EUROPEAN HEADACHE ALLIANCE

# Annual Report 2016/2017

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Elena Ruiz de la Torre, President, Spain
Paolo Rossi , Vice-President, Italy
Pam Watson, Secretary, UK
Patrick Little, Treasurer, Ireland
Marja-Leena Kinnunen, Member, Finland

# LETTER FROM THE PRESIDENT

Dear All,

As you all know, the European Headache Alliance (EHA) is a non-profit, patient umbrella group, which was launched in 2006. Since then, the Alliance has grown to represent patient groups from all across the continent.

Together with our partner organisations, EHA voices the views and concerns of headache patients across Europe. Our aim is to promote awareness and understanding of migraine and other primary headache disorders and seek improved access to appropriate diagnosis and treatment for all.

2016 was a busy year as EHA President, representing EHA at several high profile meetings resulting in deepening relationships with European Federation of Neurological Associations (EFNA), European Headache and Migraine Trust International Congress (EHMTIC), European Brain Council (EBC), Societal Impact of Pain Symposium (SIP), European Headache Federation (EHF) and European Academy of Neurology (EAN). Besides, EHA became a member of International Association of Patient Organisations (IAPO). I hope that the patient voice will long continue to be heard throughout the medical and scientific community as EHA continues to go from strength to strength.

It has given me great pleasure to see the patient voice included in more and more activities and we are being taken seriously as key partner. EHA is recognised and respected amongst those ordering priorities. A lot of time and energy has been devoted to developing and nurturing relationships with other stakeholders in the field.

There are so many things going on at this moment and I would like to share with you all the information as you can understand how important is this year 2017 for the Patient´s Organizations.

This year represent for us many wonderful opportunities to widen the network of EHA and strengthen the collaboration with our partners, medical, scientific organizations and industry.

As you all know, several new treatments for Migraine are coming to the market and quite a lot of actions, activities and projects for Patients are now starting to be implemented at European and International level. EHA is being the Patient’s voice representing all our interests.

I would like to thank all of you, who have shared their time and talents in service of all those affected by headache disorders. EHA is fortunate to be the recipient of so much voluntary effort to raise awareness of a condition that is misunderstood, under-diagnosed, under-treated and mismanaged.

I look forward to seeing EHA grow more and more, gaining new member organisations and continuing to forge new partnerships.

With best wishes and looking forward to seeing you soon in Seville.

Elena Ruiz de la Torre

Elena Ruiz de la Torre, EHA President

# MAIN ACTIVITIES 2016-2017

## General Assembly 2016

The General Assembly took place on the 24th February in Brussels and coincided with an event in the European Parliament, Brussels to which all EHA member organisations were invited.
The General Assembly took place afterwards at the Aqua Hotel and It  was followed by a celebratory dinner marking the 10th anniversary of EHA.
Three membership applications were accepted  from Greece (Hellenic Headache Alliance), Germany (Migraenliga) and Switzerland (AssociazioneCefalea Ticino).

## Cluster Headache Day

Cluster Headache Day took place on 21st March 2016 with people living with cluster headache posting photos and stories on social media drawing attention to the disorder. Great support and online activity was organised by European Cluster Headache Groups, which resulted in people around the world sharing their photos online.

The lunchtime event, which was held in conjunction with the European Headache Federation, highlighted Cluster Headache – 'One of the worst pains known to man'. MEPs (5 participants including Helga Stevens who will hosted the second edition in 2017), EHA board and media representatives were invited as well as representatives from other neurological associations. Speakers included Nessa Childers MEP (who hosted the event), Audrey Craven (EHA), Dimos

Mitsikostas (EHF), Paolo Martelletti (EHF), David Vodusek (EAN) and Steve Verbruggen (Belgium patient) who gave a moving account of living with cluster headache. The event officially launched the first ever Cluster Headache day on 21st March.

### European Federation of Neurological Associations (EFNA)

As an active member of EFNA, EHA was represented at several EFNA events throughout the year, notably the Brain, Mind and Pain MEP Interest group European Parliament session on ‘Neurological and Chronic Pain Disorders at Work’ on 24th February in the European Parliament. The event discussion resulted in a Written Declaration, launched in autumn 2016 for MEPs to sign. EHA member organisations were asked to support the Written Declaration by contacting their MEPs and encouraging their members to do so also to obtain the necessary number of MEP signatures by the deadline.  Migraine was also used as an example of patient involvement in research at the following event in June 2016. Further details can be found on www.brainmindpain.eu

EHA was represented again at the EFNA Training Initiatives for Neurology Advocates event in Dublin in October 2016. Audrey Craven, Elena Ruiz de la Torre, Pam Watson, Patrick Little and attended the training event. As EFNA Past-President, Audrey Craven was involved in the event planning and facilitated an interactive workshop and moderated the final panel discussion. EHA General Manager was invited to speak on migraine as an exemplar for setting the scene for the interactive workshops.

Event presentations are available on:
https://www.dropbox.com/sh/72ftqfpfwamird5/AABqA3DbNK7Vsk7YCm0rQADfa?dl=0

Audrey Craven was awarded a Lifetime Achievement Award at the EFNA Advocacy Awards. Eveline Sipido of the European Academy of Neurology presented the award at a ceremony in October in Dublin.

## European Academy of Neurology

The 2nd European Academy of Neurology Congress took place in Copenhagen in May 2016 where Audrey Craven co-chaired the session 'EFNA Open Dialogue: "Let's talk about sex, sleep and stress'.

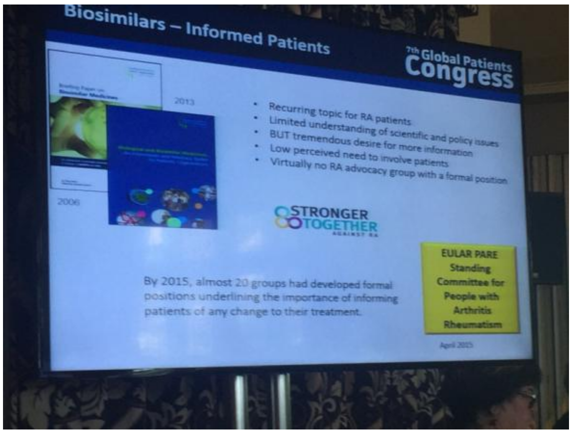
## European Patient Federation- Societal Impact of Pain Symposium (SIP)

European Pain Federation EFIC® and sponsor by the pharmaceutical Grünenthal GmbH had created in 2010 SIP , an international platform created as a joint initiative.
EHA was invited to attend the symposium on the "Societal Impact of Pain" (SIP) which took place on 23rd and 24th May 2016 in the European Parliament and Concert Noble in Brussels during which

represented EHA in a working group on ‘Pain, rehabilitation and reintegration of workers in the working force.’ Following this participation, EHA was invited to be a member of the steering committee for the next symposium scheduled for 8th and 9th June 2017 in Malta.
Further information can be found at https://www.sip-platform.eu

### International Association of Patient Organisations (IAPO)

EHA became a member of IAPO in 2016. Elena Ruiz de la Torre attended the 7th IAPO Global Patients Congress in June 2016 and started a new relationship with this organization.
New plans for future actions with the WHO and the table (dissability) that has moved migraine from 12 position to 4th.
Migraine is now classified as the 4th most disabling disease by the WHO Global Burden of Disease Study. The jump from to this position demonstrates an urgent need for action in the headache field.



Biosimilars – Informed Patients

7th Global Patients Congress

2013

- Recurring topic for RA patients
- Limited understanding of scientific and policy issues
- BUT tremendous desire for more information
- Low perceived need to involve patients
- Virtually no RA advocacy group with a formal position

2006

STRONGER TOGETHER AGAINST RA

By 2015, almost 20 groups had developed formal positions underlining the importance of informing patients of any change to their treatment.

EULAR PARE Standing Committee for People with Arthritis Rheumatism

April 2015

### European Migraine Day of Action [EMDA]

European Migraine Day of Action was held on September 12th 2016 with the theme ‘New and emerging therapies for headache disorders´. EHA wants to ensure that patients interests are represented as new and emerging therapies become available.

EHA is very concerned about the increasing number of people living with chronic headache (more than 15 days per month) and the high number of children suffering with migraine (1 in 10). Many people will self-treat with over-the-counter painkillers, which can lead to Medication Overuse Headache.

### European Headache and Migraine Trust International Congress (EHMTIC)

EHA board members and General manager attended the EHMTIC Congress in Glasgow (September 2016), where EHA had a stand in the exhibition area. A poster authored by Dr Paolo Rossi on the ‘What’s Under the Hat?’ public awareness campaign was presented during the congress. Elena Ruiz

de la Torre co-chaired the public day along with Wendy Thomas. Several important business meetings took place, a key one being a ‘Corporate partners’ meeting to which EHA invited industry representatives to present EHA projects for 2017
The board meeting was celebrated before the Congress. The top line priorities were discussed following the launch of preparation of a strategic planning.
The EHA Board highlight the need of:

- Partnerships development with science industry HCP, policy makers and other organisations.
- Supporting existing members, gathering and sharing of best practice.
- Member Development – recruiting new members
- Scoping of material to create toolkits / library of videos, leaflets etc.
- Development of new projects in research, education, training...

### European Brain Council- VoT project

EHA was invited to be a member of a working group on headache in the Value of Treatment Study, which was launched at a kick off meeting in 2015. This study builds on the Cost of Brain disorders study to explore the effectiveness and sustainability of a coordinated healthcare model by analysing the socio-economic impact of patient interventions. EHA contributed to the working group representing the patient voice, ensuring that the real-life experience of someone living with migraine was included in the patient journey aspect of the study.

### Educational programs

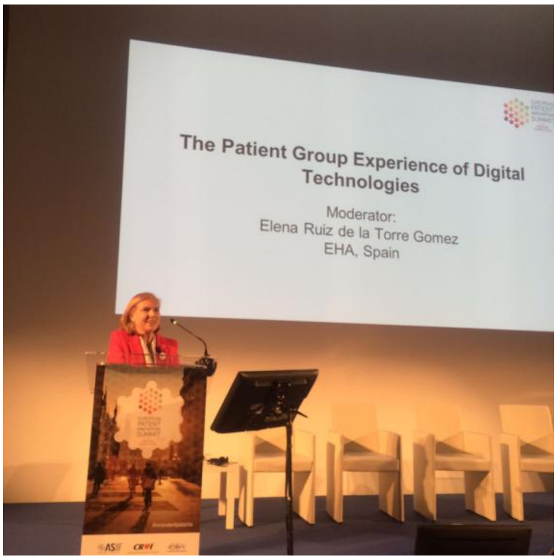
Elena Ruiz de la Torre participated in several Novartis events for the Neuroscience Franchise with more than 30 participants in Basel and with the European General Managers in Barcelona to share their personal experience of the impact of living with migraine.

Elena Ruiz de la Torre also attended Teva internal event. "Improving Health, Global Patient Advocacy Dialogue".

Audrey Craven participated in the Novartis Staff Family Day in Basel on 10th Sept 2017

### European Patient innovation Summit

Several EHA members (UK, Ireland, Switzerland, Spain, Italy, Germany, Finland, Russia, Netherlands) represented headache disorder patients at a Novartis ‘European Patient Innovation Summit’ in Milan in October 2016. The event covered 8 disease areas and was attended by 180 delegates.



# FUNDRAISING

## Fundraising (otro apartado) laboratorios & Otras organizacions

Relationships with industry stakeholders (Novartis, Teva, Grunenthal, Medtronic, ATI Spg, Eli Lilly, Allergan, eNeura, ElectroCore, CoLucid, Curelator) to obtain ongoing support to sustain EHA.

## Germany Annual Report

- Participation to the fair MEDIZIN 2016 in Stuttgart
- EHA-GA in Brussels
- Participation to the Day of Rare Diseases (Feb. 28th) in:
  - Essen
  - Flensburg
  - Aachen
- Changes in our Clusterheadache-Comptence-Centers
  - One CCC moved from Bayreuth to Bad Neustadt/saale
  - Bochum was splitted in two parts: At Dr. Studes surgery is now the ambulant care an at University-Clinic „Bergmannsheil" the stationary care
  - New CCC in Berlin (the ninth-one, further are in preparation)
- Meetings with MEPs Sabine Verheyen and Dr. Peter Liese in Aachen and Brussels
- Public patient-events in
  - Seesen
  - Halle/Saale
  - Jena
  - Freiburg
- Participacion to ACHSE (alliance of chronic rare diseases), BAG (federal association of self-supporter groups) general assemblies,
- Entered as a member to EURORDIS (European Organisation for rare diseases)
- Several changes in our national network of contact-persons (some new-ones; two quitted their job, one died)

## Switzerland Annual Report

**ACTIVITIES 2016:**

- Information on socials media , organization of information events.
- Awareness of migraine and headache and its impact on daily personal, family, social and professional activities.
- Information about optimal treatment strategies.
- Advising about diet, brochures ecc.
- Advising about exercises, activities of daily life, relaxation , meditation, yoga.
- Management 4 support Migraine group on Facebook
- Management self-help group
- Collaboration with doctors for projects and scientific studies

**COOPERATION WITH MEDIA:**

- Information in popular magazines, radio programmes, interviews, educational materials;

**COOPERATION WITH PHARMA COMPANIES**

- Materials , handouts for patients and doctors.

## Ireland Annual Report

- Working in 16 different regional areas (out of a total of 26)
- 11 Migraine Awareness Campaigns
- 13 Information stands at health events
- 15 Regional Information/Self Help group meetings
- 11 Public Seminars
- 4 Health Professional events
- 1 Migraine and Children event
- 9 presentations/information events in workplaces
- MAI Website now averaging 8000 hits per month
- Short-listing of our Annual Report for the Ireland Good Governance Awards
- Our President Audrey Craven receiving the Lifetime Achievement Award at the EFNA Awards
- Extensive coverage in national and local media- 40 articles in national newspapers; 53 in local press; 4 items on national radio; 20 on local radio and 2 items on national breakfast television.
- 81,630 visits to our website
- 1,887 Facebook followers; 2052 followers on Twitter
- 1,808 subscribers to our monthly E-Zine
- 1,300 calls to our Helplines
- Launch of new migraine book – ‘Not Just Another Headache’
  €15 + postage http://www.migraine.ie/product/migraine-book/

  Written by experts, this book describes the role of the GP, nurse, pharmacist, pediatricians, physiotherapist and psychologist in the treatment of migraine. It advises about the management of migraine in the home, at school, in the sports centre and workplace. It gives crucial information from neurology and from specialist migraine clinics about pain management, migraine in children and adolescents, and the legislation to support people in educational and employment contexts.
  A book that should be read and shared with family, friends, colleagues or anyone who would welcome the understanding that migraine is not just a headache.

## Denmark Annual Report

### Trigeminal Neuralgia

- Trigeminal Neuralgia is a relatively rare suffering which affects somewhere between 1 and 2 ‰ of the Danish population. The suffering is characterized by very strongone-sided attacks of pain in the face, lasting a few seconds up to 2 minutes, but repeating itself every few minutes. Further to the pain attacks, a lasting pain is present in around half the patients. The suffering typically comes in a period of some months, then reduces or disappears for some months, only to repeat itself again.
  Untreated, the suffering is of the same severity as cluster headache, and treated, the patients are heavily drugged. Both sufferings are often referred to as “Suicide Headache”.

### The Danish Trigeminal Neuralgia Association

- The activities of the Danish Trigeminal Neuralgia Association have in the last year comprised the following main activities:

**Support to patients contacting the organization.**

- The suffering is not sufficiently known even by many neurologists, and as a consequence we offer telephone and/or email support to patients (and/or relatives) contacting us – naturally at the same time suggesting them to become a member of our organization.

**Follow up on questionnaire filled in by new members**

- People joining our organization are requested to fill in a questionnaire on their medication and other experiences with the suffering (including alternative treatments possibly tried).
- These questionnaires are used for feedback to the members, e.g. commenting on the medicines they have been prescribed (if typical medication hasn't been prescribed), and advising them on the specialized doctors to consult.

**Information-programme towards dentists**

- The pains of trigeminal neuralgia patients can be difficult to determine, and many patients consult their dentists to see if there is a dental explanation, many times resulting in extraction of teeth or other dental treatments without effect. We therefore have collaboration with the Danish Dental Practitioners Association, and have articles published in their Magazine for dentists.

**Information meetings for Trigeminal neuralgia patients**

- We arrange meetings with participation of key members of our organization in different locations of the country, and reach a large proportion of the members in the area who can exchange their experiences and learn how other TN-patients live with their trigeminal neuralgia.
- We further support local patient groups who arrange meetings with the same purpose (without necessarily having participation from the formal participants of our organization). These meetings are advertised over Facebook, and also prove to be a source of new members of our organization.

**Collaboration with the Danish Headache Centre**

- We have an active collaboration with the Danish Headache Centre, who for the last several years has had a PhD student researching within Trigeminal Neuralgia questions.
- Also the Danish Headache Centre has started a specific master degree education within headache disorders, a study, which our organizations is supporting though some of the moneys collected by our organization.

**Our Member magazine**

- Three times a year we issue our membership magazine, with patient histories and with news on the research and treatment with Trigeminal Neuralgia and associated sufferings.

**Collaboration though "Hovedpinesagen".**

- Though a formal collaboration with the Danish Migraine and Headache Association named "Hovedpinesagen", we have thought to spread emphasis on headache disorders, and to seek more attention hereto.
- The major event the last year was a joint effort to arrange a hike along the historic path of an ancient Danish military road "Hærvejen", with attempts to spread the news over TV and newspapers, in order to seek support for people suffering from headache disorders.
- Unfortunately the event attracted only around 75 participants, and the attempt to arrange money collections related to the event had very little success.

# EHA MEMBERS ANNUAL REPORT

## Itally Annual Report

### Advocacy

- AICe succesfully advocated the CH patients' right for the reimbursement of oxygen. A negotiation with the regulatory agency has been opened to remove the restrictions actually included in the national legislation.
- AICe advocated the introduction of chronic migraine and chronic CH into the new "elementary level of assistance" regulatory book recently released by the Ministry of Health
- AICe regional coordinators assisted their members in every request for medico-legal protection
- AICe advocated the introduction and spreading of the generic form of sumatriptan vials obtaining indirectly the reduction of the cost of the drug

### Financing

- AICe is supporting with OuCH Italy independent research on the effectiveness of ketogenic diet for the prevention of Chronic Cluster Headache

### Information/Education

- Information/education is regularly released on traditional and new media channels (a citizen's corner has been activated on a peer reviewed international journal, Functional Neurology, where EHA publications have been guested; AICe publishes every month an e-journal entitled Cefalee Today; the website is continuously updated and our members are very active on the social media)
- A partnership has been estabilished with editorial groups for regular educational articles distributed to a large number of health operators (nurses, pharmacists, GPs)
- AICe has actively participated to the EHA What's Under The Hat Campaign by dedicating a special section of its website to the event and collecting a large number of patients' narratives. The initiative has been presented in offline activities as well. The patients' contributes have been qualitatively analyzed by our physician and psychologists. The results of this have been presented to the Migraine Trust and the National Congress of the Italian Society for the study of Headache
  (Here we report the abstract of the above mentioned study
  *"What's under the hat?" Examining patients' stories about headache. A qualitative research of implementing a public awareness campaign*
  *Background*
  *"What's under the hat?" a headache awareness story-telling campaign launched by the European Headache Alliance, aims a) to increase awareness of and compassion for the real and everyday impact of headache disorders amongst the general public; b) to help those affected to know that they are not alone and that headache disorders are treatable*
  *Aim of the study*
  *We evaluated if the stories posted online reached campaign objectives*
  *Methods We conducted a qualitative analysis of patient stories posted during the first 4 months of the campaign and asked a selected team to rate the stories on their appropriateness, appeal and clarity.*
  *Results 30 stories were analyzed. Most patients described the dramatic impact of headache on their working and private life. Predominant feelings portrayed were anger, unhappiness and resignation. A lack of empathy from social groups and colleagues was reported. Appropriateness and clarity of patients' stories were rated as 'very good' whereas their appeal was scored as 'sufficient'.*
  *Conclusions*

*Stories posted online reached the campaign aims, representing a potential powerful educational tool on the burden and impact of headache disorders,. The hopelessness evident in the stories however may wrongly suggest that headache disorders whilst common and disabling cannot be treated. )*

**Networking**

Productive partnership have been estabilished with

- OuCH Italy
- Cittadinanza Attiva (Alce applied for the best practice 2017 with an EHA supported project entitled “lessons from the expert patients”)
- SISC (italian society for the study of headache)
- Academic Institutions (Pavia University, Sapienza University Rome)

## Netherlands Annual Report

- We expanded our regional infrastructure; organized more meetings of headache patients all over the country and got more volunteers.

- We changed our name into Hoofdpijnnet , which is more modern than Dutch association of headache patients. A lot of our members don’t want to see themselves as patients.
-
- We organized a telephone round among our members with the request for a rise in their yearly contribution. A call center with employees over 55 years old made the calls. This cost about 10.000 € and resulted in a return of the same amount. But the costs are paid only once, while the return is yearly.

- We continued to promote the new Migrainefund, but the results in fundraising are small yet.

- We expanded the activities of our working group Youth and migraine with new young volunteers.

- We merged with the Dutch Cluster Headache Foundation, so now we are the only patient organization in the field of headache in the Netherlands.