**Hereditary Angioedema (HAE) Fact Sheet**

About hereditary angioedema (HAE)

* HAE is a rare disease affecting around 1 in 10,000 to 1 in 50,000 people worldwide[1,2]
* (…add number diagnosed in your country…)
* 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 (airway).[3]
* Swelling in the throat is the most dangerous aspect of HAE because the airway can be closed and, without treatment, can cause death by choking (suffocation).
* Swelling in the abdomen (intestinal wall) can result in excruciating abdominal pain, nausea, vomiting, and/or diarrhea.[1]
* It can take more than eight (8) years[4] to recognize and then diagnose HAE.
* HAE is a rare and relatively unknown disease, and many doctors aren’t familiar with HAE symptoms. The symptoms are also similar to those of other common illnesses.[5] This often leads to a wrong diagnosis and consequently the wrong treatment.
* A simple blood test can confirm an HAE diagnosis.
* People with HAE experience a significant disease burden and reduced quality of life.[3]
	+ Due to pain and other debilitating symptoms of attacks, HAE can impact an individual’s ability to carry out daily activities like attending work or school or participating in leisure or social activities.[3]
	+ People with HAE experience higher levels of depression and anxiety due to the unpredictable nature of attacks, the potential for choking (suffocation) from a throat attack, and the possibility of passing the disease on to future generations.[3]
* HAE can be successfully managed with effective preventative (prophylaxis) and on-demand (acute) treatment. When people with HAE can access modern therapies to manage their HAE, their quality of life improves.[6]
* Modern medications are not consistently available to all people with HAE.
* You can learn more about HAE at <https://haei.org/hae/faq/>

About HAE International (HAEi)

* HAE International (HAEi) is a global non-profit network of patient associations dedicated to improving the lives of people with HAE.
* 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 93 Member Organizations around the world.
* You can find out more about HAEi at <https://haei.org/about-haei>

About (…add name of your organization…)

* (…add short presentation of your organization…)

About **hae day :-)**, 16 May

* **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.
* HAEi runs a global activity campaign from April to the end of May.
	+ We ask everyone interested to take part in physical or wellbeing activities and regularly record the time they spend on each activity on the campaign website [www.haeday.org](http://www.haeday.org)
	+ Every activity reported will be converted into steps for a virtual walk around the world.
* Through increased awareness, we can create an environment to support better care, earlier and more accurate diagnosis, and knowledge that people with HAE can lead a healthy life.

***References***

1. Agostoni 2004: Agostoni A, Aygören-Pürsün E, Binkley KE et al. Hereditary and acquired angioedema: problems and progress: proceedings of the third C1 esterase inhibitor deficiency workshop and beyond. J Allergy Clin Immunol. 2004 Sep;114(3 Suppl):S51-131.
2. Bowen T, Cicardi M, Bork K, et al. Hereditary angiodema: a current state-of-the-art review, VII: Canadian Hungarian 2007 International Consensus Algorithm for the Diagnosis, Therapy, and Management of Hereditary Angioedema. Ann Allergy Asthma Immunol. 2008 Jan;100(1 Suppl 2):S30-40.
3. Bork 2021: Bork K, Anderson JT, Caballero T et al. Assessment and management of disease burden and quality of life in patients with hereditary angioedema: a consensus report. Allergy Asthma Clin Immunol. 2021 Apr 19;17(1):40.
4. Lumry 2020: Lumry WR, Settipane RA. Hereditary angioedema: Epidemiology and burden of disease. Allergy Asthma Proc. 2020 Nov 1;41(Suppl 1):S08-S13.
5. Zuraw 2008: Zuraw BL. Clinical practice. Hereditary angioedema. N Engl J Med. 2008 Sep 4;359(10):1027-36.
6. Castaldo 2020: Castaldo AJ, Jervelund C, Corcoran D et al. Assessing the cost and quality-of-life impact of on-demand‐only medications for adults with hereditary angioedema. Allergy Asthma Proc. 2021 Mar 13;42(2):108-117.