

(J) TEMPLATE “Letter to other rare disease or community groups”

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

[Please translate and adapt if necessary]

Dear [insert contact name],

I am the [insert role] of [insert organization name], the national patient organization for people living with a rare genetic disease called Hereditary Angioedema (HAE).

As a [insert reason for approaching this particular community e.g. as a group with an interest in rare diseases], we wanted to contact you. On 16 May 2018 patient organizations from around the world are coming together for the fifth time to support the global HAE awareness day **hae day :-)** and we wanted to firstly, let you know about our awareness day and secondly invite you to support our efforts in any way you feel you could.

The primary aim of the **hae day :-)** is to raise awareness of 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.

We believe that by acting together we can better secure the engagement of the general public and the medical community.

The **hae day :-)** provides us with a perfect opportunity around which to conduct awareness raising activities and we would be delighted if you would consider joining in [insert detail regarding your activity] or perhaps posting information about the **hae day :-)** on your website and sharing the details with your members.

If you would be willing and able to support and/or participate in the activity in any way we would be delighted. To discuss the opportunity further, please contact [insert name and contact details, e.g. phone number and email address].

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

(J) TEMPLATE “Letter to other rare disease or community groups”

- www.haeday.org and www.haei.org
- www.facebook.com/haeday
- www.twitter.com/haeday
- www.youtube.com/haedaychannel
- #haegc18 (HAE Global Conference in Vienna, Austria 17-20 May 2018)
- #haejakobsweg18 (HAE Jakobsweg Walk through Vienna, Austria 16-17 May 2018)

In this letter you will find more information on the 2018 **hae day :-)** and HAE. Many thanks for your time and we hope to speak with you soon.

Yours sincerely,

[Insert organization name]

[Insert name and role]

[Insert contact information, e.g. phone number and email address]

About hae day :-) and HAE

- The aim of **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.
- 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.
- 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.
- 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 their quality of life.
- Patient organizations from around the world come together to raise awareness of HAE on the global **hae day :-)** taking place on 16 May 2018.

[Insert pictures and patient story if available]