(…add your organization’s logo…)

**PRESS RELEASE**

(…if embargoed, add here: Embargo till date/ time)

**People with Rare Life-Threatening Condition to Walk Around the World for Global Awareness Day**

[Date. Place] People from across [Country] will be converting their activity time to steps to walk around the world and raise awareness of the rare disease, hereditary angioedema (HAE) for 16 May **hae day :-)**.

[Country organization] is supporting these efforts by also (…provided your organization has its own activity/activities for **hae day :-)** add headline details here…).

“We are very excited to be part of the global HAE activity for **hae day :-).** By coming together, we spotlight HAE and strengthen our voice to call for improved time to diagnosis, and consistent access to lifesaving therapies for everyone with HAE” said (…add your title and name as well as the name of your organization…) “We are also …add quote about your activity if you are conducting any…).

People with HAE experience recurrent, painful episodes of swelling of the skin or mucous membranes. This results in swelling of various body parts, including the hands, feet, face, abdomen (gastrointestinal tract), and throat. Swelling in the throat can be fatal; the airway can close and cause death by choking.

(…add a quote from a health care professional supporting you, an HAE patient, or other relevant people…)

**hae day :-)** is organized by HAE International (HAEi), a global non-profit network of 93 patient associations dedicated to improving the lives of people with HAE.

“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,” explains Henrik Balle Boysen, Executive Vice President & Chief Operating Officer of HAEi. “Global awareness initiatives such as **hae day :-)** are necessary in order to help people with HAE receive a faster diagnosis and appropriate medical care to manage their disease. We hope everyone will be ‘Stepping Up for the Global HAE Movement’ and helping us to walk around the World as many times as possible in time for 16 May.”

# Ends #

*Contact:*

(…your name…)

(…your email, phone number…)

(…website of your organization, social media…)

*Notes to editors:*

(…consider adding the document “HAE fact sheet” to the information you present to the media…)

About **hae day :-)**

* **hae day :-)** is organized by HAE International (HAEi), a global non-profit network of patient associations dedicated to improving the lives of people with HAE.
* **hae day :-)** unites the global HAE community with 16 May as a focus for activities to raise awareness of HAE amongst the general public, healthcare professionals, healthcare decision-makers, and industry representatives.
* The theme for **hae day :-)** is ***#active4HAE****.*
* The activity challenge starts in early April and runs through to the end of May.
* Everyone is encouraged to participate in all types of activity – physical activities and those helping overall wellbeing. Any activity time reported on [haeday.org](https://haeday.org/) will be converted into steps, and the total will power us around the World.
* Regularly taking part in activities and recording the time spent at [www.haeday.org](http://www.haeday.org) will ensure your efforts count. You can also share photos of your activities, earn badges, and join a team if you want to.

About HAEi

HAEi works to raise awareness of HAE, improve time to diagnosis, and fiercely advocate for approval and reimbursement of lifesaving therapies to everyone suffering from HAE. HAEi currently supports 96 Member Countries around the world.

HAEi can be found online here:

Facebook – page: www.facebook.com/haeinternational

Facebook – group: www.facebook.com/groups/HAEinternational

Twitter: https://twitter.com/HAEDAY

Instagram: www.instagram.com/hae\_international

LinkedIn: www.linkedin.com/company/haeinternational

(…if your organization has its own social media outlet(s) we suggest you add details here…)