



Using social media

Social media such as Facebook, Twitter, Instagram, and LinkedIn are powerful vehicles for engaging with an audience, spreading knowledge and raising awareness. This section of the **hae day :-)** toolkit focuses on how you can use social media within your awareness campaign.

HAEi is presently on Facebook, Twitter, LinkedIn, Instagram, YouTube and will be issuing updates leading up to **hae day :-)** as well as on the awareness day itself. You will find us here:

Facebook	www.facebook.com/haeday
Twitter	www.twitter.com/haeday
YouTube	www.youtube.com/haedaychannel
LinkedIn	www.goo.gl/2LHcUx
Instagram	www.instagram.com/haecamino

First of all, please visit our sites and “like”, “tweet”, “share” or whatever you find appropriate – just keep the information flowing.

If you already have social media sites set up for your own organization, please maximize their use prior to **hae day :-)** and obviously around 16 May 2019.

If you are not already a social media user, please consider setting up a site for your organization, for instance on Facebook or Twitter. Here you can put updates regarding **hae day :-)** and the activities you will be running for this year’s global awareness day. However, please do so well in advance of the day in order to maximize the reach of your communications efforts. Also, please ensure regular updates so that you continue to engage with your audiences.

In the case of **hae day :-)** the main goal of social media communications is to engage the audience via posts, tweets, status updates, likes, re-tweets, sharing, followers, and more. Therefore, you should encourage social media users in your organization and professional as well as personal network to participate as much as possible and contribute to a groundswell of support around the awareness day.



Leading up to **hae day :-)** your organization should post status updates containing general facts about HAE, countdowns to the day, and any other items you feel that your audience would find engaging and of value to support the awareness day. At the end of this document you will find some suggestions for updates that may be used to help promote **hae day :-)** during the weeks leading up as well as on the day. Please use them as a guide and feel free to incorporate your organization’s personal voice. It will also be essential that the updates are translated to your native language as appropriate.

Furthermore, it will be beneficial if your organization follows patients, doctors, member organizations of other countries, HAEi, and the industry on the social media in order to build a relevant group of people interested in what is being told about **hae day :-)** and indeed about HAE.

HAEi has issued a few short films that can be seen on YouTube. Please feel free to share the films on your website as well as on any social media you might use.

You are also very welcome to make use of the patient stories on www.haei.org in any way you see fit to promote the global awareness day.

<i>Date</i>	<i>Content</i>
Late April	Have you seen the hae day :-) website? Be sure to check it out, as hae day :-) is about three weeks away! See www.haeday.org .
Late April	On average it can take about 13 years for a patient to be diagnosed with HAE because the symptoms are similar to those of many other common conditions such as allergies or appendicitis. Check www.haei.org for details.
1 May	hae day :-) is coming up later this month! Please share your plans to celebrate the day – visit www.haeday.org .
2 May	We are just two weeks away from the annual global hae day :-) so please visit www.haeday.org and see how you can get involved.
Early May	By the time HAE is diagnosed correctly, the patient has often been through a long lasting ordeal. Diagnosis of HAE can take up to 13 years. See www.haei.org for more.
Early May	HAE (Hereditary Angioedema) is a disease that causes significant swelling to various parts of the body, resulting in



	pain and disfiguration, and can be life-threatening. See more at www.haei.org .
Early May	HAE is rare, and is thought to still affect up to as many as 1 in every 10,000 people worldwide. See more at www.haei.org .
9 May	The final countdown: just one week away from hae day :-) so please visit www.haeday.org to learn more about ways you can show support for HAE awareness.
10 May	The 2019 hae day :-) coincides with patients, relatives, caregivers, and people from the industry walking part of the ancient pilgrimage route <i>Camino Inglés</i> in northwestern Spain.
12 May	Your support will help us maximize the success of hae day :-) so please visit www.haeday.org and see how you can take part. Everyone is welcome.
15 May	Patient organizations from around the world come together to support the global HAE awareness day hae day :-) taking place on 16 May. See www.haeday.org .
15 May	Tomorrow is hae day :-) but it is not too late to get involved. Check www.haeday.org and find out how.
16 May	The goal of hae day :-) is to raise awareness of HAE – a potentially life threatening disease. Learn more at www.haeday.org .
16 May (+ 17 and 18 May as well)	Today patients, relatives, caregivers, and people from the industry are walking part of the ancient pilgrimage route <i>Camino Inglés</i> in northwestern Spain.
16 May	HAE is a rare genetic disorder. It is characterized by spontaneous and recurrent episodes of swelling (edema attacks) of the skin in different parts of the body, as well as in the airways and internal organs.
16 May	Edema of the throat, nose or tongue is particularly dangerous and potentially life threatening as it can lead to obstruction of the airway passages.
16 May	Although there is currently no known cure for HAE, it is possible to treat the symptoms associated with edema attacks.
16 May	HAE affects about 1 in 10,000 to 1 in 50,000 people world-



	wide.
16 May	Today is the global hae day :-) making the world aware of HAE. Find out more at www.haeday.org .
17 May	Thank you so much for your support of hae day :-) and your help in spreading awareness of HAE. Don't forget to check www.haeday.org for more information.
...	[Insert your own updates before, on and after 16 May 2019, telling about the planning of events, how to participate, results etc.]

Please note that ideally a Facebook post should incorporate the link to the **hae day :-)** website (www.haeday.org) while a Twitter post should include hashtags such as #hae-day. This will more rapidly spread the knowledge of the global awareness day as well as HAE as such.

Your **hae day :-)** team