



Aim, objectives and key messages

Aim

The aim of the 2018 **hae day :-)** is:

To raise awareness of Hereditary Angioedema (HAE) among the general public and medical community in order to create an environment in which there is better care, earlier and more accurate diagnosis and knowledge that HAE patients can lead a healthy life.

We believe that the **hae day :-)** is a fantastic opportunity to unite and mobilize everyone from the national HAE organizations and partners to members of the general public across the world to coordinate all of our efforts in raising awareness of HAE.

As relatively few people per country have HAE, we know it can be difficult to make your voice heard in a crowded media environment, a busy political agenda, and even within the clinical community. We believe that by acting together, with one voice on one day, we will have a better chance of securing the engagement of the general public, the medical community and other key audiences.

The **hae day :-)** provides a focal point in 2018 around which organizations will have the opportunity to generate local awareness with the backing of a global campaign.

Ultimately, we want more people to understand the significant impact of HAE for those who live with this disease, and to support the improvement of HAE diagnosis rates and secure effective care, by increasing awareness of its symptoms amongst the public and the medical community.

The 2018 **hae day :-)** will also help to raise the profile of HAE organizations amongst those patients who have already been diagnosed. It is vitally important that patients and families affected by HAE know where they can turn to for help, advice and support when they need it.

Finally, with our organizations having a more established profile within the HAE community and beyond, it should help give us more leverage with politicians and the media when striving to improve the lives of the people we represent.



In summary, the 2018 **hae day :-)** seeks to:

- Unite and mobilize the national HAE organizations to coordinate efforts for raising HAE awareness
- Provide an international 'hook' which organizations can all utilize to focus activity and subsequently better secure the engagement of the general public and the medical community
- Increase awareness of the significance and impact of HAE as a rare disease amongst the general population
- Support the improvement of HAE diagnosis rates by increasing awareness of its symptoms, and providing information about how to access appropriate management/treatment options.

Key objectives

People and patient organizations from around the world are supporting the global **hae day :-)** on 16 May 2018.

The **hae day :-)** 2018 intends to:

- Support better care and an earlier and more accurate diagnosis for HAE patients
- Engage the general public and the medical community
- Raise funds for further national and international initiatives
- Strengthen the voice of patients, uniting HAE patient organizations globally.

Key messages

Key messages are the core of any communications activity. They are the messages we want our target audiences to hear and remember about the **hae day :-)** and HAE.

Below are the key messages we have developed for the global awareness day. These are for everyone to use in their communications but naturally you may tailor them to make them most relevant to your country. For example, under key message no. 2, adding in the number of people who may have HAE in your country and the number of diagnosed HAE patients in your country.

- 1) The aim of the **hae day :-)** is to raise awareness of Hereditary Angioedema (HAE) among the general public and medical community in order to create an environment in which there is better care, earlier and more accurate diagnosis and knowledge that HAE patients can lead a healthy life.
- 2) HAE is a rare disease that affects about 1 in 10,000 to 1 in 50,000 people worldwide. HAE causes swelling to various parts of the body, resulting in pain and disfiguration, and can be life threatening in the case of throat attacks.



- 3) On average it can take about 13 years for a patient to be diagnosed with HAE as the symptoms are similar to those of many other common conditions such as allergies or appendicitis.
- 4) By the time HAE is diagnosed correctly, the patient has often seen a number of physicians, may have undergone unnecessary operations, and could have felt a major impact on his or her quality of life.
- 5) Patient organizations from around the world have come together to raise awareness of HAE on the sixth global **hae day :-)**, which takes place on 16 May 2018.
- 6) Log on to the **hae day :-)** website at www.haeday.org to show your support by adding your steps in the HAE Global Walk.

Internationally the 2018 **hae day :-)** coincides with patients, relatives, caregivers, and people from the industry walking part of the ancient pilgrimage *Jakobsweg* route through Vienna, Austria where the fourth HAE Global Conference is taking place 17-20 May 2018.

HAEi – the HAE umbrella organization for all national organizations around the globe – is active on a number of media platforms. Please feel free to follow the HAE development at

- www.haeday.org and www.haei.org
- www.facebook.com/haeday
- www.twitter.com/haeday
- www.youtube.com/haedaychannel
- #haegc18 (the HAE Global Conference in Vienna, Austria 17-20 May 2018)
- #haejakobsweg (the Jakobsweg Walk through Vienna, Austria 16-17 May 2018)

Your **hae day :-)** team