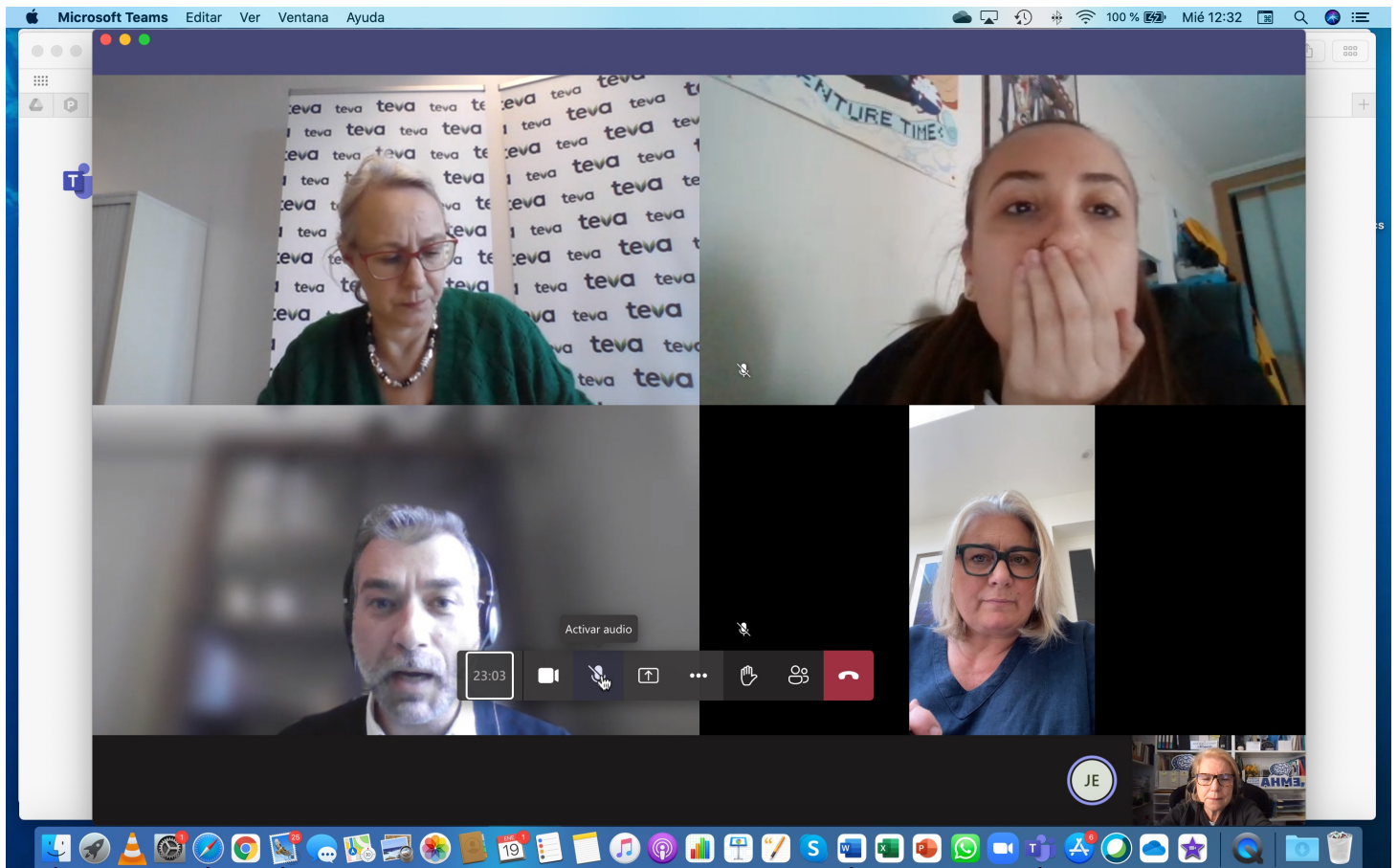
Migraine Advocacy Advisory Board-Lundbeck



Grünenthal Foundation:
The challenge of care for people with chronic pain in the Valencian Region

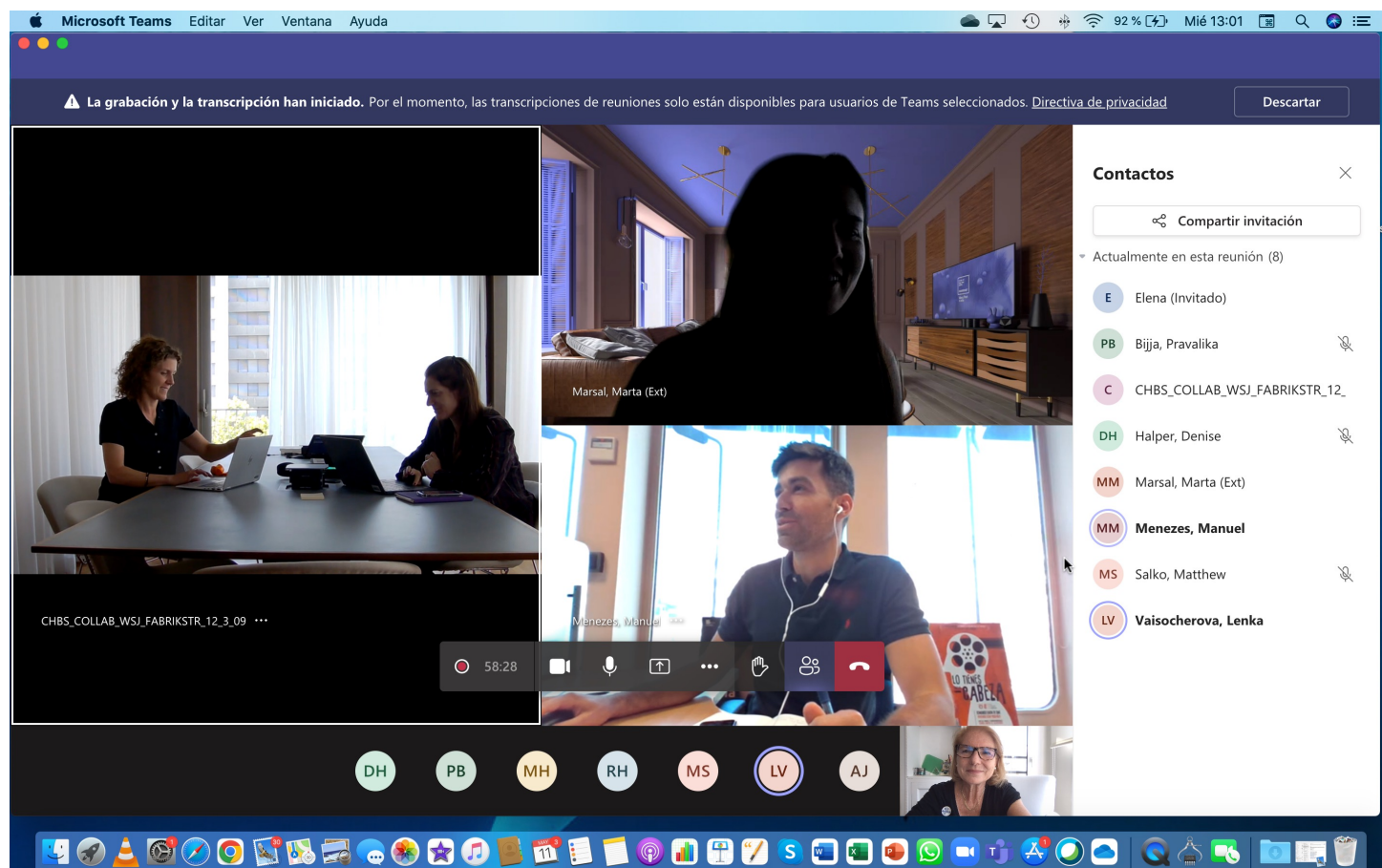
Industry

Teva



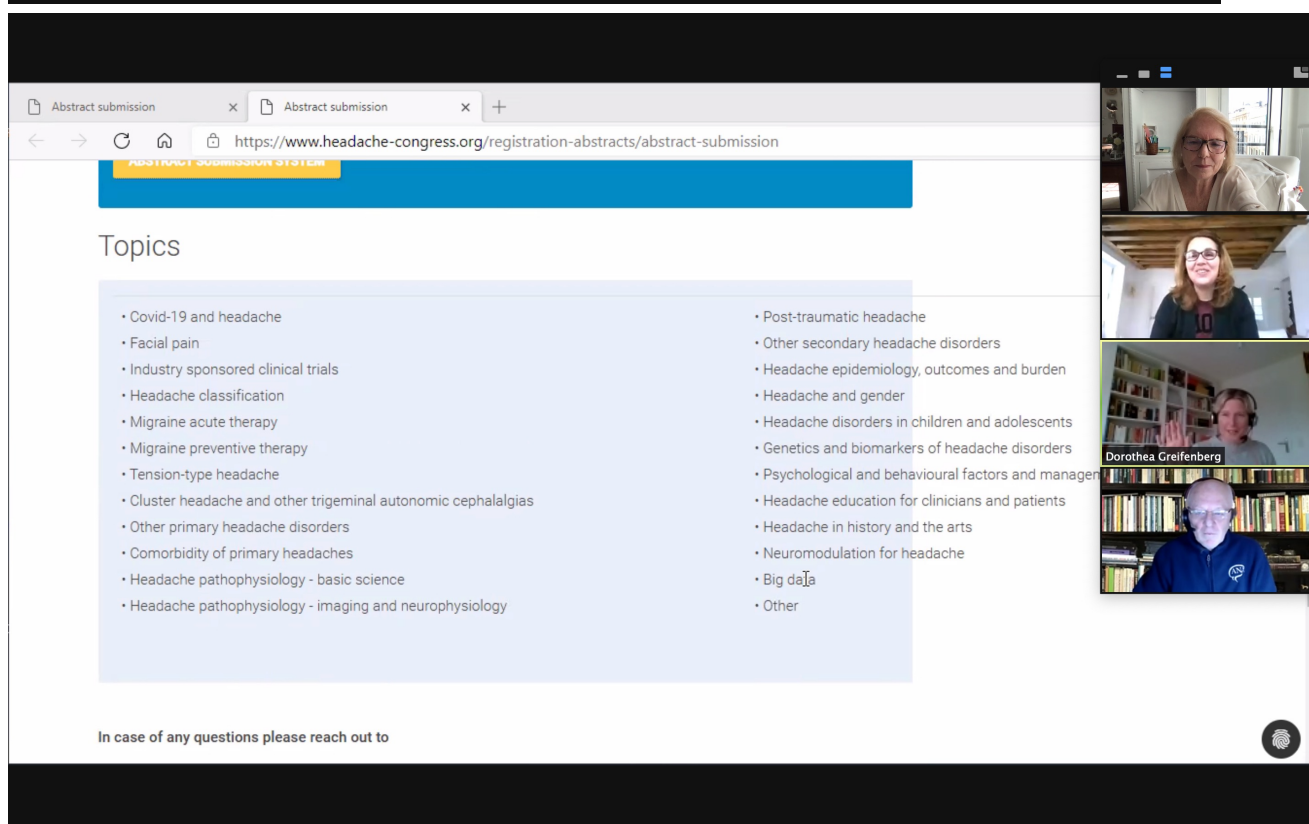
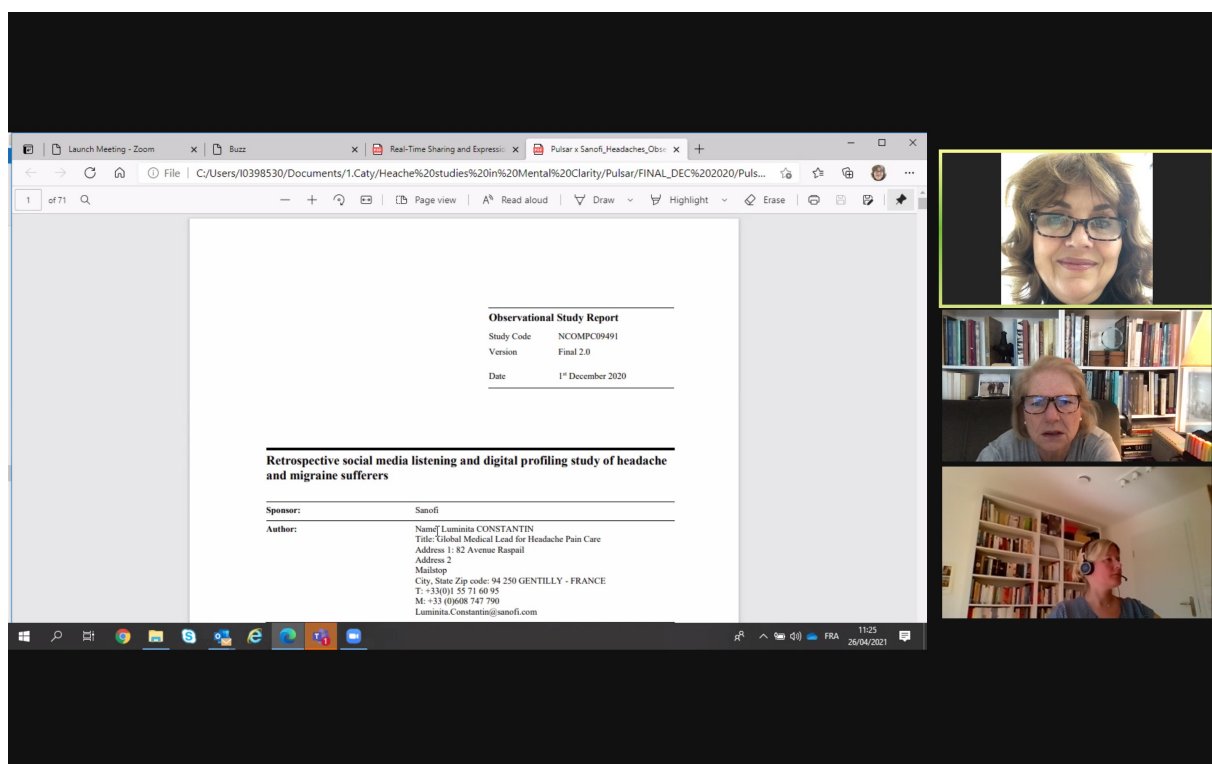
Industry

Novartis



Industry

Sanofi: Publications on social media and Migraine interaction



Industry

Sanofi: Publications on social media and Migraine interaction

EMHA participates actively in several projects and research of new molecules and treatments.



Thank you.

EMHA European
Migraine &
Headache
Alliance