



STRATEGIC PLAN 2017-2020

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What is the European Headache Alliance?

The European Headache Alliance (EHA) is a non-profit patient umbrella group, representing over 20 headache disorder patient organisations across Europe. EHA was created to speak on behalf of and to advocate for the rights and needs of the 80 million people in Europe living with a headache disorder.

Vision

A European society which understands and recognises headache disorders, and health systems in which patients are well informed and have equal access to appropriate diagnosis and treatment.

Mission

The European Headache Alliance will:

- Give visibility to migraine, cluster headache and other headache disorders
- Voice the views and concerns of headache patients across Europe
- Inform and influence policy makers on headache disorders
- Work in partnership with other relevant organisations to promote common aims and goals
- Co-ordinate and add value to the efforts of national advocacy groups in Europe
- Provide hope for those affected by headache

Aims

EHA aims to:

- Promote awareness, understanding and recognition of migraine and other primary headache disorders as real and complex neurological disorders.
- Improve patients' access to appropriate diagnosis and treatment.

Values

EHA strives to be open and accountable in all of our operations. We represent our members in a professional and respectful manner, valuing the contributions of each. We endeavour to make EHA sustainable in the longer term.

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Current Landscape



Elena Ruiz de la Torre, EHA 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
June 2017

Strategic Priorities

The strategic priorities outlined below must be underpinned by a strong and united network of headache disorder patients. In addition, we recognise that we are joined in our work by patients, clinicians and representatives of the pharmaceutical industry. We each have our part to play, sharing our specific expertise, in improving the lives of patients, and we each gain from our mutual cooperation. EHA will encourage an holistic approach to the understanding of headache disorders, knowing that patients will benefit from the input of many disciplines.

EHA hopes to see a transformation in the experience of headache patients. In 10 years, by 2027, we would like to see:

- Equal access to treatment and care for all headache patients in all EU countries.
- Equal consideration in the workplace for headache patients, with flexibility shown by their employers and the elimination of stigma, allowing employees with headache disorders to thrive at work. Implement better working conditions for affected people by severe migraine or cluster headache.
- A broad general understanding of headache disorders throughout society.
- People affected by headache disorders appreciated for their abilities and contribution in the workplace and to society.
- Decreased chronification by educating patients on prevention and self management.

EHA will evaluate its performance on each of these strategic priorities areas using the indicators outlined in each section. A review will take place at the midpoint in early December 2018 to assess progress and adjust as required.

EHA will be satisfied with progress if we have met the performance indicators outlined for each action area by 2020.

1. INCREASING VISIBILITY AND CREDIBILITY

- Ensuring a high-level presence and constructive input at relevant health events, on behalf of our membership and all those affected by headache disorders.
- Developing internal and external communication tools and strategies including awareness campaigns – with a focus on new and social media.
- Working to ensure that European Migraine Day of Action and the European Cluster Headache Day become more visible, awareness-raising days. There should be an annual EHA event, for each, at European/international level. This should be supplemented by the increasing involvement of national organisations, with growing multi-stakeholder endorsement and participation.
- Positioning EHA as the ‘go-to’ organisation for all relevant stakeholders seeking a patient perspective on headache disorders in Europe.
- Reviewing and updating EHA’s governance policies and procedures – including the roles and responsibilities of Board Members – to ensure that we work with a transparent and ethical framework, maintaining our status as a responsible and independent NGO.

Evaluation

- EHA will have implemented an effective Communications Strategy, which focused on both internal and external communication.
- *EHA will organize workshops on how to better communicate and how to make the invisible, visible and other important topics to the national advocates.*
- *EHA will provide the needed toolkits to its national members to be able to provide the same qualified and rigorous information to all the EU affected people.*
- EHA will have become positioned as the ‘go-to’ organisation for all relevant stakeholders seeking a patient perspective on headache disorders in Europe
- Understanding of headache disorders will have improved across Europe.

2. DEVELOPING AND DISSEMINATING EVIDENCE

- Coordinating, supporting and/or disseminating headache patient-relevant research and opinion to the pool of data which highlights the impact and burden of headache disorders.
- Using this data to advocate for headache disorders to become a political priority via annual activities and meetings at the EU Institutions, and disseminating to our members for use at the national level.
- Providing headache patient testimonies and perspectives to conferences, debates and other events.
- Using evidence as effectively as possible so that change is the outcome for patients.

Evaluation

- EHA will have chaired the Global Burden of Migraine Patient Survey, as well as the Comorbidity of migraine and central sensitivity syndrome survey of patients throughout Europe. The results of both surveys will have been disseminated via our online and offline communication channels.
- EHA will have gathered 10 patient testimonies from patients throughout Europe via one to one interview and disseminated these via our communication channels.
- Members will have been encouraged to cascade all data gathered by EHA via their own communication channels.
- *EHA will participate in the publications of the results of the surveys*
- *The new EHA website includes an active participation of the national members*

3. ENSURING ACCESS

- Working with our partners to educate those affected by headache on the topics of pricing, access and reimbursement.
- Empowering headache patient advocates to be part of these decision-making processes.
- Campaign to policy and decision-makers both in the EU and at the national level for the reimbursement of any new migraine medications with positive, patient-relevant outcomes.
- Partner with other organisations who are actively advocating on access issues.

Evaluation

- EHA will have worked with partners to deliver effective education campaigns for patients advocates on pricing, access and reimbursement.
- EHA will have worked with partners to provide information and training through workshops and the EHA magazine to patient advocates, developing their skills in areas relevant to policy making.
- EHA will have worked with partners to ensure that new and existing migraine and cluster headache medications and treatments with positive, patient-relevant outcomes are made widely available in all health systems across Europe.
- EHA will have worked with partners to ensure that new and existing migraine and cluster headache medications and treatments with positive, patient-relevant outcomes are reimbursed in all health systems across Europe.
- *EHA will have repeated the Access to Care Survey among its members looking for the measurement of the access and satisfaction of the affected people.*

4. WORKING IN PROACTIVE PARTNERSHIP

EHA will continue its programme of external outreach and representation with:

- Other umbrella health and social NGOs and networks (including the European Federation of Neurological Associations, European Patients' Forum, International Alliance of Patient Organisations, Active Citizenship Network, etc.) – ensuring that the issues of those affected by headache disorders are represented in these fora; whilst sharing best practice, encouraging cooperation and reducing duplication of effort.
- Relevant EU-level Health Professional Organisations active in the area of headache disorders (including the European Headache Federation, International Headache Society, European Academy of Neurology), ensuring the headache patient perspective is central to the research and education agenda.
- Strengthen the relationship with the Directorate General for Health and Food Safety at the European Commission, developing a plan for EHA to be included in policy events, have increased access to key personnel, and working to ensure DG Sante understands the importance of headache disorders for European patients and health systems.
- Building relationships and working transparently and ethically with our industry partners with whom we share mutual interests in relation to research, the development of and access to new treatments for the patient community we represent. However, EHA must ensure that we are proactively setting the agenda which is shaped by our members.
- EHA will also work more closely with our membership, offering our support in access to treatment and communications, to ensure that we are adding value to their work nationally – through ongoing consultation and annual meetings. EHA will also reach out to prospective new members to ensure as wide a representation as possible in this sector.

Evaluation

- EHA will have maintained close working relationships with EU-level and international health professional organisation through attending and participating in each other's events and contributing to each other's projects.
- Patients will have been active participants in and contributors to events organised at EU-level relating to headache.
- EHA will have maintained working relationships with industry partners, keeping them informed of the symptoms experienced by patients, as well as the impact of headache on patients' lives.
- EHA will have established new relationships with industry partners.

- EHA will have met regularly and consulted closely with member organisations at Board meetings and General Assembly meetings, as well as having travelled to meet with members in their own country.
- EHA will have developed relationships with patient organisations for headache patients in countries which were not represented in EHA's membership, encouraging them to join EHA.
- EHA will have developed relationships with patient representatives in countries which did not have organisations for headache patients, particularly focusing on countries in Eastern Europe. EHA will have provided guidelines and support to encourage the formation of new patient organisations.
- EHA will try to strengthen the patient organizations of the Scandinavian countries.
- EHA will have increased its membership, particularly in Eastern European countries.
- EHA will have established new partnerships with other organisations active in the field of patient's rights and health policy.

5. EMBRACING THE INNOVATIVE AND THE POSITIVE

- Continue to partner with those who are producing novel ways to better diagnose and manage headache disorders.
- Actively engage with new, more effective and efficient ways of working.
- Ensure that EHA messages in relation to those affected by headache disorders have a positive tone – where appropriate – to provide a more accurate and holistic representation of patients. Headaches have a major impact on our lives, but we cannot be defined only by the disorder we experience.

Evaluation

- EHA will have reached out directly to researchers and industry partners who were developing new approaches to headache diagnosis and treatment.
- EHA staff will have attended workshops, webinars and training events to develop more efficient ways of working.
- EHA will have adopted GSuite and other IT tools to make exchange of information between staff and membership more efficient.
- EHA will have monitored all its communications to ensure a positive tone was maintained, where appropriate. EHA will have worked with its members to create a consistent approach in this regard.
- EHA will have delivered a communications campaign with the specific goal of reflecting a holistic view of headache patients as active members of society, not only as patients affected by headache disorders.