



EUROPEAN HEADACHE ALLIANCE

ANNUAL REPORT 2017

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Board Members

Elena Ruiz de la Torre, President, Spain
Paolo Rossi, Vice-President, Italy
Willem Sleddering, Secretary, Netherlands
Patrick Little, Treasurer, Ireland
Kalina Tyminski Member, France

LETTER FROM PRESIDENT

I have taken on the Presidency of the European Headache Alliance during exciting times. The work we have done up until now has placed us in a strong position for the future. Together we have successfully placed EHA as a key reference in Europe for the advocacy movement in migraine and other headache disorders. We must ensure EHA remains strong and sustainable, and with that in mind, this Strategic Plan outlines the journey we, the patients, will take together. EHA enjoys a position of strength based on our established network of patient-led organisations in over 25 European countries. We maintain excellent working relationships with a number of important stakeholders, including European Headache Federation, European Federation of Neurological Associations, European Academy of Neurology, European Brain Council, European Patients Forum, International Headache Society and International Alliance of Patients' Organizations.



We are active participants and partners in various projects and events, representing the patient voice.

We have worked successfully to improve public awareness of headache disorders, and we will strengthen our focus on communications, particularly online, to increase our impact. We will maintain and extend our contact with European policy makers and continue our involvement in European projects and initiatives.

Currently, there are four new and promising preventative migraine medications in the final stages of clinical development. New technologies and innovations for the diagnosis, management and treatment of headache disorders are also being created. So, for those of us affected by these disabling conditions, we are hopeful that the coming years will bring significant improvements in access to care.

Obviously, increased interest from industry in the area of headache disorders presents us with many opportunities to work collaboratively, with the indirect benefit of potential funding for projects of mutual interest. This has allowed us at EHA to go beyond being a volunteer-led organisation, to an organisation which can contract staff and consultants in a strong infrastructure to better enable us to participate in the activities and projects that are coming downstream.

This also brings its own challenges, however, in the need to ensure that our governance structure is solid, transparent and ethical – and that our way of working is sustainable. We benefit from a wide network of partners and friends in the policy arena, and in industry. It is important that we continue to work respectfully together,

acknowledging each other's strengths, as we strive for access to better services and treatment options for those affected by headache disorders.

The problem persists of how we can convince key opinion leaders in the area of policy, politics and in wider society, of the impact of headache disorders and the need to focus attention on lifting this burden. 'Headache' continues to be perceived in many quarters as a minor complaint, and those who are affected are stigmatised for being weak, neurotic and unreliable. I am hugely mindful that we need to continue to work together to illustrate the socio-economic impact of headache on our societies, and the negative effect these disabling disorders can have on the quality of life of those affected and their families. I am convinced that we also need to show society that these people are hard-working, resilient, adaptable – as a result of living with and managing migraine or other headache disorders. We need to turn the negative into a positive, and we need to activate our community to take control; to take the lead.

As you are reading this plan, I hope you are already convinced of the need for us to work together to optimise this new era for those affected by headache, to overcome the challenges together and to make a real difference in the coming years.

Elena Ruiz de la Torre, EHA President

MAIN ACTIVITIES 2017

MARCH

MILAN (1th-3th) - VOT (Value Of Treatment)

Meeting with Prof. Steiner and Prof. Matilde Leonardi to discuss “Migraine Patients Journey” and Presentation of “Patient journey” to the Italian Matilde’s Hospital Team .

LONDON (4th) - ALLERGAN

ERT meets with Sophia James – through the International Allergan Foundation - who offers us to present a project to create a new Migraine Awareness Campaign.

BARCELONA(8th- 9th) - EPIC

ERT went to Barcelona to attend the Steering Committee EPIS 2017 where the development of a new HUB with National organization + 1 central Hub was discussed. Besides, there was an AGORA meeting – Advisory Group On Reimbursement and Access . HTA

BRUSSELS (20th-21th) - C.H Day

The VH day took place on the 21st of March at the EU Parliament where different people living with CH met together to hear the presentations and the TV VoxBox.

There were new and future projects to be decided with Paolo Rossi (EHA Vice-president)

- EHA Cluster Headache group of interest (Already created)
- Health Ministry from each member
- Second survey (To be launched in February, 2018)

LONDON (26th) - IHS

IHS corporate advisory round table meeting AC+ERT. Audrey made a presentation on behalf of the patients and Prof David Dodickvmade a presentation about IHS new campaign in US.

WASHINGTON (27th-29th) - TEVA

A Migraine Patients Advocacy roundtable was held, followed by a dialog on “ Improving health global patient advocacy”.

APRIL

ZURICH (4th-5th) - NOVARTIS

ERT went to Zurich for the Global survey- Steering Committee meeting organised by Novartis with the aim of finding a definition of the final survey.

BARCELONA(6th) -NOVARTIS

ERT was invited to attend the NOVARTIS Conference ABOUT “what are the brutal truths about migraine” in which 150 Presidents of Novartis took part.
ERT asked for a call to action, strengthen and support for the local patient organisations.

MAY

BRUSSELS (4th-5th) – EFNA

EFNA held a workshop on communication for their national advocates . AC attended all the workshop and ERT and OS arrived on the second day.

JUNE

AMSTERDAM (1st-3th) - EU Migraine Council Steering Committee Novartis

ERT , AC, PR, PL, WS, KT, and OS went to the EHA meeting in TEVA's Office, followed by a dinner with Novartis.

On the next day, the EU Migraine Council Steering Committee meeting was held to discuss about Novartis Campaign and patient toolkit.

BRUSSELS (21st- 22nd) – VOT

EHA Vice President Paolo Rossi attended “ Time is Brain” Final conference under the auspices of the EU Maltese Presidency and received an award on Best Practices.

AMSTERDAM (23th- 26th) - EAN + EFNA

ERT attends the 3rd Congress of the European Academy of Neurology and EFNA General Assembly. Besides, ERT took part i _EFNA Ideas Exchange Forum were new projects , such as *Clinical Trials Guide* (in collaboration with Anita Mensing) and *HTA* (Access Guide in collaboration with Simon Evans) were discussed.

JULY

MADRID (11th) – AEPAC

ERT attended AEPAC (Spanish headache patient association) General Assembly..

BRUSSELS (11th) – EFNA

OS and AT attended EFNA’S partner meeting as well as the Brain, Mind & Pain Meeting, at European Parliament

BRUSSELS (20th) – EHA

EHA Officers Board meeting

AUGUST

TALLIN (23rd) – Novartis

ERT attended the Novartis Scandinavian Countries Conference where she made a 45’ speech about EHA organization and how does the EHA sees that we can work together with the Scandinavian countries and how to engage the Nordic Patients Organizations to be more active and empowered.

SEPTEMBER

VANCOUVER (4th-9th) - IHS

ERT, AC, OS, AT attended IHS Global Patient Advocacy Summit, as well as the première of "Out of my Head" film.

Besides, EHA had Booth at 18th Congress of the IHS (International Headache Society) where both AC and ERT made a presentation about EHA + Patient perspective.
ERT held several project development meetings with Novartis + AMGEN + Teva's, CEOs.

LONDON (10th-13th) - Migraine Day of Action 2017

ERT + OS went to Women's Health headquarters in London to hold the "Facebook Live Event" for Migraine Day of Action.

ERT took part in a meeting with TEVA's team to find support for the F2F CH meeting and Rome's workshop and national delegates introduction and held another meeting with Omniamed to talk about how they can help the EHA

Sigmund Brauer proposed to use their secretariat and to create a project to train the physicians

AMSTERDAM (25th-26th) - TEVA

ERT participated in Improving Health, Global Patient Advocacy Dialogue meeting
What was achieved during March (Washington DC) Meeting.

ERT Participation as member of the Steering Committee
Improving Health, Global Patient Advocacy Dialogue meeting
Talk to Teva "New engagement campaign "
ERT Participation as member of the Steering Committee

OCTOBER

MADRID (4th 5th) - AEPAC

Day 1: Congress of patients- Minister of Health
Platform of Spanish Patient Organisations (POP)
Where does the health system go?

Day 2: Congress of patients- Platform of Spanish Patient Organisations POP.
Mechanism of the AEMPS (Agencia Europea de Medicamento y Productos Sanitarios)

ZURICH (10th) - Novartis

Media Advisory Board Novartis

Taking the Headache out of migraine communications

ERT made a presentation to relevant head of Newspapers, Magazines and Blogs.

Mannheim 14th - Novartis

Migraine Science Day 5 hours of virtual Hybrid Standalone meeting in two sessions: the first one across Europe and the second one across Germany, Canada, and Latino America.
ERT Presentations about the Burden of living with Migraine.

Dublin (5th – 17th) – EPIS – European Patients Innovative Summit.

Development of a new HUB with National organizations + 1 central HUB in Dublin. ERT was in charge of presenting the programme of the day.

Valencia (26th – 27th) – TINA Training initiatives for neurology advocates

ERT coordinates EFNA’s workshop in Valencia. The day before, ERT hosted the Working dinner with neurological Spanish Organizations.

On the following day, the workshop presented by ERT took place at Campus Diversia, Valencia, where 30 different associations from Spain attended the Training in HTA and Communication skills workshop where Denis Costello made a presentation on “How to improve your presence in social media”.

NOVEMBER

Amsterdam (21st – 22nd) – TEVA

ERT, PR, KT, OS AND IC attended the CH SIG meeting and CH SIG F2F Meeting with TEVA : discussion about Enforce Trial and engagement to participate.

Enforce Trial discussion and engagement to participate.

Rome (29th) – Board Meeting

ROME (30th) – Novartis

EHA Multi stakeholders meeting :workshop on “Enhancing migraine services and access to Appropriate Medicines”and positive campaign brainstorming teamwork.

DECEMBER

Rome (1st – 3rd) EHA Booth at EHF’s 11th Congress

EHA 2017 Communications at a Glance

379 Likes on Facebook

910 followers in twitter

126 Newsletter subscribers

FULL MEMBERS (25)

- 1. Austrian Self-Help Group (KOPFEWPH)**
- 2. Belgian Migraine Association**
- 3. Hellenic HEadache Alliance**
- 4. Migraine Action Switzerland**
- 5. Servian Migraine Association**
- 6. Migraene & Hovedpineforeningen**
- 7. The Danish Trigeminal Neuralgia Association**
- 8. Migraine Association of Finland (Suomenmigreeniyhdistys)**
- 9. French Association against CH (Association Française contre l'aglie Vasculaire de la Face)**
- 10. Federal Association of Cluster Headache self-help groups (Bundesverband Der Clusterkopfschmerz-Selbsthifegruppen-CSGe.V.)**
- 11. Headache Foundation (Stiftung Kopfschmerz)**
- 12. Migräneliga**
- 13. Icelandic Migraine Association (Migrensamtokin)**
- 14. De Migraine Association of Ireland**
- 15. Alleanza cefalalgici**
- 16. Dutch association of Headache Patients (Hoofdpijnnet)(The Netherands)**
- 17. Romanian Headache Society (Asociatia "Headache Society" România)**
- 18. Russian Headache Association (RHA)**
- 19. Asociación española de pacientes con Cefalea (AEPAC)**
- 20. Sweden Headache Federation (Huvudvärksförbundet)**
- 21. Associazione Cefalea Tizino**
- 22. Ouch UK**
- 23. The Migraine Trust**
- 24. Migraine Action**
- 25. Polish Headache Association**

PROVISIONAL MEMBERS (2)

- Ouch belgium**
- Headache Norway (Hodepine Norge)**

Thank you for joining the EHA in 2017, the journey continues in 2018!