

US Hereditary Angioedema Association

Patient Declaration of Rights for HAE Treatment

This Declaration of Rights provides patients with the fundamental treatment principles and practices established by leading HAE physician experts.

Every HAE patient has the right to:

- work in partnership with their HAE treating physician to establish an optimal treatment program,
- have their preferences respected when determining an HAE management and treatment plan,
- treatment that will control their HAE and provide the opportunity to lead a normal life,
- access to at least 2 standard doses of an FDA-approved therapy for on-demand treatment of acute HAE attacks,
- have all attacks, irrespective of location, considered for treatment as soon as the attack is recognized,
- not be required to fail treatment with anabolic steroids before being prescribed an FDA-approved therapy.

Hereditary Angioedema is a rare, debilitating, and potentially fatal genetic condition that causes swelling in various body parts including the hands, feet, face and airway. Patients often have bouts of excruciating abdominal pain, nausea and vomiting that is caused by swelling in the intestinal wall. Airway swelling is particularly dangerous and can lead to death by asphyxiation.

US HAEA Vision: Lifelong health for HAE patients

The US Hereditary Angioedema Association, Inc. (HAEA) is a non-profit patient advocacy organization founded by and staffed by HAE patients and HAE patient caregivers. The Association provides HAE patients and their families with a support network and a wide range of services including physician referrals, disease information, and individualized peer support.

Our goal is to increase awareness of Hereditary Angioedema by providing patients and physicians with authoritative and readily accessible information. We are committed to advancing and conducting clinical research designed to improve the lives of HAE patients and ultimately find a cure.

Visit www.haea.org for more information on HAE diagnosis and treatment.

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