

[Insert organization logo and **hae day :-)** logo]

PRESS RELEASE

[insert date]

A global awareness day for a rare life-threatening condition

On 16 May 2019 patient organizations from around the world will come together to support the global awareness day for the rare life-threatening condition Hereditary Angioedema (HAE).

[Insert description of your **hae day :-)** activity with quote and information about group.

This is an example:

In the UK some 200 people will be taking part in a 24-hour walk-a-thon to raise awareness of HAE and support HAE patients. [Insert name] of HAE UK says:

"HAE patients often experience very poor quality of life, living in fear of their next attack. Through the annual **hae day :-)** we hope to educate more people in the UK about HAE so that patients no longer have to wait an average of 13 years for an accurate diagnosis and the right treatment. We are very grateful for the support we have seen so far – and we look very much forward to the **hae day :-)** that will take place at [insert place and time]."

hae day :-) aims to raise the global awareness of the potentially life-threatening disease HAE, to help ensure each and every patient receives faster diagnosis and the care they deserve to enable them to lead a healthy life.

[Insert any local statistics regarding HAE diagnosis and management]

"HAE is a rare genetic disorder that causes swelling to various parts of the body, and can be fatal when the swelling affects the throat due to the risk of suffocation", explains Mr.

Henrik Balle Boysen, Executive Vice President & Chief Operating Officer of HAEi, the international patient organization leading the day:

“Global awareness initiatives such as the **hae day :-)** are necessary in order to help patients receive faster diagnosis and care to manage the disease.”

As part of the awareness initiatives HAEi introduces “Support Family Testing” tools on the organization’s campaign website www.haeday.org:

“As HAE is a hereditary disorder, it is very important to have other family members tested. To help patients in this process we have developed two documents for patients and one for physicians”, says Henrik Balle Boysen.

HAEi is a global organization dedicated to raising awareness of C1 inhibitor deficiencies as HAE patients have a defect in the gene that controls a blood protein called C1-inhibitor, and therefore the disorder is also commonly referred to as C1-inhibitor deficiency. HAEi is a non-profit international network of presently 61 national HAE patient organizations spread across the globe.

“HAEi is established to promote co-operation, co-ordination and information sharing between HAE specialists and national HAE patient associations in order to help facilitate the availability of effective diagnosis and management of C1 inhibitor deficiencies throughout the world. Our purpose is to join the efforts and experience of the global HAE community to achieve optimal standards of care and treatment for all those patients affected by C1 inhibitor deficiencies”, says Mr. Balle Boysen.

[Insert local quote from medical professional. This is an example:

“We are delighted to support the global **hae day :-)** and hope that by increasing awareness of HAE symptoms people who might be unknowingly suffering from HAE will seek help”, said Dr. [name]:

“Helping to ensure that patients receive an accurate diagnosis and the right help to manage their condition most effectively is imperative in managing this debilitating disease.”]

[Insert local quote from patient. This is an example:

"I had never heard of the condition when I was diagnosed. Actually, I didn't find out I had HAE before 12 years after my first attack," said [insert patient name]:

"I hope that the **hae day :-)** means more people get to know about HAE, and feel motivated to talk to their doctor if they think that they may have this condition."

The main symptom of HAE is swelling of the skin, which doctors call "edema", occurring mainly in the face (e.g. lips, eyelids), although the extremities and genitals are often affected. Swelling of the internal organs, specifically the mucous membranes of the larynx, nose or tongue, is potentially life threatening as it can cause death by suffocation. More than 50 per cent of HAE patients will experience at least one attack of this type in their lifetime.

"Patients are frequently misdiagnosed because HAE symptoms often resemble those of more common conditions. Through the 2019 **hae day :-)** we hope to spread the word about HAE, so patients can receive an accurate diagnosis and appropriate medical care," Mr. Balle Boysen explains:

"We are very excited by the level of participation from the HAE national organizations across the globe and hope that the awareness day will make a real difference to lives of HAE patients in the future."

HAE places extraordinary strain on patients, often restricting their ability to lead normal lives. Untreated HAE patients can lose 100 to 150 workdays per year, if not more. Currently there is no cure for HAE, but treatment options are available to try and prevent attacks from occurring or to treat attacks when they do occur.

Various events are taking place across the globe in aid of the global awareness day. These include [insert information on local/national activity/activities].

The 2019 **hae day :-)** coincides with patients, relatives, caregivers, and people from the industry walking part of the *Camino Inglés* pilgrimage route in northwestern Spain.

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Notes to the editor

The primary 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 with better care, earlier and more accurate diagnosis and knowledge that HAE patients can lead a healthy life.

Spreading the word about HAE could be crucial in saving the lives of undiagnosed HAE patients around the world.

For more information:

For further information on HAE, access to patient case studies and clinicians or details about local activities taking place around the day, please contact **[insert name and contact details, e.g. phone number and email address]**.

- The official **hae day :-)**
 - Website at www.haeday.org
 - Facebook page at www.facebook.com/haeday
 - Twitter account at www.twitter.com/haeday
 - YouTube channel at www.youtube.com/haedaychannel
- Other sources
 - HAEi website: www.haei.org
 - **[Insert website of national organization]**