

What is Hereditary Angioedema?

Hereditary Angioedema, or HAE, is a rare, potentially disabling and life-threatening genetic disease that involves attacks of swelling (angioedema) in various parts of the body, including the hands, feet, genitals, stomach, face and/or throat.

Swelling in the hands and feet can be painful and interfere with daily activities. HAE attacks that involve the face or throat are a medical emergency. Anyone with this type of swelling should seek immediate medical treatment. Without treatment, throat or tongue swelling can cause death by blocking air from the lungs. Symptoms of throat swelling may include difficulty swallowing and a change in how the voice sounds.

Stomach attacks can cause severe pain, vomiting, diarrhea and dehydration. Because the pain of a stomach attack is similar to conditions that require emergency stomach surgery, many HAE patients have been exposed to unnecessary operations.

Untreated, an HAE attack often lasts for 3 days, sometimes even longer. Because HAE is so rare, patients may not receive an accurate diagnosis for as long as 9 years after experiencing their first HAE symptoms.

HAE Type I patients have low levels of a plasma protein called C1 Inhibitor (85% of patients).

HAE Type II patients have adequate levels of C1 Inhibitor, but the protein does not function properly (%15 of patients).

HAE with Normal C1 Inhibitor patients have normal C1 Inhibitor levels, but experience swelling similar to Types I and II. This type of angioedema is not yet clearly understood – research continues.



It is important to remember that HAE is highly variable – not everyone has the same triggers, severity or number of attacks. Even members of the same family may experience very different HAE symptoms.

It is also important to remember that swelling from Hereditary Angioedema is not the same as swelling due to allergies and cannot be treated as an allergic reaction.

For more information about HAE and the US Hereditary Angioedema Association (HAEA), please email info@haea.org or call 866-798-5598. And be sure to visit the HAEA's web site at www.haea.org to learn more about living with HAE and to connect with others in the HAEA community.

Learn more about the US HAEA Angioedema Center at UCSD at <http://www.angioedemacenter.com> or find us on Facebook: US HAEA Angioedema Center at UCSD.