



MEDIA KIT

10,500+
active
members

677
unique
monthly
visitors

2000
year HAEA
was established

Instrumental
in bringing
8 new
FDA-approved
therapies to
people affected
by HAE

ABOUT US

The US Hereditary Angioedema Association (HAEA) is a 501 (c)(3) non-profit advocacy and research organization serving people living with the rare genetic condition, Hereditary Angioedema (HAE), and their families. Founded and staffed by people with HAE and caregivers, the US HAEA is committed to actively engaging our community in a wide variety of grassroots activities that promote HAE education and awareness. We provide personalized services to address the unique needs of people with HAE and their families, which include helping them secure access to and reimbursement for modern HAE medicines. Our great success in supporting clinical research has resulted in a variety of FDA-approved therapeutic options. We work closely with expert physicians to continuously upgrade quality of life for people with HAE through improving diagnosis and knowledge of the condition, and encouraging a tailored, patient-focused use of available therapeutic options. The HAEA is product and company neutral, and continues to enthusiastically support drug discovery research aimed at the next generation of HAE therapies.



OUR MISSION

To lead a nationwide advocacy movement that focuses on increasing HAE awareness and education, empowering patient access to suitable treatment, and fostering ground-breaking research that includes searching for a cure.



OUR VISION

Unrestricted access to therapy so people affected by HAE are unburdened by symptoms and able to experience life to the fullest.



OUR VALUES

To fulfill our community's highest priority needs with innovative programs, services, and activities that are delivered with an extraordinary level of empathy, kindness, and compassion.

OUR PILLARS



WHAT IS HAE?

Hereditary Angioedema, or HAE, is a very rare and potentially life-threatening genetic condition that involves recurrent attacks of severe swelling (angioedema) in various parts of the body, including the hands, feet, genitals, stomach, face and/or throat. Swelling in the airway can restrict breathing and be fatal. Episodes may be triggered by physical trauma or emotional stress, however, swelling often occurs without a known trigger.



COMMUNITY INVOLVEMENT

We offer an array of activities that unite our HAE community. Highlights include:

- **HAE IN-MOTION® 5K Run/Walk Events** that consistently attract 500-1,000 participants per year nationwide
- **Educational Webinar Series**, which provide authoritative information on a broad range of topics relevant to living a better life with HAE
- **HAEA Annual Capitol Hill Day**, during which over 180 HAEA friends (including a motivated group of HAE Youth) visit more than 60 congressional offices to ask for continued access to HAE medicines
- **Youth Programs**, designed for our youngest community members to provide specialized education on HAE, advocacy training, peer to peer support, and information sharing
- **Pam King HAEA Scholarship Fund**, which awards 100+ annual scholarships to help people with HAE afford higher education
- **Brady Club**, a safe online space where children, ages 4-12, can engage in fun, yet educational HAE-related activities
- **HAEA Meet & Greet Events** offer members the opportunity to meet other people affected by HAE and their families in their local area and share experiences





RESEARCH

The HAEA actively educates our community on the value of participating in all forms of research, particularly those aimed at improving HAE clinical care. We also recruit for clinical trials, investigator-initiated studies, focus groups, and research initiatives at the US HAEA Angioedema Center at UCSD.

Pharmaco-Economic Study

The US HAEA initiated a comprehensive study to assess both on-demand treatment and use of the new preventative medicines in the real-world. Almost 750 people with HAE participated in the study and the results point to a high cost and quality of life burden of HAE treatment with on-demand only therapy. The real-world data also reveals that the new preventative therapies yield can deliver (1) remarkable decreases in attack frequency and (2) statistically significant and clinically relevant improvements in patient quality of life. After an extensive peer review, the study 'Assessing the cost and quality of life impact of on-demand-only medications for adults with hereditary angioedema' is now published and available in print and free online.

HAE Primer

The HAEA worked with HAE expert physicians and scientists to produce an HAE Primer targeted to a nationwide list of allergy/immunology practitioners as well as residents and fellows. The Primer is a stand-alone supplement to the peer-reviewed medical journal Allergy & Asthma Proceedings, and is dedicated to assisting healthcare providers with a comprehensive roadmap to deliver optimal care to patients with HAE.

Study of HAE Therapy Insurance Reimbursement Issues

The HAEA has been systematically gathering data from people with HAE, insurance reimbursement coordinators in physician offices, and payers (including major and regional Managed Care Organizations and Pharmacy Benefit Managers) to 1) identify patterns in insurance denials or delays for prior authorizations and reimbursement, and 2) characterize the viewpoints of payers when it comes to their processes for approving or denying HAE medicines.

Based on this research, we are developing an outreach strategy, special webinars, and educational materials to assist people with HAE and their physicians as they navigate insurance coverage obstacles.

Study of HAE and COVID-19

The HAEA, in conjunction with the physician-scientists at US HAEA Angioedema Center at UCSD, will publish data from a survey of over 1,000 people with HAE and members of their household designed to 1) determine whether people with HAE are more susceptible to the virus, and 2) if HAE or taking HAE medicines affect the duration and/or severity of an infection.

A New HAE Blood Test

Scientists at the US HAEA Angioedema Center at UCSD have developed a promising assay that appears to distinguish between bradykinin and histamine mediated angioedema in cases where the diagnosis is not clear. In 2021, the HAEA will recruit subjects to validate the accuracy of this assay.

Advance HAE Scientific Registry

The Advance HAE Scientific Registry collects and disseminates scientific data with the objective of arming scientists with information that expands the understanding of patient needs, and leads to tangible strategies on optimal use of modern HAE medicines to increase quality of life.



Read more about our impact in our latest Annual Report. Visit www.haea.org and click on "About Us" and then "Impact".

SOCIAL FOOTPRINT



@US_HAEA
1.6K followers



@hereditaryangioedema
5.9K followers



Hereditary Angioedema
Association – HAEA
1.3K followers



@ushaea
286 subscribers



@us_haea
1.8K followers



@haeyouth
1.2K followers



@haeyouth
277 followers

MEDIA ASSETS

HAEA LOGO



HAE DISEASE IMAGES



OUR EVENTS



2019 SUMMIT VIDEO



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