

Activity Report

2023



EMHA European
Migraine &
Headache
Alliance

The Migraine Movement

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Selbsthilfegruppe
„Kopfwegh“



Migrensamtokin



HUVUDVÄRKS FÖRBUNDET



OUCH Italy



INTERNATIONAL ASSOCIATES





EMHA European
Migraine &
Headache
Alliance

The Migraine Movement

Organization Chart



Patrick Little

PRESIDENT



Elena Ruiz de la Torre

EXECUTIVE DIRECTOR



Kalina Tyminski

BOARD MEMBER



Scott Bruce

BOARD MEMBER



Isabel Colomina

BOARD MEMBER

María Damián

**FINANCE OFFICER &
PROJECT ASSISTANT**

Loles Güido

**MIGRAINE FRIENDLY
WORKPLACE**

DEAR MEMBERS AND SUPPORTERS

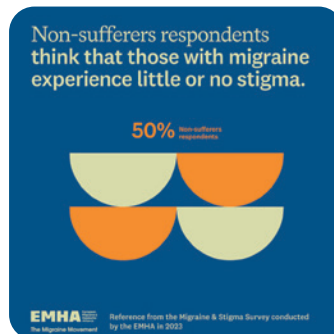
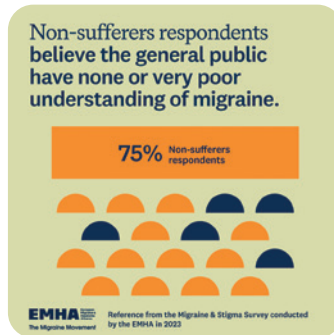
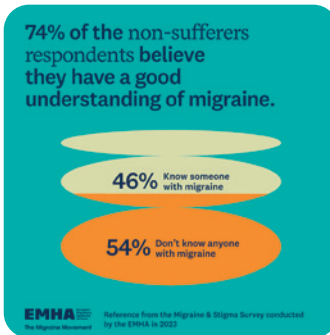
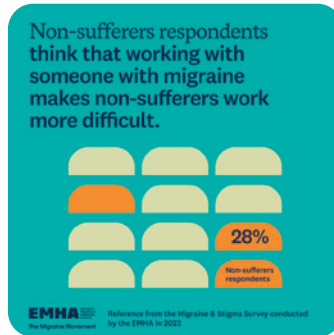
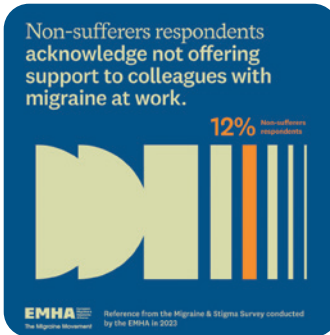
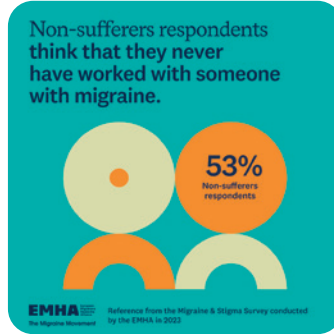
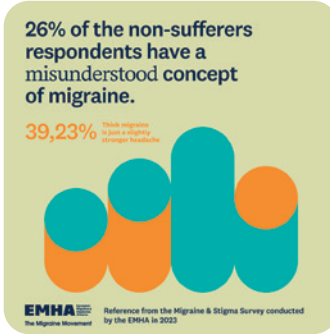
I am delighted to introduce our Activities Report for 2023. You will see that this has probably been our busiest year ever. Great credit is due to Elena, EMHA staff, our external partners and indeed all the EMHA members across Europe for their hard work in making the year such a success.

Among the many highlights of the year was our very successful MHIPAS conference which brought together members and supporters from across the world and finally allowed us to pay homage to Paolo Rossi for his many years championing the cause of patients with migraine and Cluster Headache.

I would particularly like to acknowledge the ongoing support from our corporate partners without whom we would be unable to carry out so many activities and we look forward to their continued support in the future.

**Patrick Little,
EMHA President.**

1. Migraine & Stigma



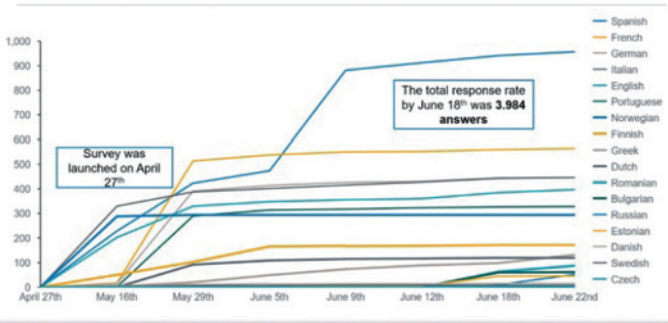
Migraine & Stigma

The EMHA conducted a comprehensive pan-European digital Survey to examine the origins of stigma surrounding migraine, its impact on patients, and their need for better understanding and support. The survey covers various topics such as patients' ease in sharing their stories, understanding of migraine terminology (chronic/episodic/refractory), areas of stigma (civil society, patients, family, work) and ways to address it.

The methodological approach involves a collaboration between the EMHA, Prescient HealthCare Group and a scientific committee to design the survey, gather information, analyze results, and share insights with stakeholders.

UPDATES MEETINGS

Response rate from 27th April to 18th June 2023



FOLLOW UP MEETINGS AFTER THE RESULTS



July 1st

BUDAPEST

After gathering enough answers to count with a robust sample, the EMHA organized the first face to face meeting with Prescient and the Scientific Committee, where the analysis of the preliminary results were presented as well as discussions were raised about the future of the project.



Launch of the results

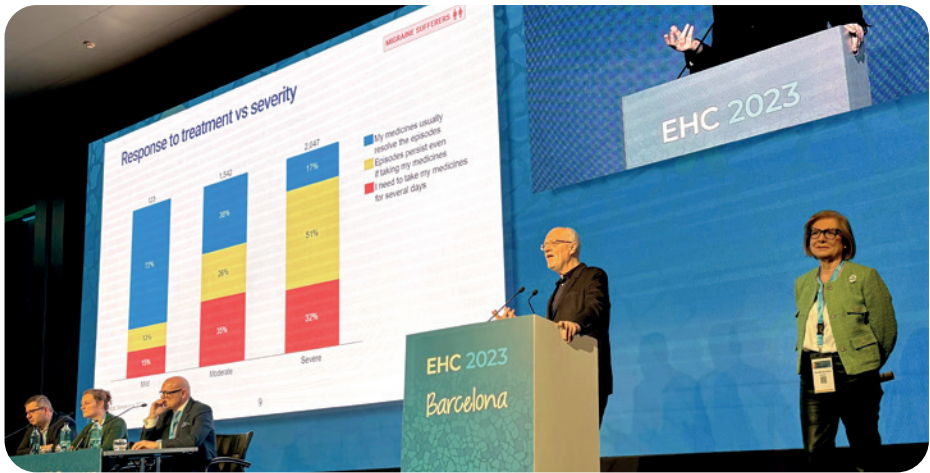
DECEMBER 6TH - EHC BARCELONA

The official launch of the results was done by Prof. Goadsby and Ms. Ruiz de la Torre during the first day of the European Headache Congress to more than 1280 neurologists, causing a lot of compliments and opinions regarding the impactful insights and queries arose among the attendees about the future of the project.



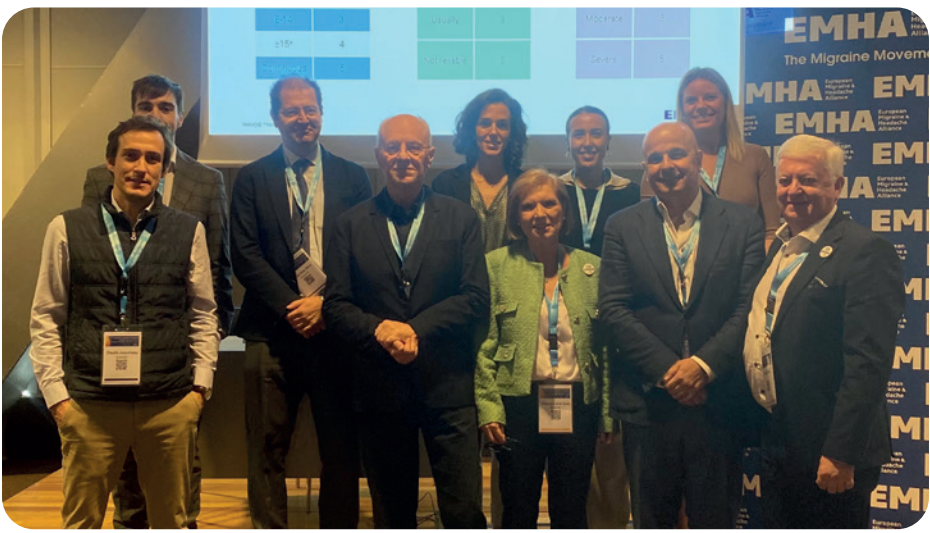
Scan the QR to access our website to see the survey full results.





NEXT STEPS

After the presentation of the results in EHC , the Scientific Committee gathered in order to organize the future of the project and how to incide in the stigma issue from the scientific community. As a result, they all agreed on working in a new Migraine Scoring System in 2024.



2. Migraine Friendly Workplace



Migraine Friendly Workplace Project

MFW is an initiative of the EMHA that aims to normalise and raise awareness of workers with migraine in order to reduce its stigma. The project is suitable to be embraced by all working spaces.

In 2023, the number of companies joining the project has significantly grown. We are now more than 91 Migraine Friendly Workplaces.

In the framework of the Migraine Friendly Workplace project, the EMHA members can offer various migraine awareness activities to the companies. For example, talks with health experts and patients, advice on the creation of migraine friendly corporate material or support in creating migraine friendly work environments.

BBVA HYBRID LECTURE

EMHA co-hosted a conference for **more than 30K BBVA employers** focused on health and emotional management.

Professor Peter Goadsby from King's College London was the guest speaker, providing valuable insights on migraine and its management, including the latest treatments available.



Migraine Friendly Workplaces

abbvie

ARPA
Asociación de Rehabilitación de la Comunidad Valenciana

aquaservice



caixa popular



JCDecaux

Lilly

Lundbeck



MELIÀ

nunsys
Tu socio tecnológico

sothis

NOVARTIS

Pfizer

randstad

teva

CECOVA
Consejo de Enfermería de la Comunidad Valenciana

EFNA
EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

ALBERTA NORWEG

ASA PCV

TRIBUS

ANIEME

ASECAM

AVALNET

ANGELA
IMPACT ECONOMY

BODY BACK-UP
HEALTHCARE

BONET
ABOGADOS

CAXTON COLLEGE
COLLEGE OF THE ARTS

CENTRO TANDEM
FOTOTERAPIA Y REHABILITACIÓN

Curelator
Take back control®

CONSULTIA
BUSINESS TRAVEL

Happyforce

salud
servicio integral de salud

HENDRIKSON DGE

EXIT



Implica
CORPORATE FINANCE

indolor
VALENCIA

KETOSWISS
FUEL FOR BRAINS

big KEVAL+

LÄBERIT
PEOPLE • INNOVATION • TECHNOLOGY

Nephila

Promonity
marketing promocional

Salvia BioElectronics

TEAM LEWIS

Vellekoop & Meesters
informatiemangement

WESTIN
HOTELS & RESORTS

25
PALACIO DE CONGRESOS
VALENCIA
EXPERIENCES

Many companies are improving the present and future for all its employees.

Here are some of the business that have committed to building more Migraine-Friendly Workplaces.





ABBVIE

Large company / 53.000 employees
SECTOR: Pharmaceutical industry



AQUASERVICE

Large company / 1k-5k employees
SECTOR: Healthcare



CAIBA

Large company / 200-500 employees
SECTOR: Manufacture



CAIXA POPULAR

Large company / 326 employees
SECTOR: Banking



GRUP DOMINGUIS

Large company / 1k-5k employees
SECTOR: Engineering services



JCDECAUX

Large company / 500-1k employees
SECTOR: Advertising Services



ELI LILLY AND COMPANY

Large company / 41.856 employees
SECTOR: Pharmaceutical industry



LUNDBECK

Large company / 5.674 employees
SECTOR: Pharmaceutical industry



MELIÀ

Large company / 14.287 employees
SECTOR: Hospitality



NUNSYS/SOTHIS

Large company / 1.386 employees
SECTOR: IT services - IT consultancy



NOVARTIS

Large company / 76.814 employees
SECTOR: Pharmaceutical industry



PFIZER

Large company / 101.570 employees
SECTOR: Pharmaceutical



RANDSTAD

Large company / 56.035 employees
SECTOR: Consulting



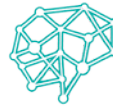
TEVA

Large company / 27.770 employees
SECTOR: Pharmaceutical



CECOVA

NGO Public law corporation
SECTOR: Associative



EFNA

EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS

EFNA

NGO Public law corporation
SECTOR: Associative



ARPA

SME Company
EU Affairs and Communications



ALBERTA NORWEG

SME company
SECTOR: Facility services



ASAPCV

SME company

SECTOR: Associative



ATRIBUS

SME company

SECTOR: IT service - IT consulting



ANIEME

SME company

SECTOR: Associative



ASECAM

SME company

SECTOR: Social and community organisations



AVALNET

SME company

SECTOR: Technology and Internet



ANGELA IMPACT ECONOMY

SME company

SECTOR: Consulting services



BODY BACK-UP HEALTHCARE

SME company
SECTOR: Healthcare



BONET ABOGADOS

SME company
SECTOR: Law



CAXTON COLLEGE

SME company
SECTOR: Education



CENTRO TANDEM

FISIOTERAPIA Y REHABILITACIÓN

CENTRO TANDEM

SME company
SECTOR: Healthcare



Curelator
Take back control®

CURELATOR

SME company
SECTOR: Hospitals and healthcare



CONSULTIA

SME company
SECTOR: Travel Organization



HAPPYFORCE
SME company
SECTOR: Human resources



HOSPITAL DE ZARAGOZA
SME company
SECTOR: Healthcare



HENDRIKSON
SME company
SECTOR: Environmental services



EXIT
SME company
SECTOR: Advertising



IMPLICA
SME company
SECTOR: Investment banking



INDOLOR
SME company
SECTOR: Healthcare



KETO SWISS
SME company
SECTOR: Biotechnology



BY KEVAL +
SME company
SECTOR: Personal Image



LABERIT
SME company
SECTOR: Technology



PROMONITY MARKETING
SME company
SECTOR: Marketing services



NEPHILA
SME company
SECTOR: Consulting



SALVIA BIO ELECTRONICS
SME company
SECTOR: Medical equipment



TEAM LEWIS

TEAM LEWIS
SME company
SECTOR: Advertising



VELLEKOOP & MEESTERS
SME company
SECTOR: Consultancy



THE WESTIN
SME company
SECTOR: Hospitality



PALACIO CONGRESOS VLC
SME company
SECTOR: Event planning



**GLOBAL MIGRAINE
AND PAIN SOCIETY**
NGO
SECTOR: Human resources

Selbsthilfegruppe
„Kopfweg“

**SELBSTHILFEGRUPPE
"KOPFWEH"**
Austria



OUCH BELGIUM
NGO - Belgium



VZW HOOFD - STUK
NGO - Belgium



**BULGARIAN ASSOCIATION OF
PATIENTS WITH MIGRAINE, CLUSTER
HEADACHE AND OTHER HEADACHES**
NGO - Bulgaria



**MIGRÉNA-HELP. SPOJENÉ
HLAVY , Z.S**
NGO - Czech Republic



**MIGRÆNE & HOVEDPINE
FORENINGEN**
NGO - Denmark



TRIGEMINUS FORENINGEN
NGO - Denmark



Eesti Migreeni
ja Peavalu
Patsientide Ühing

**MTÜ EESTI MIGREENI JA PEAVALU
PATSIENTIDE ÜHING**

NGO - Estonia



**SUOMEN
MIGREENIYHDISTYS**
NGO - Finland



**ASSOCIATION FRANÇAISE CONTRE
L'ALGIE VASCULAIRE DE LA FACE**

NGO - France

@wonder.migraine.woman

WONDER MIGRAINE WOMAN

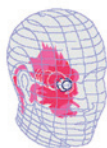
NGO - France



MIGRÄNELIGA
NGO - Germany



STIFTUNG KOPFSCHMERZ
NGO - Germany



**BUNDESVERBAND DER
CLUSTERKOPFSCHMERZ-
SELBSTHILFEGRUPPEN - CSG E.V.**
NGO - Germany



**ΣΥΛΛΟΓΟ ΑΣΘΕΝΩΝ ΜΕ ΗΜΙΚΡΑΝΙΑ
ΚΑΙ ΚΕΦΑΛΑΛΓΙΑ ΕΛΛΑΔΟΣ**
NGO - Greece



**HELLENIC HEADACHE
ALLIANCE**
NGO - Greece



LA FONDAZIONE CIRNA ONLUS
NGO - Italy



**LATVIJAS GALVASSĀPJU
PACIENTU BIEDRĪBA**
NGO - Latvia



HODEPINE NORGE
NGO - Norway



**MIGRA PORTUGAL – ASSOCIAÇÃO
PORTUGUESA DE DOENTES COM
ENXAQUECA E CEFALÉIAS**

NGO - Portugal



**ASOCIAȚIA “HEADACHE SOCIETY”
ROMÂNIA**

NGO - Romania



**АССОЦИАЦИЯ СОДЕЙСТВИЯ В
РЕАЛИЗАЦИИ ПРАВ ПАЦИЕНТОВ
С ГОЛОВНОЙ БОЛЬЮ**

NGO - Russia



MIGRENA ASOCIJACIJA SRBIJE

NGO - Serbia



**ASOCIACIÓN ESPAÑOLA DE
PACIENTES CON CEFALÉIA (AEMICE)**

NGO - Spain



HUVUDVÄRKS FÖRBUNDET

NGO - Sweden



ASSOCIAZIONE CEFALIA TICINO (ACTI)
NGO - Switzerland



**MIGRAINE ACTION
SWITZERLAND**
NGO - Switzerland



HOOFDPIJNET
NGO - The Netherlands



NATIONAL MIGRAINE CENTRE
NGO - UK



**ORGANISATION FOR THE
UNDERSTANDING OF CLUSTER
HEADACHE UK**
NGO - UK



MIGRAINE TRUST
NGO - UK



MIGRAINE CYMRU WALES
NGO - Wales



ASOCIACIÓN DE MIGRAÑAS Y CEFALÉAS DE ARGENTINA
NGO - Argentina



SOCIEDAD NEUROLÓGICA ARGENTINA
NGO - Argentina



ABRACES
NGO - Brazil



MIGRAINE QUEBEC
NGO - Canada



MIGRAINE CANADA
NGO - Canada



**ASOCIACIÓN MEXICANA
DE CEFALÉAS Y MIGRAÑA**
NGO - Mexico



MIGRAINE FOUNDATION
NGO - New Zealand

Migraine Knock
PHILIPPINES

MIGRAINE KNOCK PHILIPPINES
NGO - Philippines



**GLOBAL MIGRAINE AND PAIN
SOCIETY**
NGO - Turkey



**ASSOCIATION OF MIGRAINE
DISORDERS**
NGO - US



**NATIONAL HEADACHE
FOUNDATION**
NGO - US



CHAMP
NGO - US



MILES FOR MIGRAINE
NGO - US

Migraine Friendly Workplaces

SCIENCE SUPPORT



THANKS TO PROF. GOADSBY



THANKS TO DR. POZO-ROSICH

Migraine Friendly Workplaces

MEDIA IMPACTS

VALENCIAPLAZA.COM



ELECONOMICO.ES

La entidad comarcas ha firmado un convenio de colaboración con la European Migraine & Headache Alliance (EMHA)

ASECAM concienciará a sus asociados sobre cómo puede afectar la migraña en el trabajo

Imagen de la fuente: C. Q. | Imagen



ELPERIODIC.COM

El CECOVA firma un convenio de colaboración con la Alianza Europea de Asociaciones de Pacientes con Migraña y Cefalea

ELPERIODIC.COM - 02/02/2023



ESPACIOS AMIGABLES

Conviviendo con la migraña

La migraña afecta a más de una de cada siete personas en el mundo. **Caixa Popular** se ha sumado al proyecto de Espacios de trabajo amigables con la enfermedad, dentro de su política de responsabilidad en temas de salud con todo el equipo de trabajo.

Eduard Ureña
Valencia | 04.04.2023 18:08



VALENCIAPLAZA.COM

Empresarios y expertos se unen para visibilizar la incidencia de la migraña en el entorno laboral

Valencia Plaza

SALUD



3. Policy Affairs

3.1 MEP Migraine Alliance

3.2 Policy Affairs at the European Parliament

- VICTORIA. Healthy workspaces
- ONE TO ONE Meetings
- Positioning achievements

3.3 Legislative challenges

3.1

MEP Migraine Alliance

In 2023 the MEP Alliance has increased in five new members:

MEP Pablo Arias, MEP Francisco Millán, MEP Susana Solís, MEP Rosa Estarás and MEP Alex Agius Saliba, being now **13 MEPs** supporting migraine.

The EMHA keeps continuous contact with the Alliance members for scheduling meetings, being updated on key EU files, sending ammendments and organising and participating in events.

And is also having conversations with the spanish PPE delegation for the organising of a luceon-debate on migraine and its impact on european citizens daily lifes.





3.2

Policy Affairs at the EU Parliament

3.2 VICTORIA. HEALTHY WORKSPACES

On April 12th, the EMHA presented VICTORIA at the European Parliament hosted by MEP Pablo Arias.

The event brought the first hologram with migraine to raise awareness on this debilitating condition that affects more than 45 millions of people across Europe to the EP and gathered many key stakeholders such as EBC, EFNA, EPF, EFIC and active MEPs: Isabel Benjumea, Juan Ignacio Zoido, Rosa Estaràs, among others.





3.2 ONE TO ONE MEETINGS

Besides the presentation of Victoria in the European Parliament, the EMHA organized face-to-face meetings with its members and their local corresponding MEP in order to achieve an European approach to improve the lives of all those who suffer from migraine across Europe and at national level.



MEP PABLO ARIAS (SPAIN)



MEP NATHALIE COLIN - OESTERLÉ (FRANCE)



MEP SARA CERDAS (PORTUGAL)



3.2 POSITIONING ACHIEVEMENTS

During this year **the EMHA has had one-to-one meetings with MEPs in the health sector such as Susana Solís, Rosa Estaràs and Sirpa Pietkainen.**

On top of these meetings EMHA has been in close contact and collaboration with the MEPs and committees in charge of the key legislative files: Pharmaceutical Strategy and European Health Data Space. Conversations are still ongoing with MEPs such as Tomislav Sokol, Alex Agius and Sara Cerdas.

MEP. SIRPA PIETIKÄINEN



MEP. SUSANA SOLÍS



MEP. ROSA ESTARÀS



3.3

Legislative challenges

ACHIEVEMENTS

The EMHA is on ongoing conversations with institutional stakeholders for the two current ongoing legislative processes:

And is also working closely with **non-institutional stakeholders** (EFNA, EBC, EPF, ...) for the presentation of common position papers, inputs and proposals about the legislative files and is also involved in amendments for the legislative file "**European Disability Card**" that aim to include migraine and other neurological diseases, so they are also considered in this regard.



**Pharmaceutical
Strategy
regulation**



**PHARMACEUTICAL
STRATEGY FOR THE EU**



**Pharma Strategy,
Medicinal Products
for Human Use Directive**



**EUROPEAN HEALTH
DATA SPACE**



**European Health
Data Space**

EU Funds

The EMHA applied for a grant of EU4Health European Funding for specific 2023 activities and projects and the EMHA is now positioned as a key stakeholder in the mental health and neurology sector.



EU4health

OTHER MEETINGS ATTENDED BY THE EMHA

The EMHA has not only attended many conferences and events during the past year, namely: **Patients Think Tank (EFPIA), EPF General Assembly and 20 years anniversary, Brain, mind & Pain interest group meetings in the European Parliament.** And also jointly wrote with AbbVie an article in "The Parliament Magazine" on the topic of migraine and unmet medical needs.

SPANISH PRESIDENCY: HEALTH COUNSELOR



EUROPEAN HEALTH SUMMIT



EPF 20 ANNIVERSARY & GENERAL ASSEMBLY



"THE PARLIAMENT MAGAZINE" ARTICLE



**POLITICO HEALTHCARE
SUMMIT**



**THE PARLIAMENT MAGAZINE
EUROPEAN MEETING**



**‘REDUCING THE ECONOMIC
IMPACT OF MIGRAINE IN THE
EUROPEAN UNION’
WORKSHOP TO CO-CREATE
A EUROPEAN MIGRAINE
ACTION PLAN**



4. Special Days

4.1 Women's Day

4.2 Brain Awareness Week

4.3 Cluster Headache Awareness Day

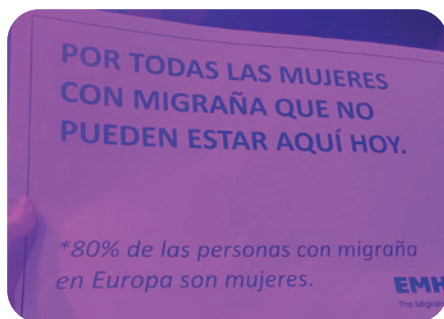
4.4 Worker's Day

4.5 Migraine Day of Action

4.1

Women's Day

On the 8th of March the EMHA and its members participated in local demonstrations, representing those who could not attend because of migraines with banners in solidarity with migraine sufferers. This action received sparked conversations with migraine sufferers who until then had remained silent.



With the support of organizations such as AEMICE, Migra Portugal, MigräneLiga and Wonder Migraine Women, **we raised awareness on social media, giving a voice to all women with migraine.**

MEHR ALS EINEN TAG
EINMAL IM JAHR - WAS
ICH BRAUCHE, IST EINE
MIGRÄNEBEHANDLUNG*.

*80% der Migränepatienten
in Europa sind Frauen.

WIR KÖNNEN NICHT
FÜR DIE FREIHEIT
KÄMPFEN, WENN DIE
MIGRÄNE UNS ZU
HAUSE HÄLT*.

*80% der Migränepatienten
in Europa sind Frauen.

NICHT ALLE FRAUEN
KÖNNEN HEUTE DIE
WELT AUFHALTEN,
DENN DIE MIGRÄNE
HAT SIE BEREITS
AUFGEHALTEN*.

*80% der Migränepatienten
in Europa sind Frauen.

HOJE NEM TODAS AS MULHERES
PODEM FAZER-SE OUVIR,
PORQUE DEVIDO À ENXAQUECA
NÃO CONSEGUEM FALAR.

*80% das pessoas que sofrem de enxaqueca
na Europa são mulheres.

MIGRA
EMHA
The Migraine Movement

MAIS DO QUE UM DIA TODOS
OS ANOS, O QUE EU PRECISO É
DE TRATAMENTO ADEQUADO
PARA A ENXAQUECA.

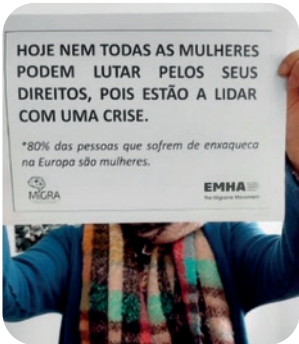
*80% das pessoas que sofrem de enxaqueca
na Europa são mulheres.

MIGRA
EMHA
The Migraine Movement

NÃO PODEMOS LUTAR PELA
NOSSA LIBERDADE SE A
ENXAQUECA NOS PRENDE EM
CASA.

*80% das pessoas que sofrem de enxaqueca
na Europa são mulheres.

MIGRA
EMHA
The Migraine Movement



4.2

Brain Awareness Week

From the 13th to 17th of March, EMHA created *Illustrating Migraine*.

The campaign consisted in 4 illustrations of healthy brains using the definitions of a healthy brain from the specialists Dr. Arao Oliveira, Prof. Peter Goadsby, Prof. Cristina Tassorelli or Ms.Linn Amanda Holmen. Things such as exercise, sleeping well or keeping a healthy diet are crucial.



ILLUSTRATIONS CREATED WITH AI

PhD. Arao B. Oliveira



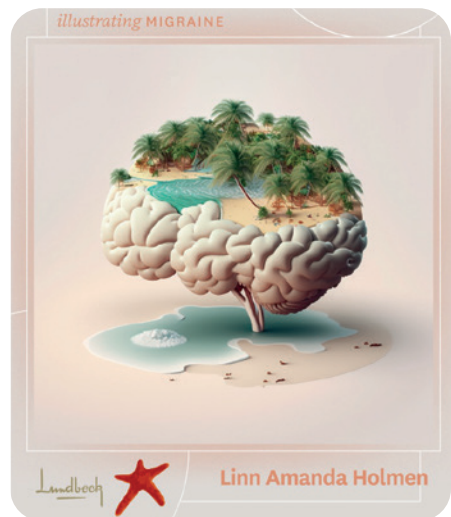
Prof. Peter Goadsby



Prof. Cristina Tassorelli



Linn Amanda Holmen



4.3

Cluster Headache Awareness Day

For March 21st, the EMHA decided to create one post to raise awareness on this serious condition addressing the idea that living with cluster headache is not living.

Also reported the fact that little research is been done to find the causes and a cure to this disease.

This campaign was spread by EMHA members in its countries and in their own languages

Let's **stop** Cluster Headache.

DID YOU KNOW THAT CLUSTER HEADACHE IS
ALSO KNOWN AS “THE SUICIDE HEADACHE”?



4.4

Worker's Day

On May 1st the EMHA launched a campaign focused on the the unpredictable nature of migraine.

Ms. Elena Ruiz de la Torre shared her personal experience of perseverance when facing a migraine attack while giving a speech at the European Parliament, sharing it also on her LinkedIn. **This initiative aimed to shed light on the stigma surrounding migraine by encouraging users to share their stories and participate in the Stigma Survey.** By presenting a personal perspective on the work-related challenges posed by migraines, the campaign aimed to raise awareness and understanding.



Elena Ruiz de la Torre GdB · 1er

Executive Director at EHA European Migraine and Headache Alliance EHA

1 semana · 🌐

I should not be working today, but I am working for the more than 40 million Migraine sufferers across Europe, a disease that does not rest, nor does its social and occupational stigma.

So today, I would like to tell you about a personal experience that happened to me very recently.

The one you see in the picture is me giving a speech at the European Parliament. I spent months preparing for that moment, contacting MEPs, associations, patients, pharmaceutical companies... and in spite of everything, the migraine that I have suffered since I was 12 years old, suddenly struck and completely stopped me just a few hours before this big moment.

I could have gone home, I could have handed it over to someone else... but the stigma surrounding this disease forced me to overcome it in a few minutes and to carry on in silence, as millions of migraine sufferers do every day. I tell you, it has never been easy.



LinkedIn

Having to feel discriminated against every time you suffer from migraine, not finding a supportive work environment or an environment adapted to your needs is difficult, but not impossible. And we are getting there with the help of many companies.

That's why today, I'm asking for 1 minute of your time to help all these people achieve a better life:

- >Sharing your story to inspire other patients.
- >Answering this survey about stigma ([link](#)).
- >Contacting Migraine Friendly Workplace through your HR team.

Let's keep working for stigma-free workplaces

Please help us by completing this survey:
<https://lnkd.in/dasmBKUw>

4.5

Migraine Day of Action

On September 12th, the EMHA hosted an event for all Migraine Friendly Workplace members and interested people . The event aimed to address migraine stigma in workplaces and highlight its benefits for companies aligned with ESG (Enviromental, Social and Governmental) principles.

This initiative responds to the European sustainability movement, leveraging regulations to drive various approved initiatives, strategies, and guidelines.

Access to information about such solutions becomes vital for companies striving to thrive in a dynamic competitive market.





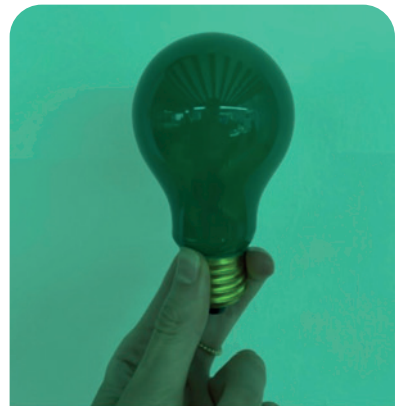
You can check some media impacts of the day here

4.5

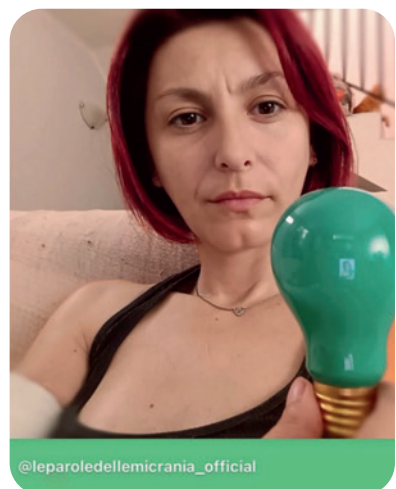
Migraine Day of Action

The EMHA initiated the social media campaign #GreenLightForMigraine to inspire our members to raise awareness about the stigma associated with migraines.

They were prompted to post an image on their social media accounts featuring the EMHA-provided lightbulb, symbolizing their support in fighting migraine stigma.



Mark your calendars,
Tomorrow is Migraine Day of Action



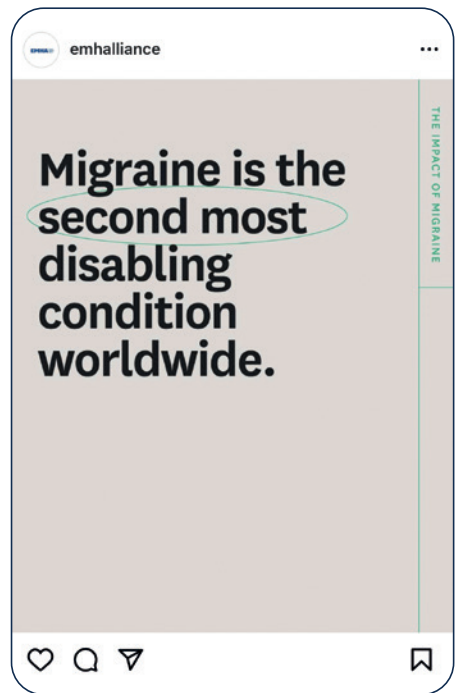
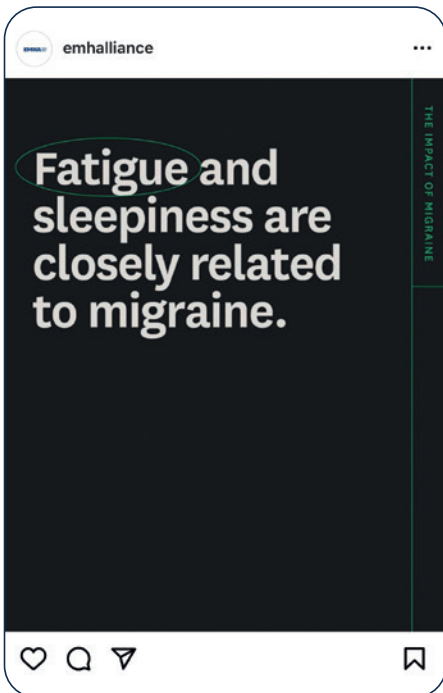
@leparoledellemicrania_official

5. Social Media Plan

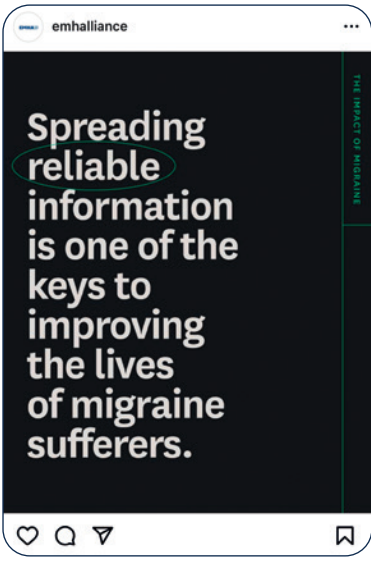
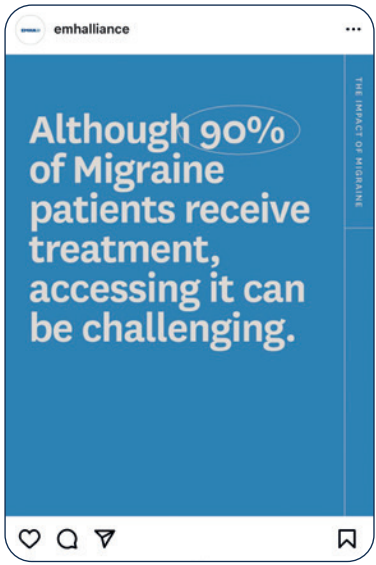
Strategy

This year's strategy has been to reach out to a wider community and build stronger links with the EMHA's existing community.

The EMHA developed continuous content around our experience as migraine patients, as well as insights from our community.



Our goal remains the same as in previous years: to spread reliable information about migraine and educate our followers on this serious neurological disease.



The EMHA's community gains strength



People reach on our social media channels thanks to the sum of the activities by the EMHA during 2023



Increase in the number of followers of our social networks (7590)



Engagement rate with our social media content in 2023



Increase in users at the EMHA's website

***RESULTS FROM JANUARY TO OCTOBER 2023
COMPARED TO SAME PERIOD 2022**

329.467

+46.61%

343.19%

+43.05%

Newsletters

Since 2022, the EMHA has been focused on creating a **regular e-mail communications to the subscribers, mainly sharing EMHA's special activities, events and achievements.**

But also interesting and useful information about migraine.



Migraine Day of action 12th September

On 2023, EMHA developed several activities to raise awareness for Migraine in different areas.

1. Migraine Friendly Workplace

The CEV Valencia (Enterprises Confederation Association) hosted the EMHA to present the Migraine Friendly Workplace. The main objective was to shed light on the stigma surrounding migraine at work and to highlight the benefits of the project for companies within the ESG (Environmental, Social, and Governance). This initiative focuses on creating supportive environments for employees suffering from migraine, as well as building more comprehensive companies, with the ability to adapt to a competitive and changing business landscape.



2. EMHA members activities

Finland

migreeni.org

"Finland's Migraine Week" from September 11th to 17th featured a significant lecture on migraine as its highlight event on September 12th. The week also included various programs organized by volunteers, a migraine-themed chat, and a pop-up group for people to discuss migraine. The focus was on raising awareness and understanding of migraine.



migraine
friendly
workplace

EMHA

Migraine Day of Action.

For this year's **Migraine Day of Action**, the EMHA will launch an online campaign to create awareness on the stigma surrounding migraine.

We encourage all our members to shed some light on this disease, that affects 41 million Europeans.

You can be part of the campaign by **sharing an image on social media with a green light or the EMHA- Green light filter** (available on Instagram) with the hashtag **#GreenLightForMigraine**.



Moreover, on **September 12th** we will host an event for all Migraine Friendly Workplace members. The event aims to address migraine stigma in workplaces and highlight its benefits for companies aligned with ESG principles.

This initiative responds to the **European sustainability movement**, leveraging regulations to drive various approved initiatives, strategies, and guidelines.

Access to information about such solutions becomes vital for companies striving to thrive in a dynamic competitive market.

September 12th conference 9.30h

Migraine Friendly Workplace. Employee care within the ESG guidelines.

On September 12th, EMHA will present its Migraine Friendly Workplace project, with the aim to give visibility to the stigma around migraine within the workplace, as well as to showcase the benefits the project brings to those companies inside the ESG (Environmental, Social and Governance) on building favourable environments to those employees who suffer from this illness.



6.Unity is strength

6.1 Annual Member's Meeting

6.2 MHIPAS III

6.1

Annual member's meeting

2023 | Madrid

As every year, EMHA brings its members together to discuss past projects and set the next steps to achieve future goals.



6.2

MHIPAS III

MIGRAINE HEADACHE INTERNATIONAL PATIENT ASSOCIATIONS SUMMIT

December 2023 | Barcelona

The MHIPAS is a Summit created by the EMHA in 2018 with the aim to strengthen the migraine and other headaches advocacy work and to encourage the collaboration among it's members (patient Organizations), Scientific Community and Industry.

The Summit also provides educational lectures on new scientific researches, patient organizations' best practices exchange and roundtable discussions that help to build a world-migraine strategic plan and strong and unified messages worldwide.



+25 countries worldwide



+30 patient organizations



+100 Attendees

MHIPAS III 2023 BARCELONA

















7. EMHA & other stakeholders

7.1 Scientific Collaborations

7.2 Collaborations with other organizations

7.3 EMHA Partners & Associates

7.4 Collaborations with Industry

7.1

Scientific Collaborations

**SCIENTIFIC GROUPS WITH WHOM
EMHA IS COLLABORATING.**

AMADEUS Project - The Danish Headache Centre

EAN guideline on “Pharmacological and interventional treatment of migraine”

EAN/EHF Guidelines on Spontaneous Intracranial Hypotension and Orthostatic Headache

EAN Scientific Panel on Headache.

IHS Documentary about Migraine

EHF SAS

EBC - LSE Migraine Cost

EFPIA Patient Think Tank

Horizon 2024: "Better integration and use of health-related real- world and research data, including genomics, for improved clinical outcomes with NorHEAD"

Horizon 2024: "MIGRATION: Validation of salivary and serum biomarkers for the prediction and prevention of migraine and its associated mental health comorbidities" with VHIR

Horizon 2024: "Tackling high-burden for patients. Under-researched medical conditions" with Leiden team

Social Media Listening and Digital Profiling Study of People with Headache and Migraine: A Retrospective Infodemiology Study

Migraine prevention in the real world: Exploring the role of anti-CGRP antibodies- touchIME

European Brain Council- Rethinking Migraine

TouchNeurology - touchCLINICAL Perspectives

Association of Migraine Disorders (AMD)

Advisory Board Member

7.1

Scientific Collaborations

EUROPEAN ACADEMY OF NEUROLOGY
SCIENTIFIC PANEL ON HEADACHE.

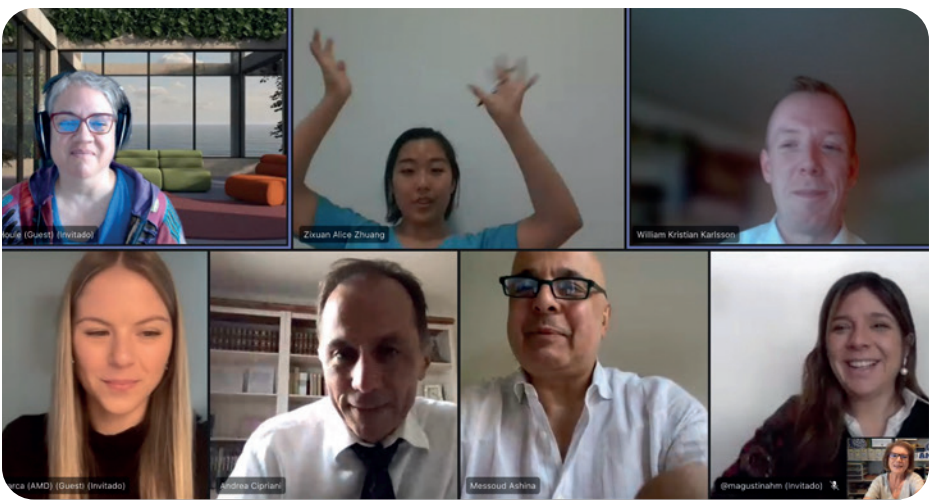


MASTER OF HEADACHE DISORDERS

Elena Ruiz de la Torre delivered a lecture at The Danish Headache Center presented as part of the lecture on "The Importance of a Patient Voice in Research and Healthcare Politics" on the Master of Headache Disorders program led by Prof. Jensen.



AMADEUS PROJECT



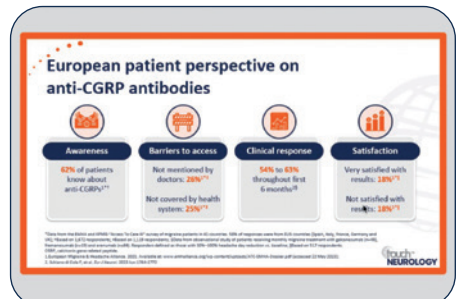
IHS [INTERNATIONAL HEADACHE SOCIETY] CORPORATE ROUNDTABLE IN BUDAPEST.

Science-Industry-Patients working together
to drive a better future for new generations.



TOUCHNEUROLOGY

TOUCHCLINICAL PERSPECTIVES



COLLABORATION WITH PATIENTS AND HEALTHCARE SPECIALISTS.

On June 2nd, Ms. Elena Ruiz de la Torre gave a presentation at the Hospital General de València, discussing the quality of healthcare access for migraine patients.



CONSORCIO HOSPITAL GENERAL VALENCIA
SERVICIO DE NEUROLOGIA

2 de junio
Salón de Actos
Hospital General Valencia



Primeras jornadas abiertas sobre migraña
Departamento Valencia-Hospital General

09:00-09:10 Introducción
Dr. Joaquín Escudero, jefe del Servicio de Neurología.
Dr. Julio Parra, neurólogo.

09:10-09:50 ¿Qué es la migraña? Diagnóstico y tratamiento no farmacológico
Dr. Julio Parra, neurólogo.

09:50-10:30 Tratamiento sintomático y preventivo de la migraña
Dr. Eduardo Bernaldo, neurólogo.

10:30-11:00 Importancia en detectar factores desencadenantes y agravantes. Diario cefalea y escala discapacidad. Forma de aplicación de tratamientos intranasales y subcutáneos
Dña. Marisa Jiménez, supervisora del Servicio de Neurología.

11:00-11:25 Calidad asistencial en el paciente con migraña
Dr. Joaquín Escudero, jefe del Servicio de Neurología.
Dña. Elena Ruiz, presidenta de la Alianza Europea de la Migraña y las Cefaleas.

11:25-11:45 Descanso

11:45-12:15 Casos prácticos

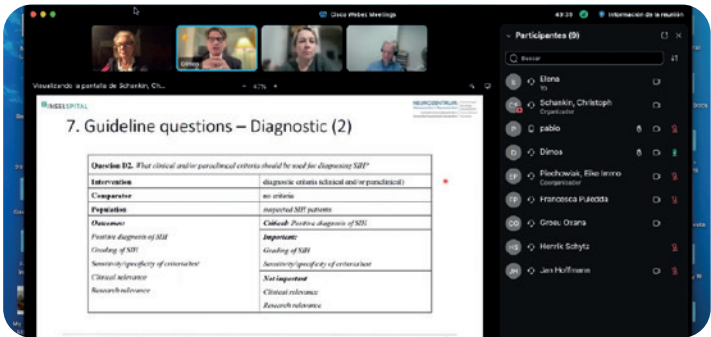
12:15-13:30 Mesa redonda y preguntas de los asistentes

Colabora:
 **NOVARTIS**



EAN/EHF [EUROPEAN ACADEMY OF NEUROLOGY / EUROPEAN HEADACHE FEDERATION]

Guidelines on Spontaneous Intracranial Hypotension and Orthostatic Headache.



HORIZON 2024:

“MIGRATION: Validation of salivary and serum biomarkers for the prediction and prevention of migraine and its associated mental health comorbidities”



7.2

Collaborations with other organisations

EUROPEAN BRAIN COUNCIL

Rethinking Migraine.



EUROPEAN BRAIN COUNCIL

Brain Innovation Days

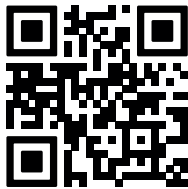
POLICY ROUNDTABLE



WORKPLACE ROUNDTABLE



MIGRAINE AND MENTAL HEALTH IN WOMEN:
Adressing the Challenge - Webinar in collaboration
with GAMIAN.



Read the
whole project

SAVE THE
DATE

21st September, 2023 | 11:00 CET
WEBINAR: Migraine and Mental Health:
Addressing the Challenge













EMHA AT PRIME TIME – NATIONAL TELEVISION
"MAÑANEROS"



Watch the
interview here



7.3

EMHA Partners & Associates

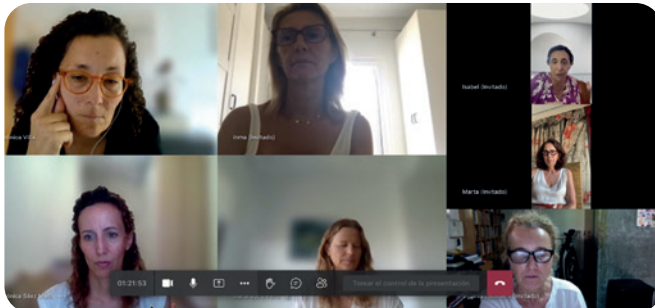
MEETINGS WITH MIGRAINE QUEBEC

Canadian Patient Association



MEETING WITH AEMICE

Spanish Patient Association

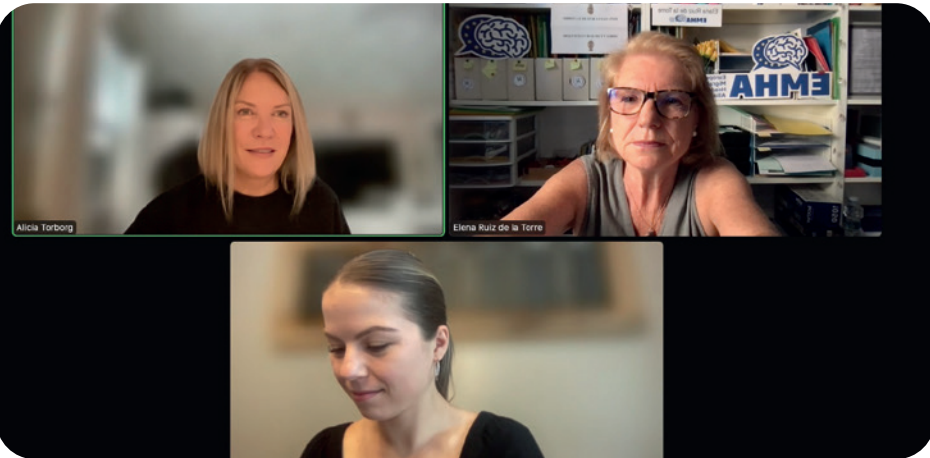


MEETING WITH HOOFDPIJNNET

The Netherlands Patient Association



MEETING WITH THE ASSOCIATION OF MIGRAINE DISORDERS - US Patient Association



WEBINAR FOR WOMEN'S DAY

A webinar for Women's Day was organized by the Global Migraine and Pain Society (Turkey) and supported by NOROM Official, IHS Official and EMHA, featured esteemed speakers as Prof. Gisela Terwindt and Elena Ruiz de la Torre, along with the participation of Betul Baykan and Hayrunnisabolay.



The poster is for a 'WEBINAR FOR WOMEN'S DAY' held on 8 March 2023 at 8 PM (Istanbul time). It features logos for the Global Migraine and Pain Society, NOROM, and EMHA. The event is moderated by Betul Baykan and Hayrunnisa Bolay, and features speakers Gisela M. Terwindt and Elena Ruiz de la Torre. The poster is decorated with blue and purple abstract shapes.

**WEBINAR FOR
WOMEN'S DAY**

8 March 2023
(8 PM with Istanbul time)

MODERATORS

 <p>BETUL BAYKAN Women's Leadership Forum of the International Headache Society, Istanbul University, Faculty of Medicine Department of Neurology</p>	 <p>HAYRUNNİSA BOLAY Gazi University Faculty of Medicine Department of Neurology & Allogogy, Neuroscience & Neurotechnology Center (NÖROM)</p>
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SPEAKERS

 <p><i>"Improving the careers of women in the headache field"</i> GISELA M. TERWINDT Chair of the Women's Leadership Forum of the International Headache Society, Department of Neurology, Leiden University Medical Center, Leiden, The Netherlands</p>	 <p><i>"Organization of a migraine- friendly workplace."</i> ELENA RUIZ DE LA TORRE Executive Director of the European Migraine and Headache Alliance</p>
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To participate in the meeting, you need to register from the link below and set a username and password. On the day of the broadcast, you can login with the username and password you have determined from the link below.

12TH ESTONIAN HEADACHE DAY WEBINAR

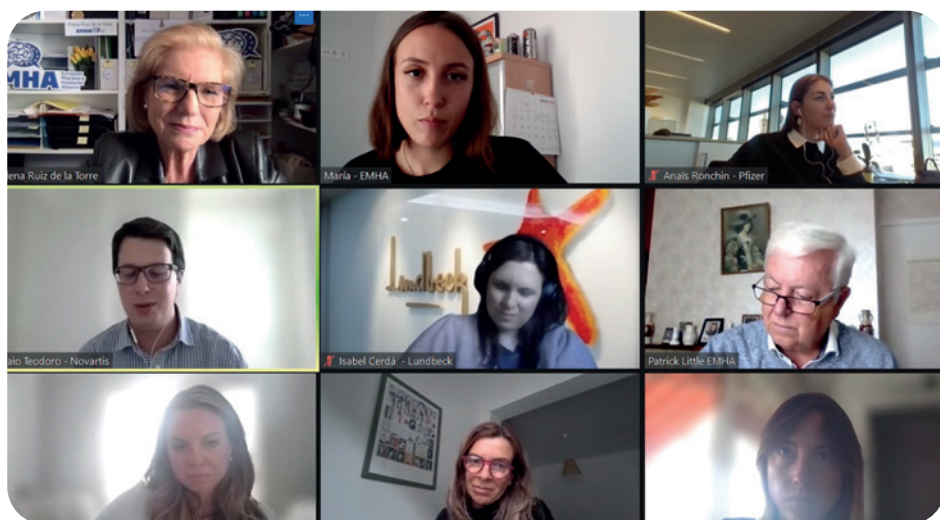
With Ms. Elena Ruiz de la Torre participation, the webinar focused on important topics such as Access To Care & Workplace.



7.4

Collaborations with industry

CORPORATE UPDATES MEETINGS








For downloadable slide deck only

Recognizing the burden of migraine in daily life

Ms Elena Ruiz de la Torre
Patient Advocate and Executive Director
European Migraine & Headache Alliance
Valencia, Spain







GUEST SPEAKER

Apagar la cámara



Elena Ruiz de la Torre
Executive Director, Company Secretary
and Immediate Past President

EMHA European Migraine & Headache Alliance

Tomar el control de la presentación



E-POSTER PRESENTATION
AT THE EUROPEAN HEADACHE CONGRESS

Impact and burden of migraine and medication-overuse headache from the perspective of people with migraine: Insights from the mixed-method Migraine Community Survey

Elena Ruiz de la Torre,¹ Alexander Pavlovskov,² Mario Fernando Prieto Perez,³ Wendy Gerhart,⁴ Isabel Cardá Marcos,⁴ Line Pickering Rosemary,⁴ Camilla Lamb,⁵ Dawn C. Buse⁶

¹European Migraine & Headache Alliance (EMHA), Europe; ²Stavros Niarchos Foundation Center, Athens, Greece; ³Univ. de la Sorbonne, Paris, France; ⁴University of Toronto, Toronto, Canada; ⁵University of Southampton, Southampton, UK; ⁶University of Pennsylvania, Philadelphia, PA, USA

Introduction

Migraine is a leading cause of disability worldwide, affecting approximately 1 billion people globally. The impact of migraine extends beyond the physical symptoms, significantly affecting quality of life, productivity, and social interactions. Medication-overuse headache (MOH) is a common complication of migraine, further exacerbating the burden of the condition. This study aims to explore the lived experiences of people with migraine and MOH, focusing on the impact of the condition and the effectiveness of various treatments.

Objectives

The primary objective of this study was to understand the impact of migraine on the daily lives of participants. Secondary objectives included exploring the effectiveness of different treatments, the prevalence of MOH, and the impact of MOH on the lives of participants.

Methods

This mixed-method study combined quantitative and qualitative data. The quantitative part involved a survey of 1,138 participants, while the qualitative part involved interviews with 15 participants. The survey collected data on demographic information, migraine characteristics, treatment effectiveness, and the impact of migraine on daily life. The interviews provided in-depth insights into the experiences of participants with MOH.

Results

The survey results showed that migraine significantly impacts daily life, with participants reporting higher levels of disability and lower productivity compared to the general population. MOH was prevalent among participants, with a higher frequency of attacks and greater impact on daily life compared to those without MOH. The qualitative data revealed that participants with MOH often felt misunderstood and struggled to find effective treatments.

Limitations

The study has several limitations, including a self-reported design, which may introduce bias. Additionally, the sample was primarily from Europe and North America, which may limit the generalizability of the findings to other populations.

KEY MESSAGES

- In this sample of participants with migraine, higher levels of disability were associated with higher frequency of attacks and higher frequency of medication overuse.
- Considering the self-reported frequency of acute treatment use, our findings suggest that MOH may be underestimated in those with migraine.

CONCLUSIONS

By demonstrating how greater headache pain severity relates to greater migraine impact, findings from this survey further support the relevance of addressing both headache severity and headache frequency for reducing burden of disease.

Differing perceptions of MOH may indicate important communication needs, with potential consequences for early identification and intervention of migraine progression.

Impact and burden of migraine and medication-overuse headache from the perspective of people with migraine: Insights from the mixed-method Migraine Community Survey

Elena Ruiz de la Torre,¹ Alexander Pavlovskov,² Mario Fernando Prieto Perez,³ Wendy Gerhart,⁴ Isabel Cardá Marcos,⁴ Line Pickering Rosemary,⁴ Camilla Lamb,⁵ Dawn C. Buse⁶

¹European Migraine & Headache Alliance (EMHA), Europe; ²Stavros Niarchos Foundation Center, Athens, Greece; ³Univ. de la Sorbonne, Paris, France; ⁴University of Toronto, Toronto, Canada; ⁵University of Southampton, Southampton, UK; ⁶University of Pennsylvania, Philadelphia, PA, USA

Figure 1: Accrual of responses to the Migraine Community Survey

Flowchart illustrating the process of survey participation and response rates.

Figure 2: (a) Mean impact of migraine on aspects of daily life in the total population and (b) increases in mean impact according to headache frequency (214 vs 215 MHDs) and headache pain severity (26-10 vs 27-10)

Two bar charts showing the mean impact of migraine on various aspects of daily life, comparing different headache frequency and pain severity groups.

Figure 3: (a) Monthly headache (N=1138) and (b) migraine frequency (N=1138)

Two pie charts showing the distribution of monthly headache frequency and migraine frequency among participants.

Figure 4: Rates of AMO by acute medication class according to the ICHD-3 criteria in the total population and populations stratified by headache frequency (214 vs 215 MHDs) and headache pain severity (26-10 vs 27-10)

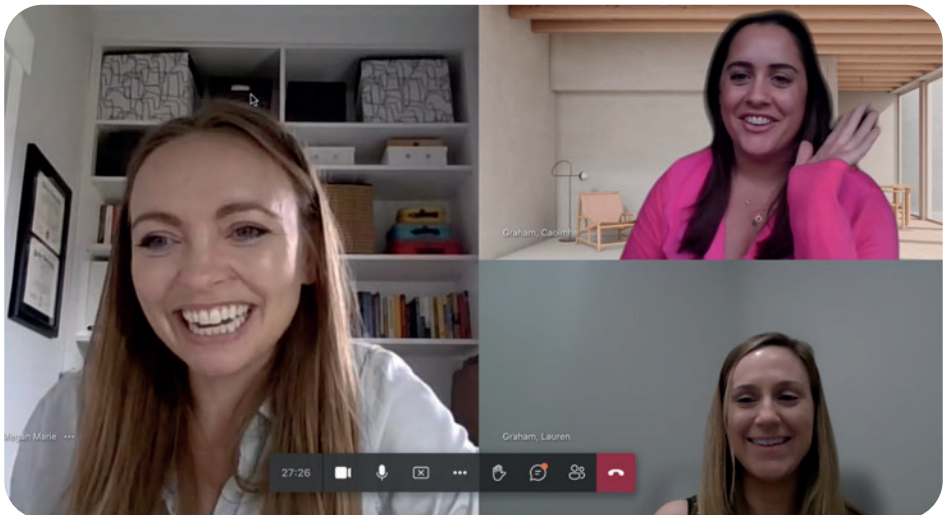
Bar chart showing the rates of acute medication overuse (AMO) by acute medication class, stratified by headache frequency and pain severity.

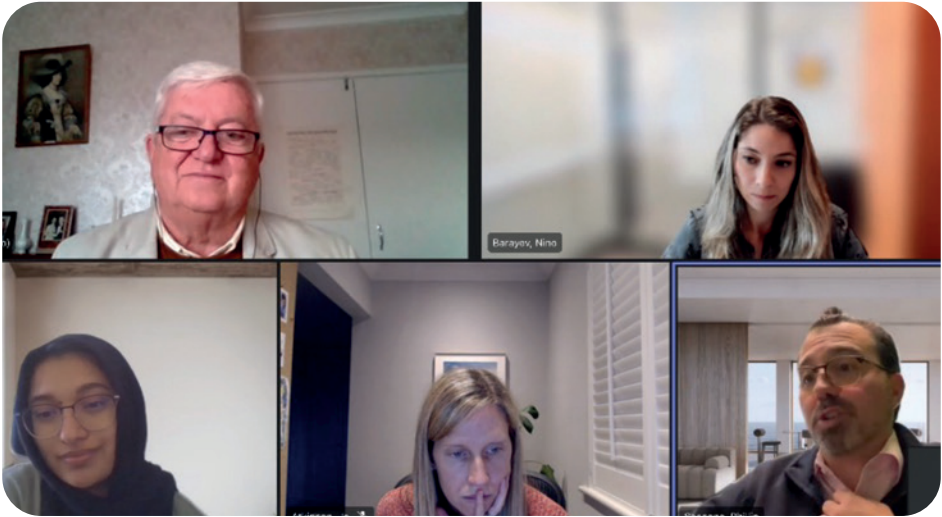
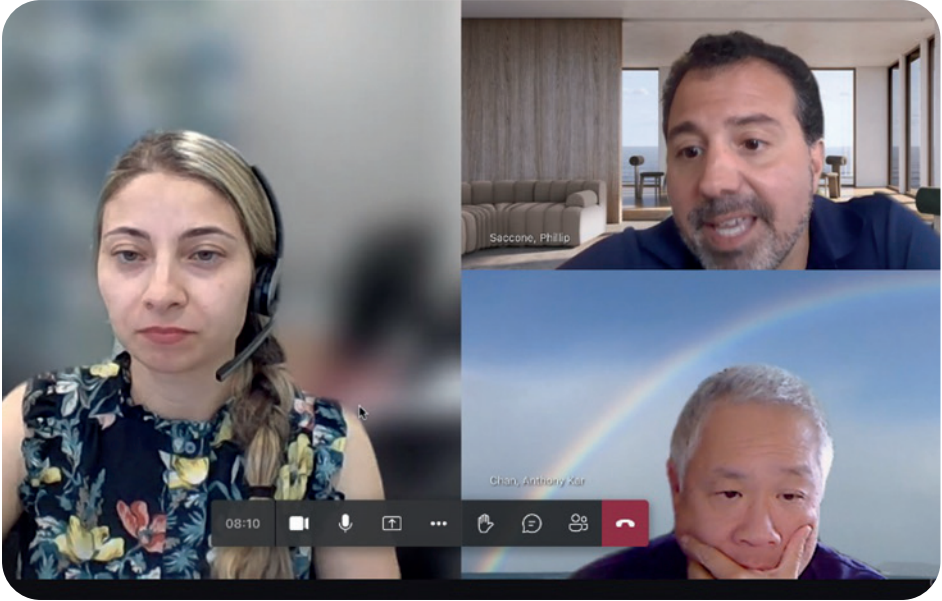
Table 1: Time from migraine diagnosis to MOH diagnosis among participants with ≥15 MHDs* (N=143)

Participants, %	0-10 years	1-10 years	11-15 years	16-20 years	21-25 years	26-30 years
Participants, %	10.3	6.2	10.3	10.2	9.8	9.1

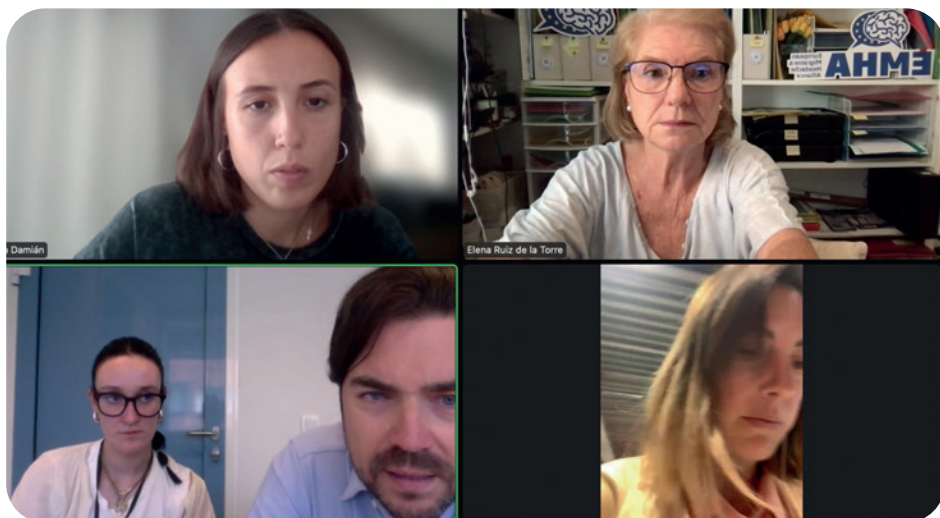
Figure 5: Knowledge and beliefs around MOH: Framework analysis of qualitative data (N=817)*

Horizontal bar chart showing the frequency of various knowledge and beliefs around medication overuse headache (MOH) among participants.





abbvie



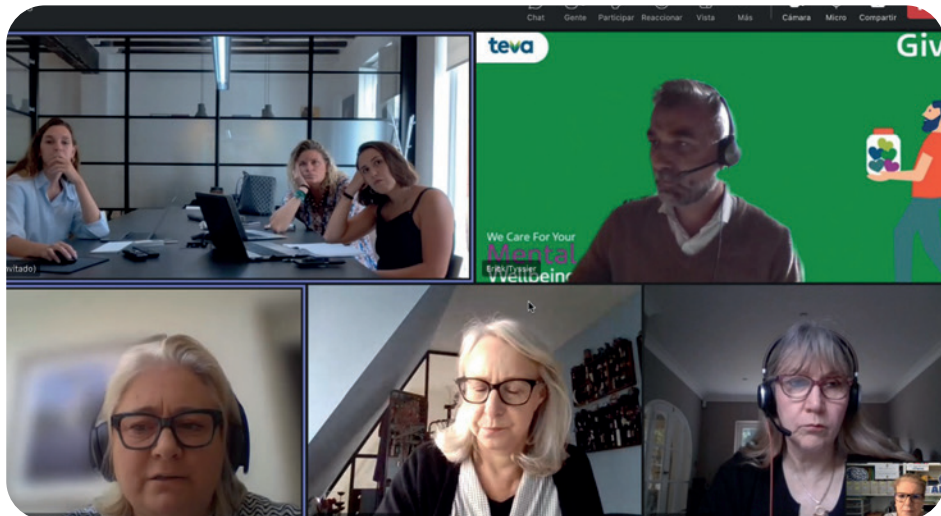


IESE TALENT FORUM ABBVIE

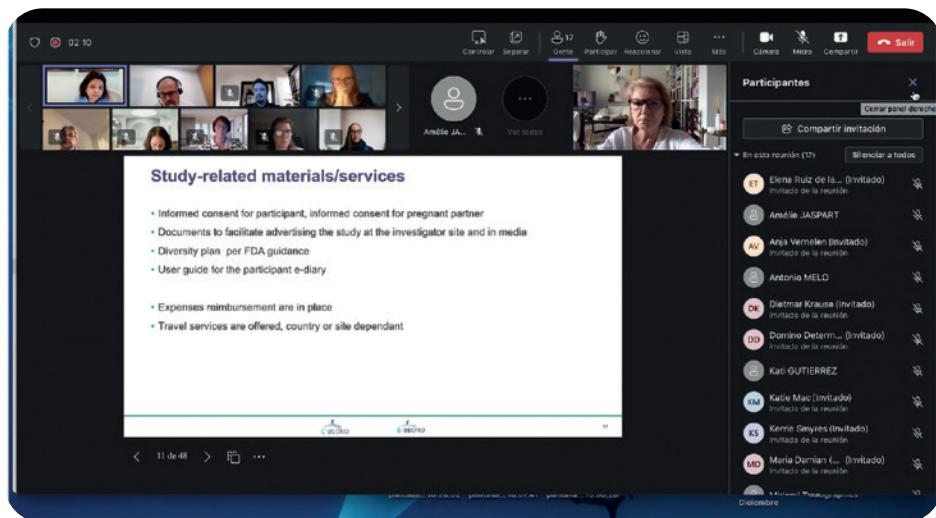




REACHING NEW HORIZONS FOR THE MIGRAINE COMMUNITY







02:10

Continuar Separar Unirse Participar Reunirse Votar Más

Cámara Micrófono Compartir Salir

Participantes

Compartir invitación

En esta reunión (17)

Si silenciar a todos

- Elena Ruiz de la... (Invitado) Invitado de la reunión
- Amelie JASPART
- Anja Venners (Invitado) Invitado de la reunión
- Antonia MELO
- Dietmar Krause (Invitado) Invitado de la reunión
- Dominik Detemmer (Invitado) Invitado de la reunión
- Kati GUTIERREZ
- Katie Mac (Invitado) Invitado de la reunión
- Kerrie Smyers (Invitado) Invitado de la reunión
- Maria Domian L... (Invitado) Invitado de la reunión

11 de 48

Study-related materials/services

- Informed consent for participant, informed consent for pregnant partner
- Documents to facilitate advertising the study at the investigator site and in media
- Diversity plan per FDA guidance
- User guide for the participant e-diary
- Expenses reimbursement are in place
- Travel services are offered, country or site dependant

8. EMHA Access to Care scientific publication

Since the launch of the results of the Access to Care Survey in 2021 and the following events organized in 2022 in some of the countries that participated in it, EMHA coordinated during 2023 a wider and more useful dissemination of the results through a scientific publication written by :

Dr. Gloria Vaghi

Prof. Peter J. Goadsby

Dr. Roberto De Icco

Dr. Teófila Vicente-Herrero

Prof. Cristina Tassorelli

Ms. Elena Ruiz de la Torre

You can read it at:



This work has been possible to our supporters:

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Co-funded by
the European Union

Funded by the European Union. Views and opinions expressed are however those of the authors only and do not necessarily reflect those of the European Union or HADEA. Neither the European Union nor the granting authority can be held responsible for them.

Thank you all for one more year of your ongoing support and helping us to fight towards a better future of the upcoming generations of migraine sufferers around the world.

All these projects would not have been possible without the invaluable work of all our members in Europe and International Associates.

MORE TO COME IN 2024

