



United States of America US Hereditary Angioedema Association

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Executive Vice President

About our US membership

USA

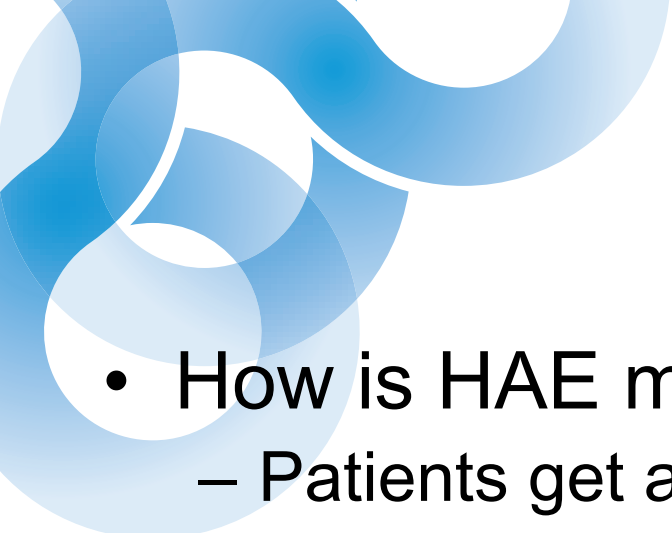
- US Population = 322,762,018
- HAE patients in the US = 10,759
(using 1:30,000)
- Total HAE patients = 3904
(Type I and II)



Management of HAE: Diagnosis and doctors

- How is HAE managed in the US?
 - In general, US physicians are only somewhat knowledgeable, but great progress has been made in the last 15 years
 - HAE patients are mainly cared for by allergists and immunologists
 - US HAEA Angioedema Center at UC San Diego provides expert care, education, research





Management of HAE: Diagnosis and doctors

- How is HAE managed in the US?
 - Patients get an accurate diagnosis through
 - HAEA Angioedema Center
 - Medical Advisory Board doctors
 - Physician referral database

HAE patients are focused on achieving lifelong health and, like others with rare diseases, are encouraged to advocate for their own care.



Management of HAE: Medication and treating attacks

- How is HAE treated in the US?
 - HAE treatments licensed in the US:
 - Androgens, Fresh frozen plasma
 - Modern HAE therapies:
Cinryze, Berinert, Kalbitor, Firazyr, Ruconest
 - How are treatments reimbursed?
 - Private insurances and most government insurances
 - Non-profit agencies help with premiums, co-pays, etc.

Management of HAE: Medication and treating attacks

- How is HAE treated in the US?
 - How are therapies able to be administered?
 - Self-administration is determined by the label – what the US FDA approves
 - HAE therapies are also available at hospitals, doctors offices, infusion centers, visiting nurse care
 - Are there any restrictions?
 - Some insurance companies are moving toward limiting the number of doses per shipment
 - Some insurance companies are moving toward access to only one therapy
- How are rare diseases viewed in the US?
 - There are more than 7000 rare diseases and only 25% have even one therapy...

Management of HAE: An emergency situation

- What happens in an emergency?
 - 2013 Recommendations on the Management of HAE (C1 INH Deficiency) (p.460)
All patients should have access to at least 2 standard doses of an FDA-approved medicine for on-demand treatment of acute HAE attacks.
 - HAE often still goes unrecognized by doctors in the Emergency Room - patients are encouraged to personally set up a plan with their ER in advance
 - If medication is available in the ER, or if a patient carries it in themselves, it is usually administered promptly

HAE Support

The US patient group

- Called the US Hereditary Angiodema Association or HAEA – est. 2000

- Our logo -



The US HAEA is a member organization of HAEi and has 5800+ members

HAE Support

The US patient group

- What activities do you undertake?
 - Website - recently redesigned
 - Social media
 - Newsletter
 - National Patient Summits



hae day :-)

The US patient group

- What activities do you undertake?
 - Fundraising and awareness through individual efforts and HAE in MOTION 5k race/walks



HAE IN Motion 5K

<http://5k.haea.org/>



Future of HAE

Plans/dreams for HAE in the US

- Greater patient identification
- Faster and more accurate diagnosis
- Increased awareness
- Legislative influence
- Improved therapies
- Advanced research for a cure



hae day :-)

hae day :-) in the US means

- increased disease awareness
- annual opportunity for the patient community to come together
- recognition that helps us impact government legislation to benefit the lives of HAE patients and families

hae day :-)

hae day :-) events

Awareness activities through hae day :-)

Patient created events

- memorial events
- dinner fundraisers
- school/student events

#myMove4HAE

CELEBRATING HAE DAY :-) THROUGH PICTURES



Stay in touch

- US Hereditary Angioedema Association
- Contact: info@haea.org
- Organization contact details
 - Web site www.haea.org
 - Facebook page
<https://www.facebook.com/hereditaryangioedema>
 - Twitter [@US_HAEA](https://twitter.com/US_HAEA) / [@TonyJCastaldo](https://twitter.com/TonyJCastaldo)
 - Instagram [US_HAEA](https://www.instagram.com/US_HAEA)

USA

hae
day :-)

MANY FACES
ONE FAMILY