

EMHA Activities Report 2020

EMHA
European
Migraine &
Headache
Alliance



1. The Migraine Movement

Visual summary of main actions

Society and patients



Manifesto

People reached: 738.473
Interactions: 48.310
Manifesto views: 7.289
Visits to the landing page: 2.217
Subscribers to the news: 492
(5 months)

Patients



People reached: 58.067
Tweets: 1.484
Interactions: 1.180
(5 days)

Associations and patients



People reached: 94.529
Impressions: 2.001.656
Webinar subscribers: 501
(2 months, 7 webinars)

Medical Community and patients



People reached: 33.560
Impressions: 8.743
Video views: 8.356
Media clipping: 45
(2 weeks)

- The Migraine Movement - (Manifesto)

In May 2020, we launched the Movement through a video Manifesto that explained the Movement in less than 1 minute with the aim of publicizing the initiative, encouraging users to join and involving EMHA's members.

Throughout the year, we have given visibility to the Movement through a specific plan of publications on social networks, we activated a special section on EMHA's website and opened a database to target promotion and critical mass within the different audiences.

The promotion has been carried out mainly organically through Facebook, Instagram and Twitter. For more information, you can visit its landing page: www.themigrainemovement.com

Data (5 months)

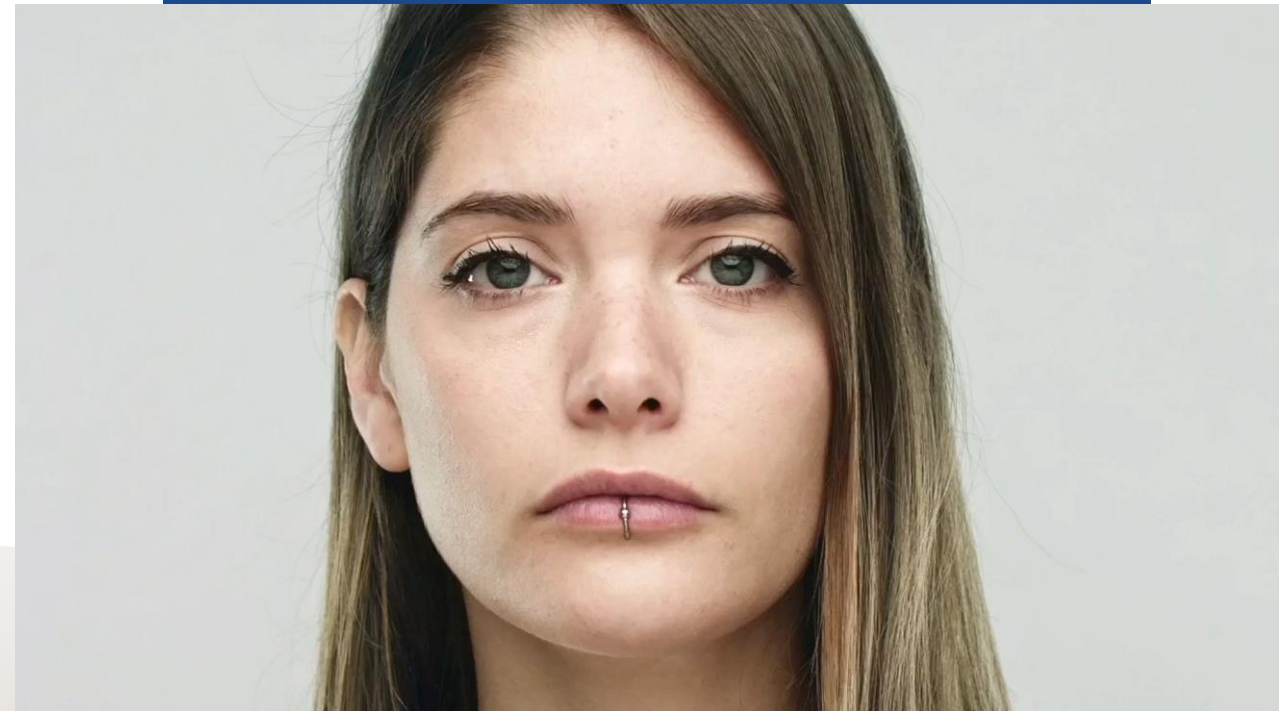
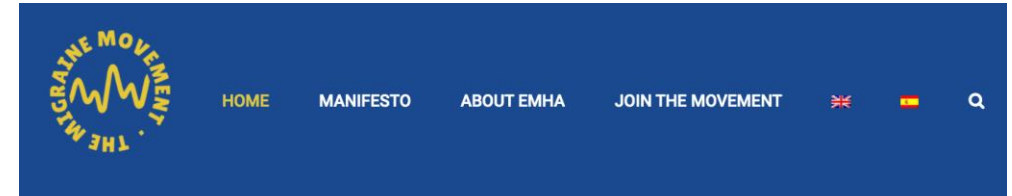
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Watch the Manifesto

1. The Migraine Movement

The EMHA's community gains strength

1.774.686

People reached in only 5 months thanks to the sum of the activities of The Migraine Movement.

46,71%

Increase in the number of followers of social networks (4410)

24,24%

We have reached in the engagement of the community. (Starting from a 4.7)



60,20%

Increase in visits to the website (from a monthly average of 500 to a monthly average of 1200)

*RESULTS OBTAINED IN 5 MONTHS.

1. The Migraine Movement

Protection at COVID panorama for EMHA Members

La Voix des Migraineux



EMHA



Migraine Association of Ireland



MIGRA Portugal



1. The Migraine Movement

Visual summary of SSMM actions

Strategy: adapted the tone and message in each social network, with the aim of covering different audiences: patients, affected people, institutions, the medical community and politicians.

Furthermore, **EMHA's graphic image** was revamped and a completely new identity was created for The Migraine Movement.

Campaign Actions

- 01_ Landing launchment
- 02_ Manifesto launchment
- 03_ Migraine Assistant Action
- 04_ Explaining Migraine Action
- 05_ The Missing Lesson Action

Campaign Content Lines

- 01_ The Migraine Movement content line.
- 02_ Explaining Migraine content line.
- 03_ Women & Migraine.

Complementary Content Lines

- 01_ Migraine getaway.
- 02_ Interactive content about migraine. (Interactive stories)
- 03_ Institutional: Events, news, associated info...

COVID19 Speacial Lines

- 01_ Migraine Spotify.
- 02_ My New Normal Life.
- 03_ Migraine Data. (Lilly, EHF...)

Special Activity

“EMHA Together”. Talks about Migraine and COVID.

- The Migraine Assistant

From EMHA we trained 5 Assistants to monitor the keyword "Migraine" on Twitter for 5 days and in 5 different countries.

As soon as someone tweeted about their pain, loneliness or despair... the Assistant answered, giving information and communicating in a personalized way and in real time, that there was a Movement to give voice to patients with migraine.

Goal: Direct impact to the user, achieving "real time engagement", in addition to attracting people to join the Movement.

Target: Patients and member organizations.

Platform: Twitter.



- The Migraine Assistant

Patients appreciated the action, reflecting in their positive response as well as very positive reach data.

Data:

People reached: 58.067

Tweets: 1.484

Interactions: 1.180

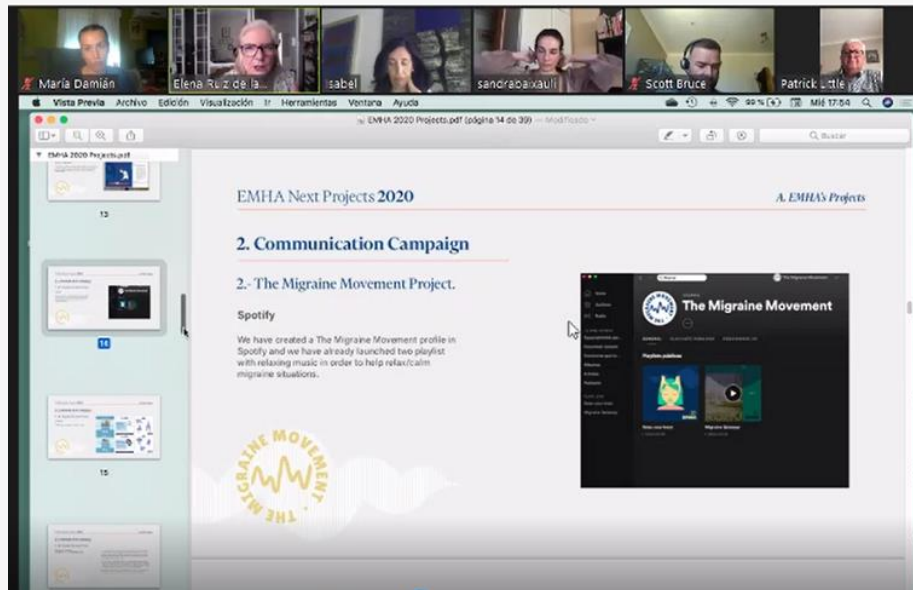
(5 days)



2. EMHA Annual Meetings

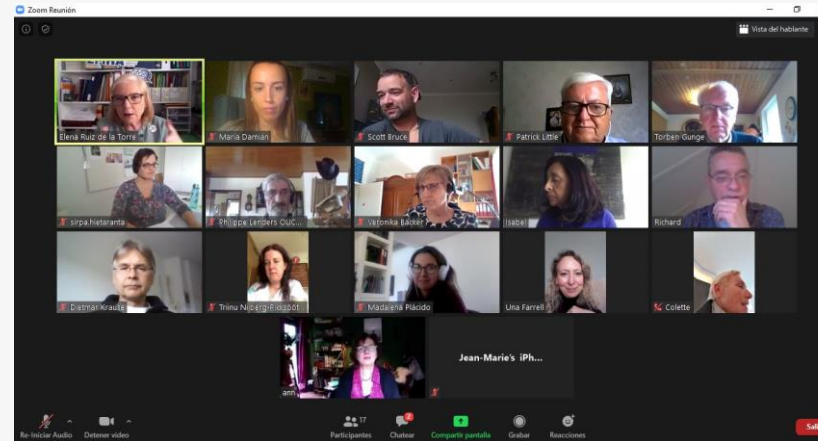
6th May

Board Meeting



12th May

General Assembly



13th May

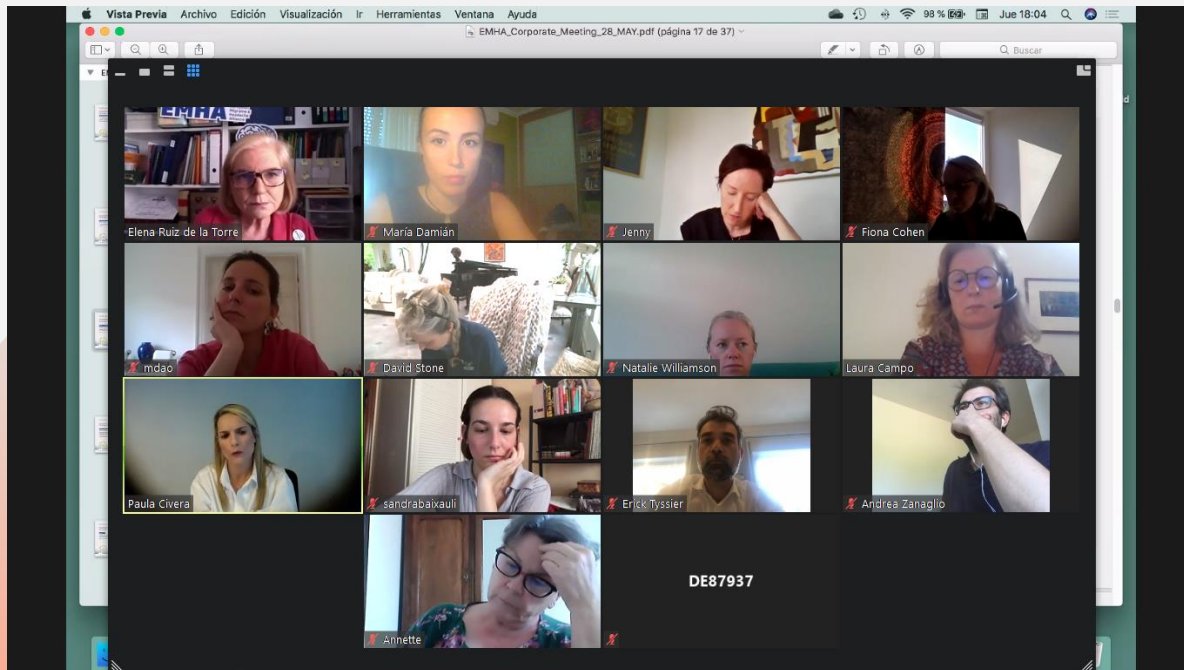
Member's Meeting



2. EMHA Annual Meetings

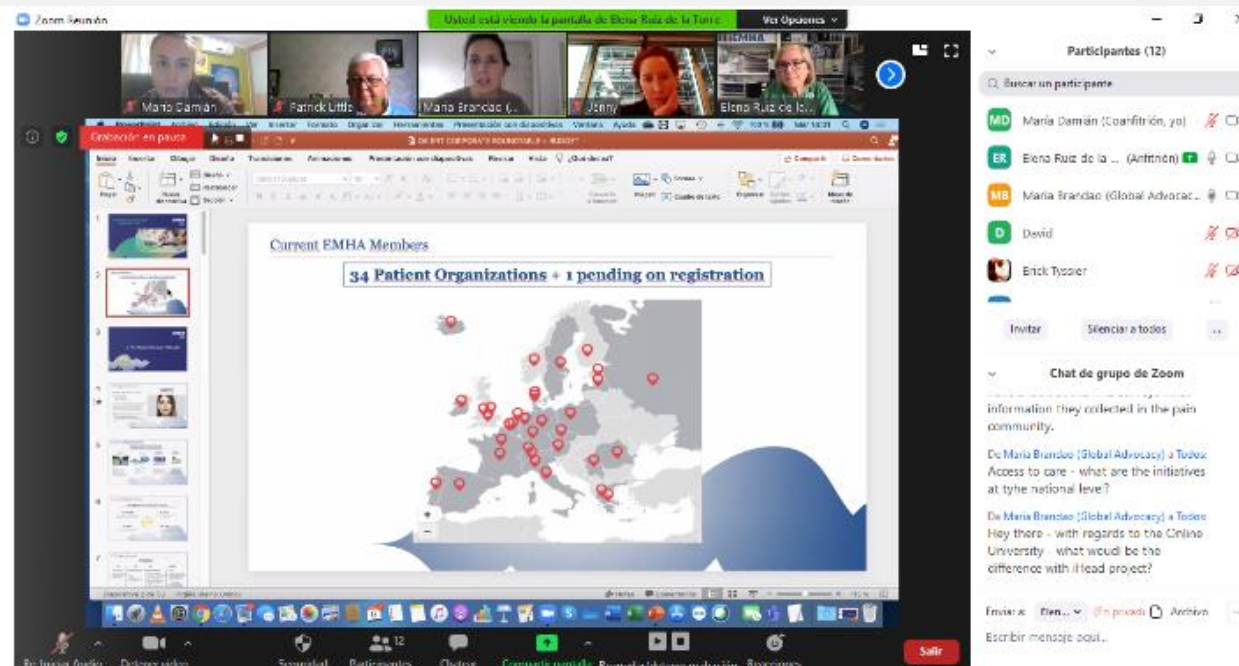
28th May

Corporate Meeting



6th October

Corporate Meeting



3. EMHA Together Talks



15th July

Germany



22nd July

Portugal



3. EMHA Together Talks



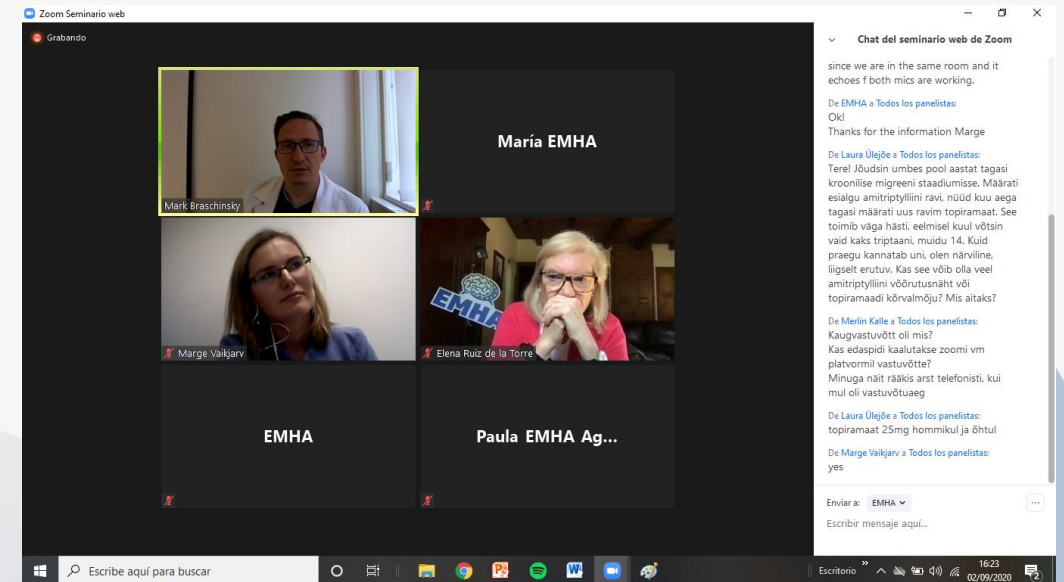
29th July

Italy



2nd September

Estonia



3. EMHA Together Talks



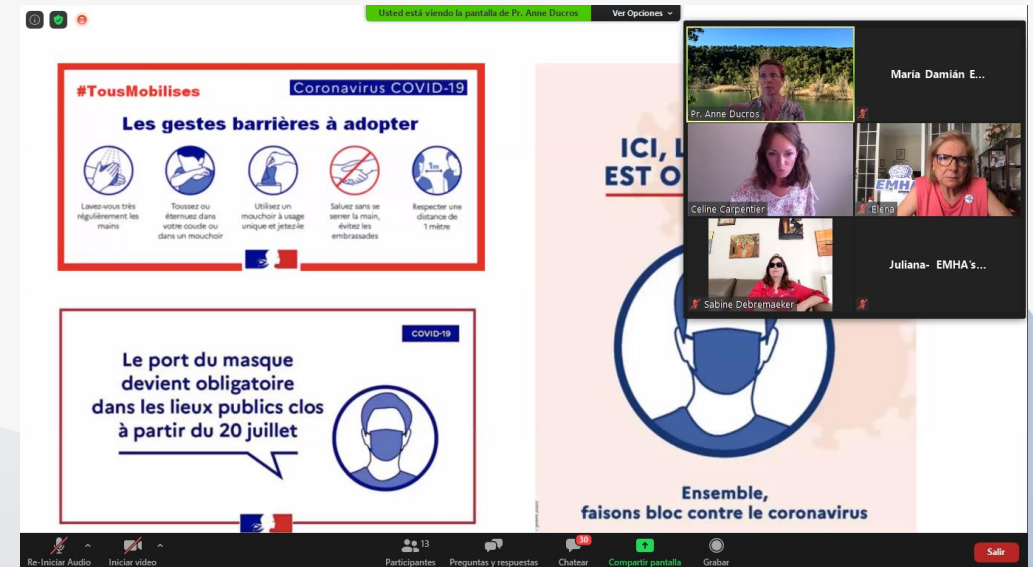
9th September

Germany



16th September

France



3. EMHA Together Talks



30th September

UK

A screenshot of a Zoom meeting interface. The main window displays a presentation slide titled "Premonitory (prodromal) Symptoms" in yellow text on a blue background. The slide lists symptoms preceding a migraine attack and includes a table of patient-reported triggers. A chat window on the left shows messages from participants. The bottom of the screen shows the Zoom interface with participant names and controls.

Premonitory (prodromal) Symptoms

- Symptoms preceding and forewarning of a migraine attack by 2–48 hours occurring before the aura in migraine with aura and before the onset of pain in migraine without aura¹

Established

- Higher centre
 - Fatigue
 - Concentration impairment
 - Mood change
- Neck stiffness
- Homeostatic
 - Yawning/sleepiness
 - Food Cravings
 - Polyuria/Polydipsia

Others²

- Photophobia
- Phonophobia
- Nausea
- Cranial Autonomic Symptoms

Patient-reported trigger ³	Corresponding potential premonitory symptom	Percentage agreement (%)
Relaxation from stress	Elation	91
Physical exertion	Movement sensitivity	88
Meal skipping	Hunger/cravings	81
	GI discomfort	85
Bright light	Photophobia	66
Loud sounds	Phonophobia	79
Under sleeping	Fatigue	34
Dehydration	Thirst	55

1. ICHD-3 Cephalalgia 2018;38:1
2. Goadsby et al., Physiol Revs 2017;97:553
3. Newman et al., Cephalalgia 2019;39(1S):282

21st October

Spain

A screenshot of a Zoom meeting interface. The main window shows a grid of four participants: Elena Ruiz de la Torre, María Damián E..., Isabel Colomina, and Pablo Lima. The bottom of the screen displays the "Agencia EMHA" logo. A chat window on the right shows messages from participants.

Agencia EMHA

3. EMHA Together Talks



28th October

Switzerland



4th November

Czech Republic



3. EMHA Together Talks



11th November

Ireland

A screenshot of a Zoom video conference. The main window displays a presentation slide titled "1.3 Chronic migraine" in white text on a dark blue background. The slide lists four criteria (A, B, C, D) for chronic migraine. To the right of the slide, there are two small video windows: the top one shows a man labeled "María - EMHA" and the bottom one shows a man labeled "Elena Ruiz de la...". The Zoom interface at the bottom shows various controls like "Cancelar silenciar ahora", "Iniciar video", "Participantes", "Preguntas y respuestas", "Chat", "Compartir pantalla", "Grabar", and a "Salir" button.

1.3 Chronic migraine

- A. Headache (TTH-like and/or migraine-like) on ≥ 15 d/mo for >3 mo and fulfilling criteria B and C
- B. In a patient who has had ≥ 5 attacks fulfilling criteria B-D for 1.1 *Migraine without aura* and/or criteria B and C for 1.2 *Migraine with aura*
- C. On ≥ 8 d/mo for >3 mo fulfilling any of the following:
 - 1. criteria C and D for 1.1 *Migraine without aura*
 - 2. criteria B and C for 1.2 *Migraine with aura*
 - 3. believed by the patient to be migraine at onset and relieved by a triptan or ergot derivative
- D. Not better accounted for by another ICHD-3 diagnosis

24th November

Serbia

A screenshot of a Zoom video conference. The main window displays a presentation slide titled "Pričajmo zajedno o migreni i Covid-19" (Let's talk together about migraine and Covid-19) in blue text. Below the title, it says "Trenutna situacija Covid-19 u Srbiji" (Current situation of Covid-19 in Serbia). The slide features a world map with Serbia highlighted in red, showing confirmed cases. The slide also includes statistics for confirmed cases worldwide and in the U.S. To the right of the main window, there are two small video windows: the top one shows a woman labeled "Maria Damian" and the bottom one shows a man labeled "Dr Srdjanom Sre...". The Zoom interface at the bottom shows various controls like "Cancelar silenciar ahora", "Iniciar video", "Participantes", "Preguntas y respuestas", "Chat", "Compartir pantalla", "Grabar", and a "Salir" button.

Pričajmo zajedno o migreni i Covid-19

Trenutna situacija Covid-19 u Srbiji

Tracking Covid-19 Global Cases U.S. Cases U.S. Hospitalizations U.S. Regions State Projections

59,373,646 1,399,983

Confirmed cases worldwide Deaths worldwide

Worldwide Migration Association

Migrena Asocijacija Srbije

3. EMHA Together Talks



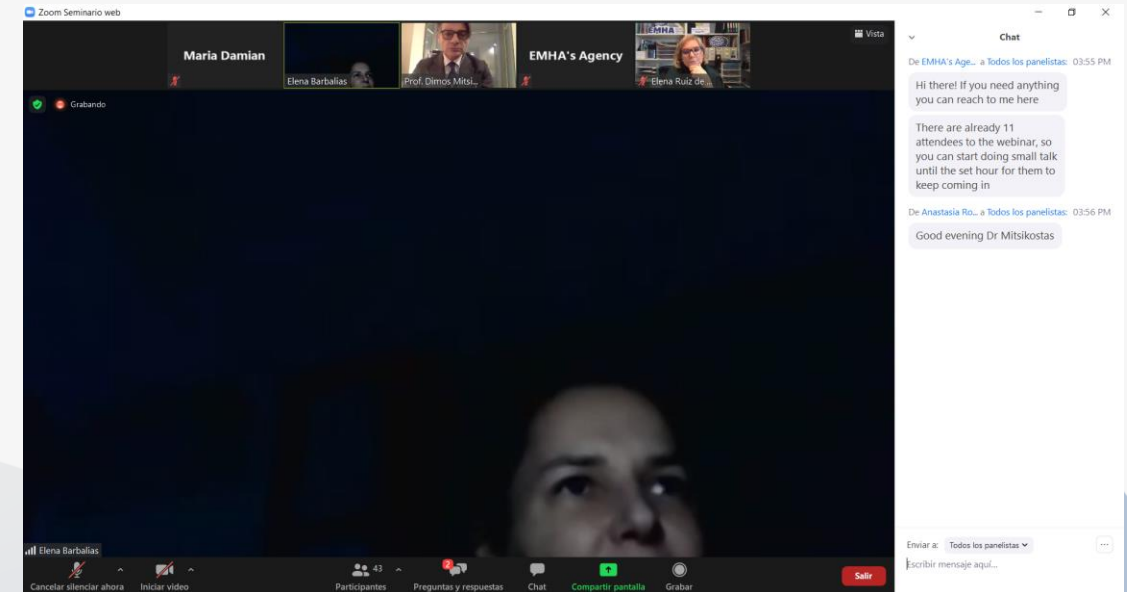
16th December

Germany



22nd December

Greece



4- The Missing Lesson – Migraine Day of Action

The big action launched by EMHA for September 12th, Migraine Action Day, was The Missing Lesson.

The action goal was to show that migraine is only studied in medical universities for a total of 4 hours (source WHO). This contributes to perceiving migraine as a less serious disease and, as a consequence, to be treated with less "urgency" in health centers.

To give more consistency to the action, we wanted to have the patient's perspective, by launching an European survey, in which we collected testimonies and data on the time it takes for a patient to obtain an effective diagnosis and effective treatment.

Using the results of this European patient survey, we developed a testimonial video: The Truth Behind Migraine.

**The
Missing
Lesson.**



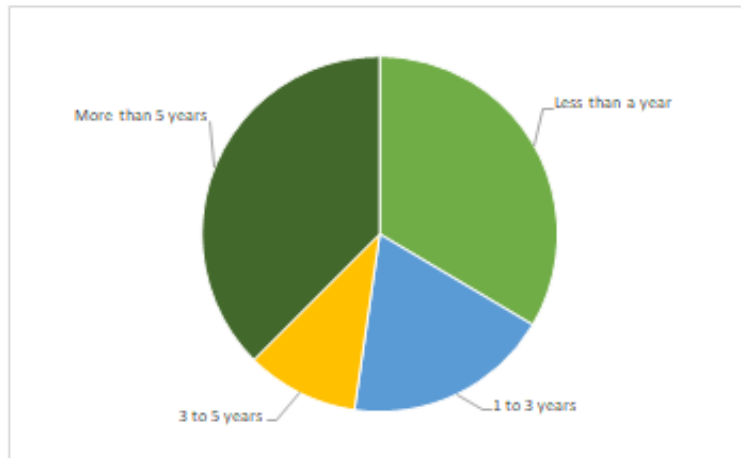
<https://www.youtube.com/watch?v=Tr64kPqLAj8&feature=youtu.be>

4. The Missing Lesson

The Missing Lesson EMHA Survey for patients. Results

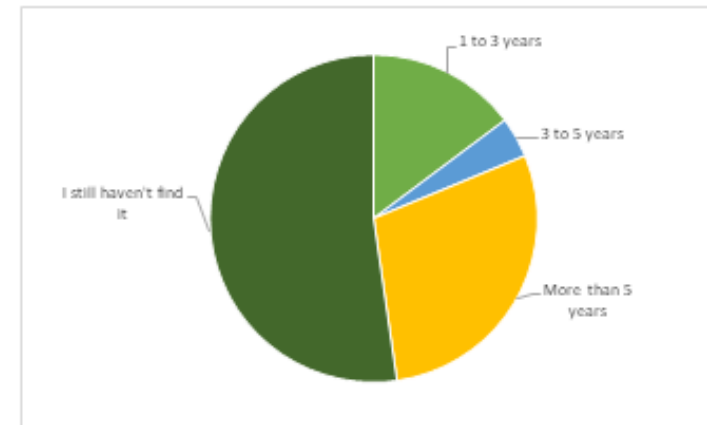
**The
Missing
Lesson.**

Q4 How many years did it take you to get a diagnosis?



ANSWER CHOICES	RESPONSES
Less than a year	33,52% 59
1 to 3 years	18,75% 33
3 to 5 years	10,23% 18
More than 5 years	37,50% 66
TOTAL	176

Q5 How long has it taken you to find an efficient treatment?



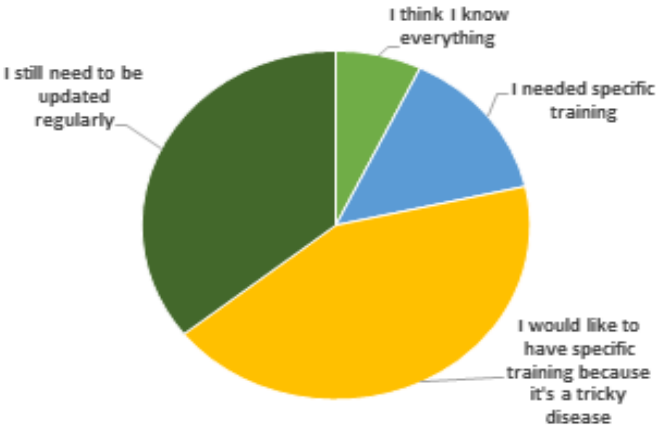
ANSWER CHOICES	RESPONSES
1 to 3 years	14,77% 26
3 to 5 years	3,98% 7
More than 5 years	28,98% 51
I still haven't find it	52,27% 92
TOTAL	176

4. The Missing Lesson

The Missing Lesson EMHA Survey for medical community. Results

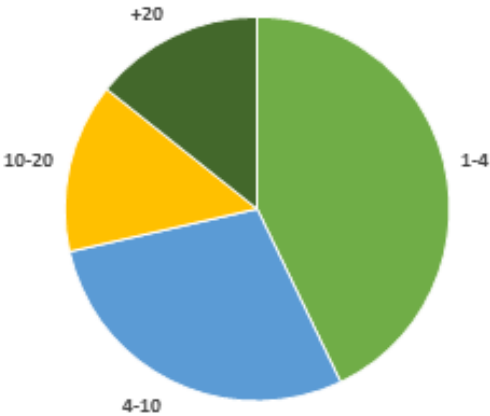


Q3 Do you think this was enough to manage migraine in the best way?



ANSWER CHOICES	RESPONSES	
I think I know everything	7.14%	1
I needed specific training	14.29%	2
I would like to have specific training because it's a tricky disease	42.86%	6
I still need to be updated regularly	35.71%	5
TOTAL		14

Q2 How many hours in your postgraduate studies did you have on headache, migraine cluster headache and others?



ANSWER CHOICES	RESPONSES	
1-4	42.86%	6
4-10	28.57%	4
10-20	14.29%	2
+20	14.29%	2
TOTAL		14

Activities for 2021

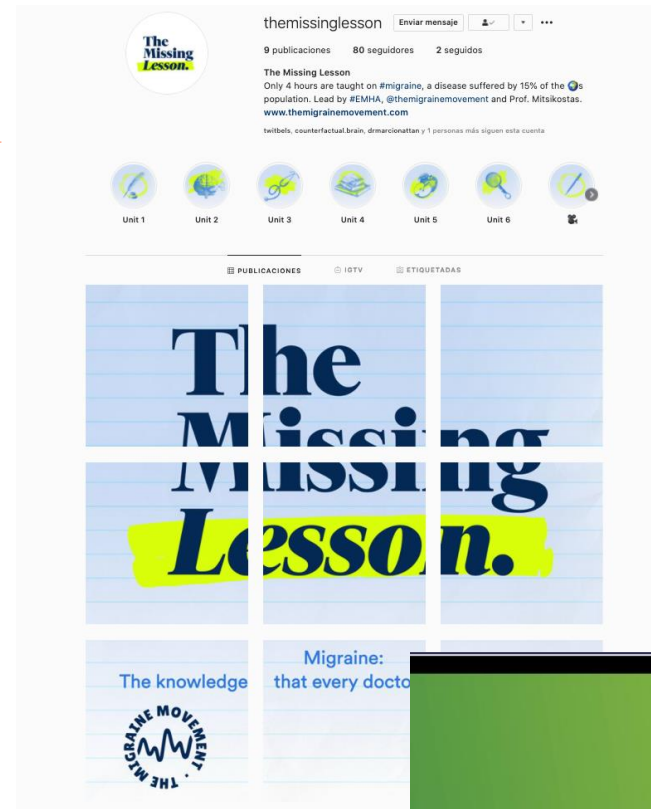
- The Missing Lesson

On September 10th, the action was officially presented at a press conference organized by TEVA and we took the opportunity to launch the educational account on Instagram “The Missing Lesson”.

An innovative and interactive place that collects all the information about migraine that every GP or medical student should know.

From EMHA we reinforced this activity by sending a European level press release, to help give visibility to the action among those affected and the society in general.

Moreover, in order to have the community's vision, on the same day September 10th, we launched a questionnaire for the European Medical Community, in which they were asked about their experience with study hours related to migraine.



5. EU Policy Makers Project

Building EP Relations

February

Meetings at EU Parliament

MEP. Montserrat and MEP. Colin - Oesterlé



EFNA EU Parliament Event

*Brain Health as a global priority,
Time for the EU to act now*



5. EU Policy Makers Project

Make Migraine a EU health priority

“CALL TO ACTION”

EMHA produced this policy document with a series of recommendations for the EU Commission, the EU Parliament, and national governments to make migraine a health priority.

This “CTA” was launched during “The Missing Lesson” Webinar and you can find it in:

<https://www.emhalliance.org/wp-content/uploads/2020/09/EMHA-Call-to-Action-Final.pdf>



“MEP MIGRAINE ALLIANCE”

EMHA planted the seeds for a MEP Migraine Alliance in the EU Parliament. The kick off of this Alliance took place during the webinar also and was founding by MEP Also Patriciello and MEP Nathalie Colin Oesterlé

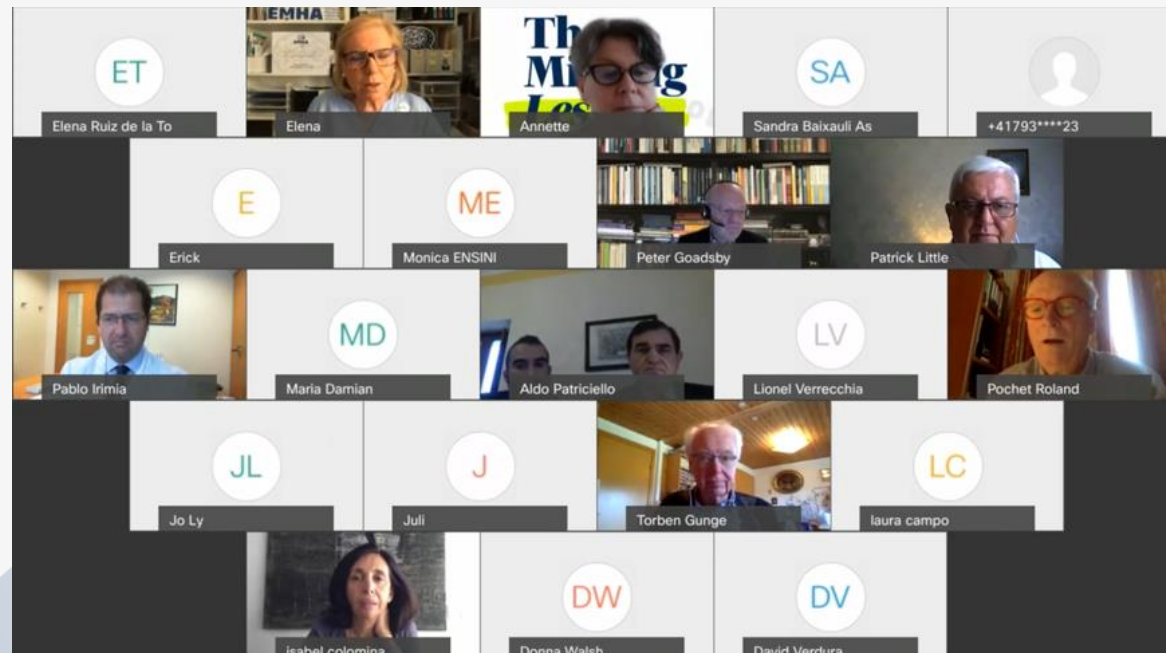


5. EU Policy Makers Project

Raise awareness

WEBINAR “MIGRAINE : THE MISSING LESSON” – HOSTED BY MEP ALDO PATRICIELLO


EMHA organized a webinar on 22nd September to mark “EU Migraine Action Day”. The 2020 theme was “The Missing Lesson” to raise awareness about the education deficit about migraine in the medical curriculum. The webinar had more than 40 subscribers and was hosted by MEP Aldo Patriciello with the participation of MEP Nathalie Colin – Oesterlé.



6. Migraine at Work

Publications and Presentations of the results


Migraine World Summit



MIGRAINE WORLD SUMMIT

[Mission](#)
[Resources](#)
[Login](#)
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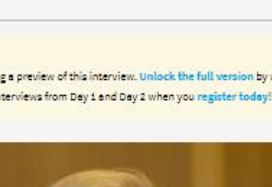
2020 Summit / Day 6 (2020) Taking Control / Migraine at Work: Issues and Progress


Migraine at Work: Issues and Progress


[Day 6 \(2020\) Taking Control](#)


Video Preview

You are currently watching a preview of this interview. [Unlock the full version](#) by upgrading to an Access Pass bundle! Get FREE access to 8 expert interviews from Day 1 and Day 2 when you [register today!](#)





Elena Ruiz de la Torre

Patient Advocate and Executive Director
 European Migraine & Headache Alliance

Elena Ruiz de la Torre is one of the leading patient advocates and researchers in the world. She is a tireless and passionate champion for people with headache disorders in the workplace and beyond, with her advocacy career beginning in her native Spain, and then expanding to Europe, and now the world. Elena leads the European Migraine and Headache Alliance, a nonprofit patient umbrella group that represents 50 patient groups from across the continent. She also co-led the creation of WHAM,

Scientific Magazines

- SEMERGEN - Mexican Neuroscience Magazine
- RESED - Medicina Balear Magazine
- Mexican Magazine of Neurology – Preventive Treatments in Migraine. Used and variations.

[illegible]

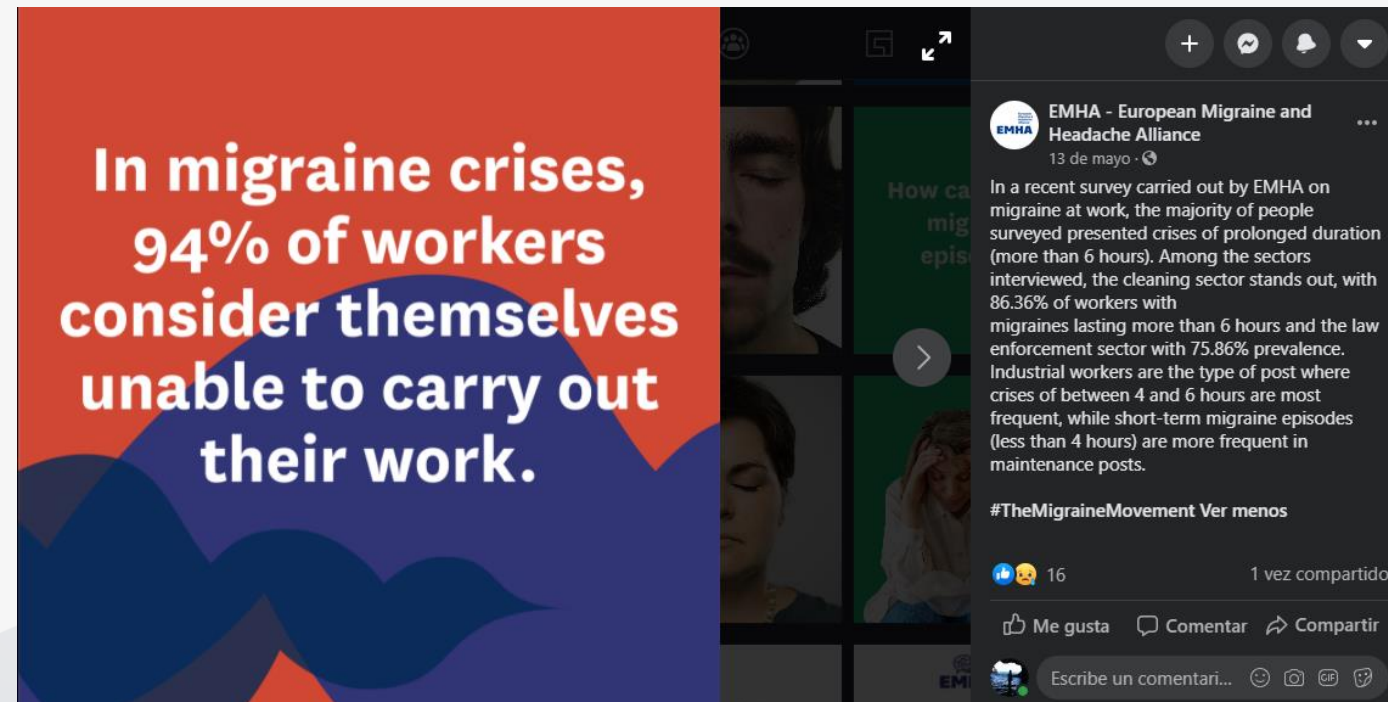
6. Migraine at Work

Publications and Presentations of the results

EMHA's results on Women at Work are presented at Women's Forum by Elena Ruiz de la Torre.



Periodic publications at EMHA
SSMM profiles



6. Migraine at Work

Women at Work Results

Have you ever requested a change in your position?

YES

18,90%

NO

81,10%

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WOMAN

Has your position been adapted?

YES



33,30%

NO



66,67%

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Having migraine classifies you as a disabled person?

No

26,40%

Yes, but only during crises

60,60%

Yes, all the time

13,10%

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Headache
Alliance
WOMAN AT WORK


6. Migraine at Work

Phase 2 . New countries

During 2020 the EMHA has replicated the Migraine at Work Survey in 8 new countries :

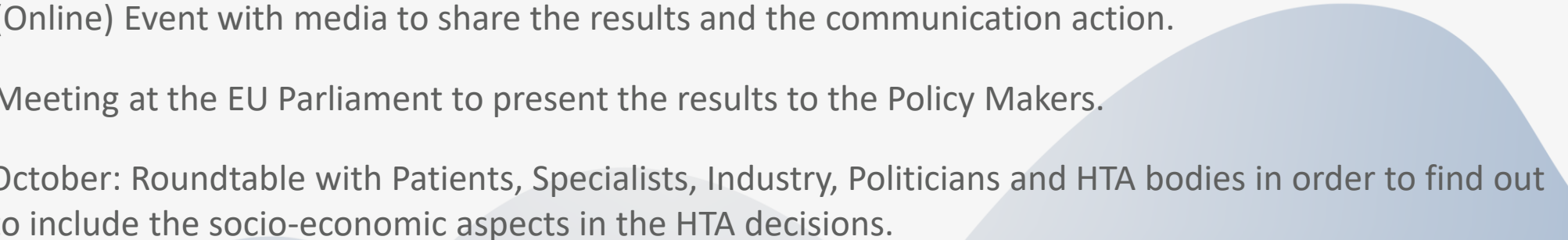
Poland, Finland, Belgium, Estonia, Portugal, Mexico, Argentina and Canada.

The survey is being run at the moment and will be studied at the end of the year to be able to amplify the information of the Migraine at Work Dossier, continue publishing and presenting the new data and become a reference for plenty of new projects around the workplace.



7. “Access to Care “

First steps of 2020 and Future plans for 2021

- 1.- Reach the national organizations who would like to be included in the survey.
 - 2.- EMHA, together with the AEEMT (Spanish Association of Specialists in Occupational Medicine), Medical experts (Prof. P. Goadsby and Prof. C. Tassorelli), Industry and HTA experts are building the final survey .
 - 3.- During October the Survey will be launched in UK, Spain, France, Italy, Germany, Ireland, Norway, Portugal, Czech Republic, Austria and Greece.
 - 4.- During March the data will be collected and analyzed .
 - 5.- Between March and June a communication action will being developed.
 - 6.- September: (Online) Event with media to share the results and the communication action.
 - 7.- September: Meeting at the EU Parliament to present the results to the Policy Makers.
 - 8.- September/October: Roundtable with Patients, Specialists, Industry, Politicians and HTA bodies in order to find out what's needed to include the socio-economic aspects in the HTA decisions.
- 

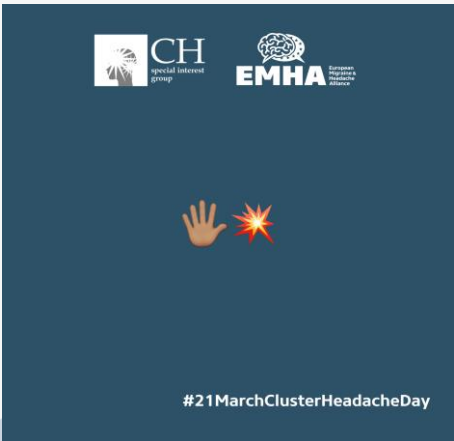
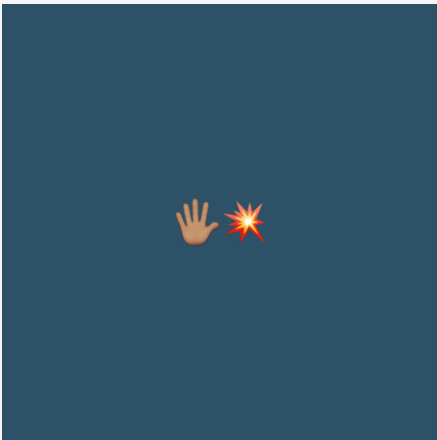
8. CLUSTER HEADACHE

Cluster Headache Special Action Global Day Data

The Cluster Headache Day campaign was activated in EMHA’s social media channels: Facebook, Twitter and Instagram.

There was no ad investment involved; all the results obtained were gained through the organic promotion of the campaign.

Members Participation	Share	Interactions	Reach	% Engagement
24	19	285	5343	0,054



Key metrics from each social media channel:

Facebook: On the 21st of March, we obtained a 1,2k reach.

Instagram: *On both days we increased the engagement rate by 220%.*
On the 20th of March we reached an engagement % of 9,06%
On the 21st of March we reached an engagement % of 7,32%

Twitter: The daily engagement rate reached a 1,7% on the 20th of March and a 2,1% on the 21st.

Activities with other Stakeholders



Visit to Allergan's Headquarters

Training on Migraine Patient's Real Burden

23rd January



Beyond Migraine : The Real You
New Research Findings in Migraine

10th September

Beyond Migraine: The Real You

Results from Living with Migraine in Europe, 2020 Survey

10 September, Virtual meeting

teva

10:43

📺

🔊

📶

⋮

💬

👤

Solicitar control

📞

Liz Ferguson (Ketchum)

+3

Joshua Cohen

Dimos (Guest)

FC

Con Franklin (Ketchum)

Fiona Cohen

Contactos

Actualmente en esta reunión (8)

E

Elena (Invitado)

CF

Con Franklin (Ketchum)

D

Dimos (Guest)

FC

Fiona Cohen
Organizador

JC

Joshua Cohen

LF

Liz Ferguson (Ketchum)

MG

Magali Geens

MD

Matthias Dusselier

Dimos (Guest)

Con Franklin (Ketchum)

Joshua Cohen

Matthias Dusselier

24:54

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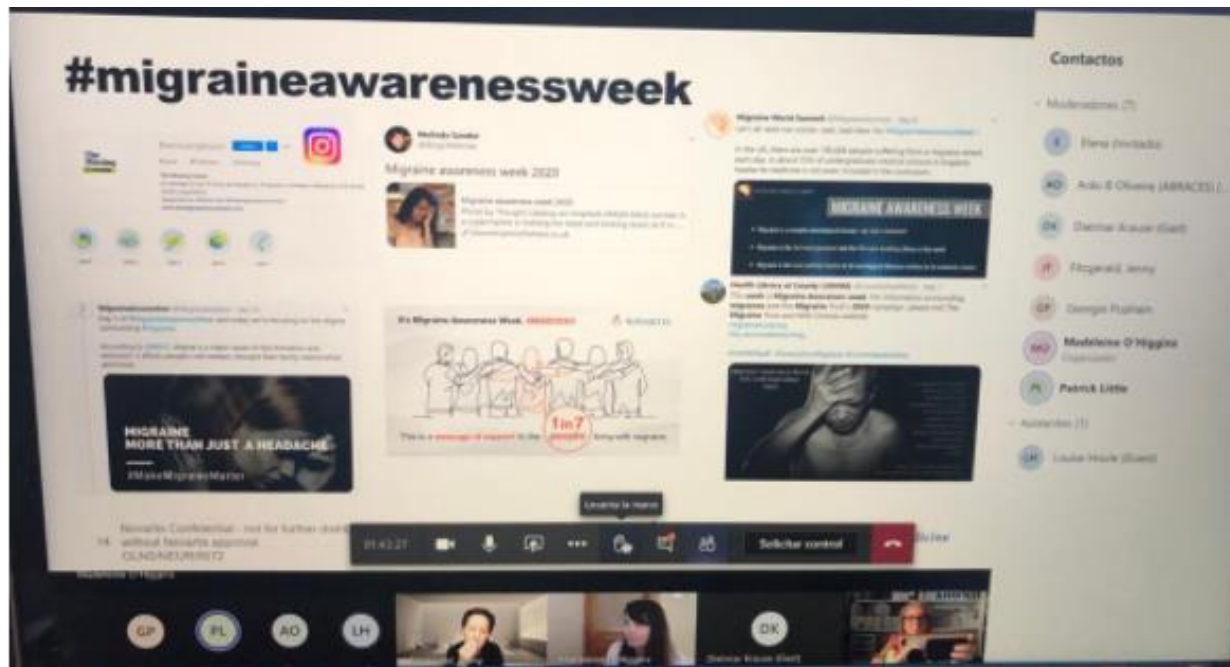
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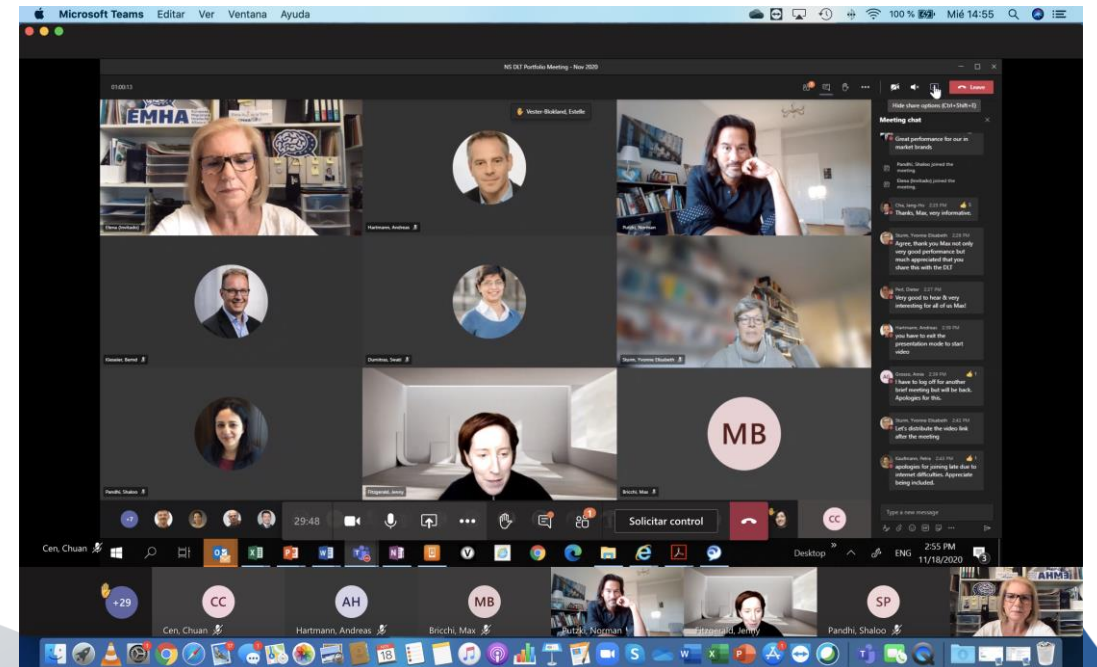
LF

FC

International Migraine Council Quarterly Meetings



Migraine Webinar



International Forum on Women's Brain and Mental Health

20th September



Global Patient Advocacy Coalition Online Meetings

Twice a month

The screenshot shows a Zoom meeting interface. At the top, there are five video thumbnails of participants. Below them is a presentation slide titled "2020 Sustainable Initiatives: Employer Engagement Program Update". The slide content includes:

- The Employer Engagement Program is gaining traction despite the COVID-19 climate**
- Interest From Employers Continues**
- Economic Impact on Company**
 - FUJITSU**: Methodically identified that migraine impacted *employee productivity and absenteeism*
- Commitment to awareness of invisible illnesses**
 - MITRE**: MITRE's Invisible Illness Committee is committed to *raising awareness of migraine*
- Employee Sentiment**
 - MARRIOTT BONVAY**: Identified need to demonstrate *care for their furloughed employees* during COVID-19
- Virtual Employee Support**
 - BARCLAYS**: Expressed interest in the GPAC initiative & *supporting employees virtually* during COVID-19

On the right side of the screen, there is a list of participants (15) with names and status icons. Below the list is a chat window with a message from "De Allen Finley - IASP" asking if slides will be shared.

The screenshot shows a Zoom meeting interface with a grid of participants. On the right side, there is a presentation slide titled "Strategy: Resource Creation". The slide content includes:

- Strategy: Resource Creation**

The first step is to develop the content that will shape the program. Learning on the existing resources within AMF and the coalition, Yikety Yak will develop a multi-media approach that tells a story. We will lean on our in-depth knowledge of the field to identify content gaps, which we will fill internally.
- Structure: Technology Development**

User experience is extremely vital when it comes to an online program. Yikety Yak will build a portal that combines WordPress, HubSpot and existing video streaming, while keeping budget top of mind. While the curriculum will remain the same, we will have the ability to replicate these hubs and customize them for each business. This is a cost-effective way to work with many organizations at one time and measure the individual impact.
- Engagement: Program Customization**

In order for our program to be effective, it must meet our target audience where they are. Starting with the employer group, we want the program to be branded accordingly, with messaging integrated from leadership, such as a welcome video. But it also means making sure that we customize the content and website experience to overcome language and cultural barriers. This means translating the program into multiple languages and using culturally-appropriate imagery.
- Participation: Outreach and Enrollment**

We want to make sure leadership has the tools necessary to engage new employees and advocacy organizations who will help drive participation. From marketing collateral to email communication, Yikety Yak will develop the materials that will facilitate outreach. In addition to maintaining the platform and reporting on results, we will promote it through public relations.

Interview “Migraine at Work: Issues and Progress”

26th March

Migraine at Work: Issues and Progress

Day 8 (2020) Taking Control

Video Preview

You are currently watching a preview of this interview. [Unlock the full version](#) by upgrading to an Access Pass bundle! Get FREE access to 8 expert interviews from Day 1 and Day 2 when you [register today!](#)



Elena Ruiz de la Torre

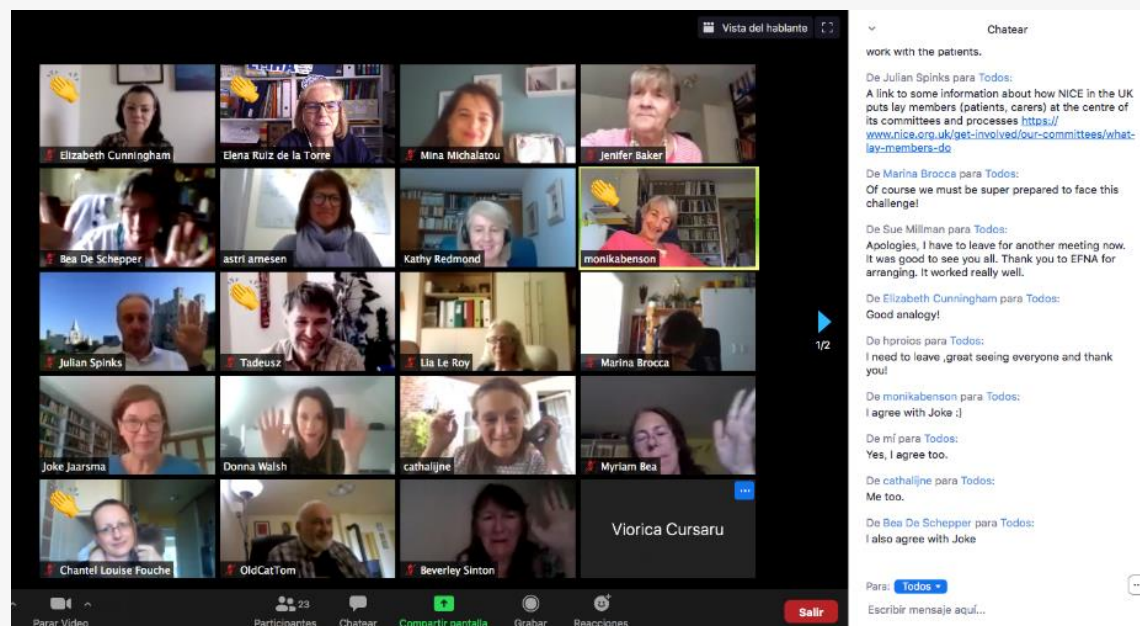
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European Federation of Neurological Associations

General Assembly



Brain Mind and Pain Webinar

43 MEPS HAVE SIGNED THE REGISTER OF SUPPORT 2019-2024

THE MEP INTEREST GROUP ON BRAIN, MIND AND PAIN IS CO-CHAIRD BY:



THESE MEPS SIGNED THE REGISTER OF SUPPORT DURING THE 2014-2019 MANDATE AND HAVE NOW SUPPORT OF THE 2019-2024 MANDATE:



Elena Ruiz de la Torre

Donna Walsh

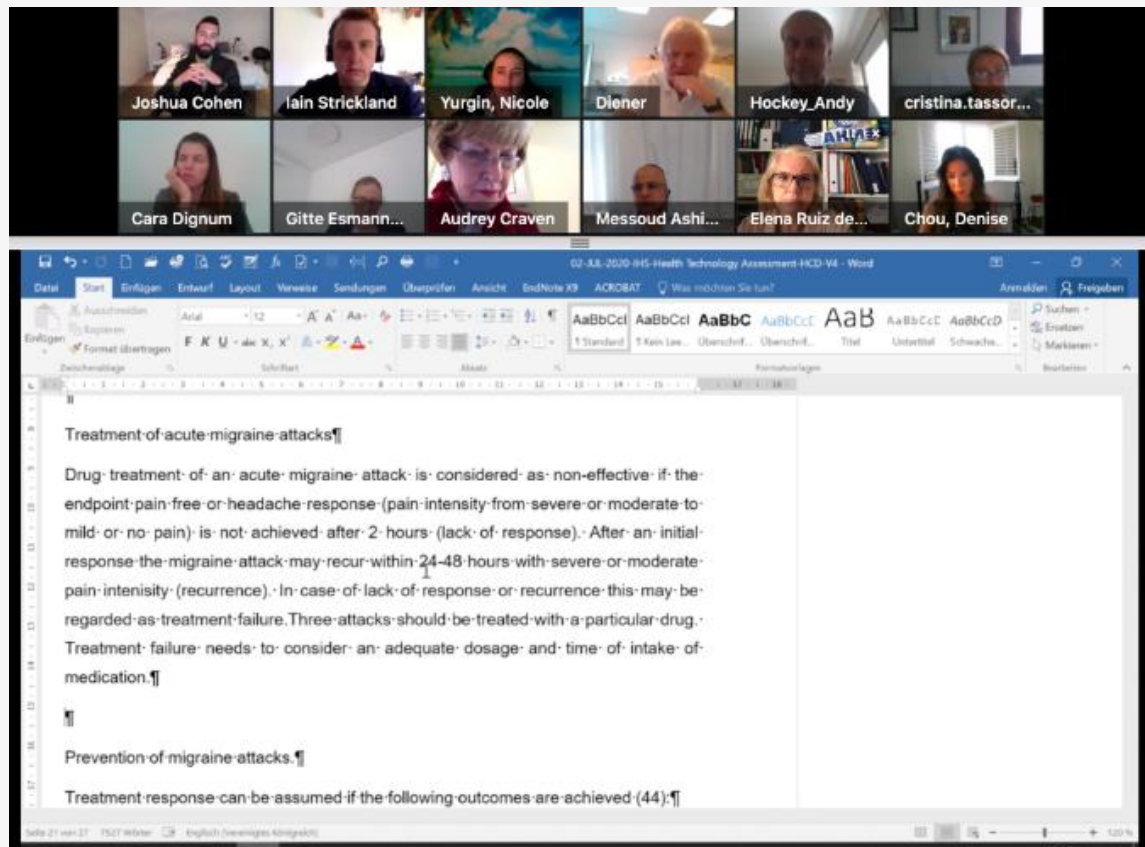
DANIEL TANESSE

Jina Swartz

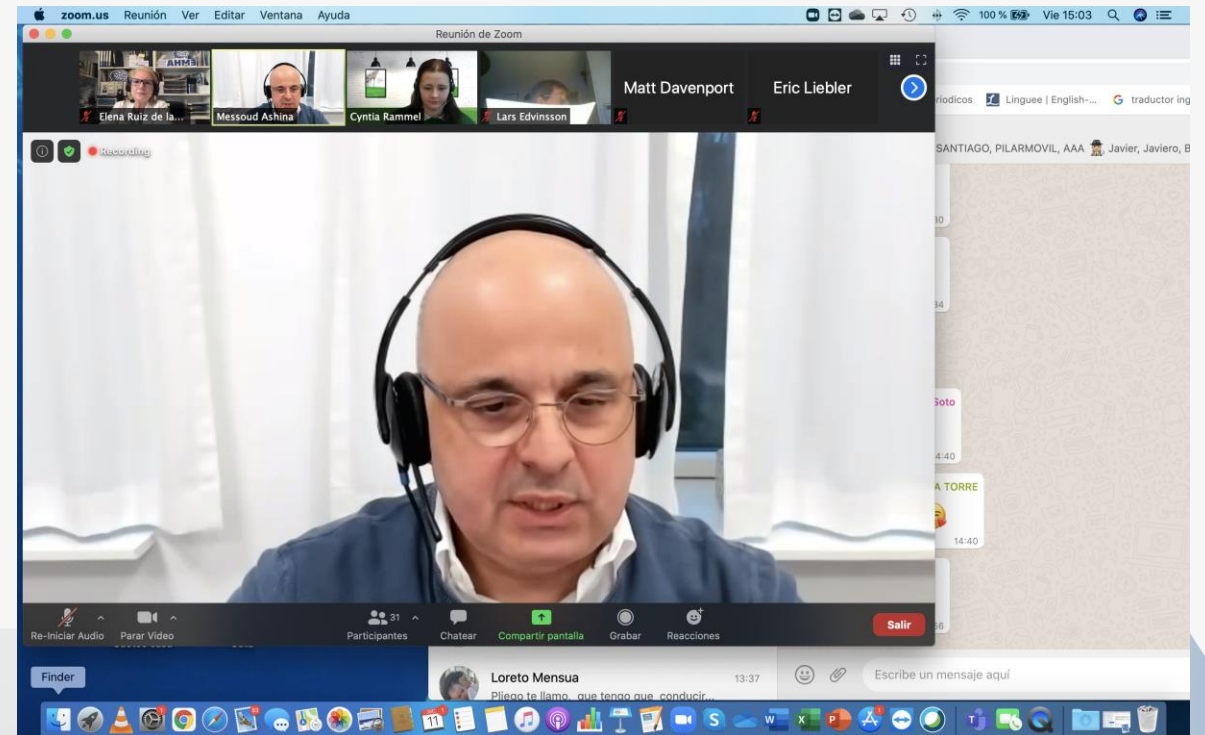


International Headache Society

Roundtable



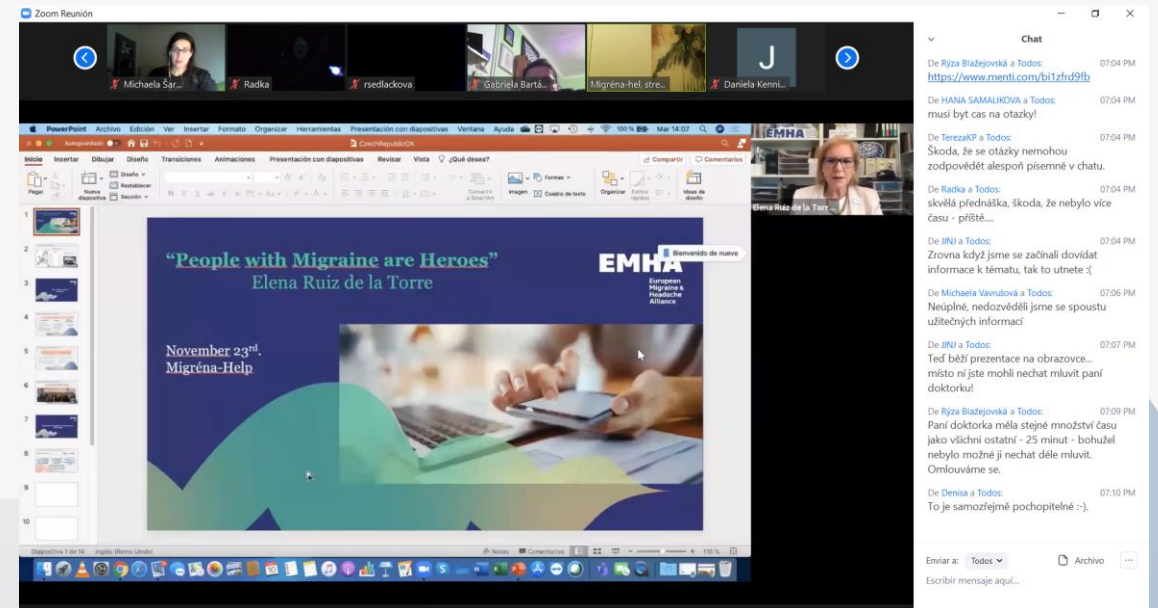
Board Steering Committee



AEMICE (Spain) Migraine Day of Action Webinar



Migrena – Help (Czech Republic) “Conference on Migraine”



Migraine Association of Ireland (Ireland) Webinar “Migraine in the Workplace”



icgp

Workplace Factors in Migraine

Dr Mary Kearney
GP with Extended role in Headache care

Moderated by Marie Ennis
Communication Officer
Migraine Association Ireland

Friday 23rd Oct 2020 - Virtual

European Reference Network
for rare or low prevalence
complex diseases

Network
Neurological Diseases
(ERN-RND)

Cochrane Library



MigräneLiga (Germany) 73rd Migraine Symposium



Migräneprophylaxe nach den Leitlinien der DMKG und weitere Therapieoptionen
Priv.- Doz. Dr. med. Charly Gaul
Chefarzt der Migräne- und Kopfschmerzambulanz Königstein i. T.

Migräneprophylaxe nach den Leitlinien der DMKG - Dr. med. Charly Gaul

Migräne Prophylaxe

Dr. med. Charly Gaul

VZW HOOFD – STUK (Belgium)
“Webinar on Migraine with free book for our members”

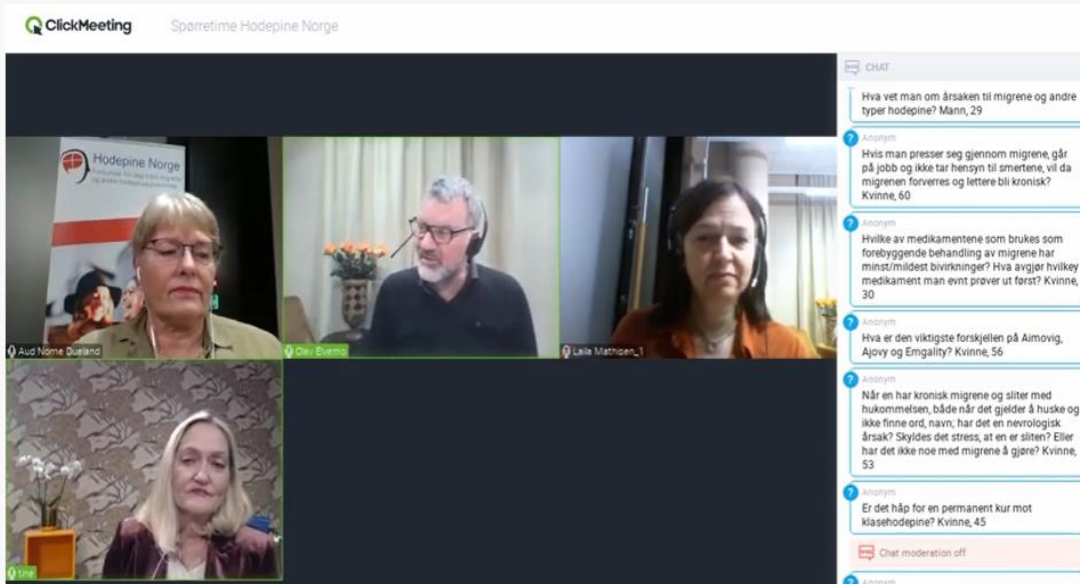


Greek Society of Migraine and Headache
Patients
“Webinars on Migraine”



Hodepine Norge (Norway) “Q&A Open Webinar”

ClickMeeting Spørretime Hodepine Norge



CHAT

Hva vet man om årsaken til migrene og andre typer hodepine? Mann, 29

1. Hodepine Norge
Hvis man presser seg gjennom migrene, går på jobb og ikke tar hensyn til smertene, vil da migrenen forverres og lettere bli kronisk? Kvinne, 60

2. Hodepine Norge
Hvilke av medikamentene som brukes som forebyggende behandling av migrene har minst/mildest bivirkninger? Hva avgjør hvilke medikament man evt prøver ut først? Kvinne, 30

3. Hodepine Norge
Hva er den viktigste forskjellen på Aimovig, Ajovy og Emgality? Kvinne, 56

4. Hodepine Norge
Når en har kronisk migrene og sliter med hukommelsen, både når det gjelder å huske og ikke finne ord, navn, har det en neurologisk årsak? Skyldes det stress, at en er sliten? Eller har det ikke noe med migrene å gjøre? Kvinne, 53

5. Hodepine Norge
Er det håp for en permanent kur mot klasehodepine? Kvinne, 45

Chat moderation off

La Voix Des Migraineux “Migraine Day of Action Marketing Campaign ”

Les grandes actions en 2020 exemples



Journée d'action contre la migraine.

Campagnes de presse avec

Le Monde, LA DÉPÊCHE, LA VOIX DU NORD, RTL, Inter, Le Soleil, rtbf, franceinfo, La Provence, L'EST, @la DOCTEUR.fr, RTL, handicap.fr, BFMTV.

et bien plus encore !

12 24/01/2021 Pied de page

LA VOIX des MIGRAINEUX
SOUTIEN POUR VOTRE

Hoofdpijnnet (Netherlands)

12th September Webinar : “Life with Migraine,
from complain to power”



Thank you