



# United States of America US Hereditary Angioedema Association

**Janet F. Long**

Executive Vice President

# About our US membership

## USA

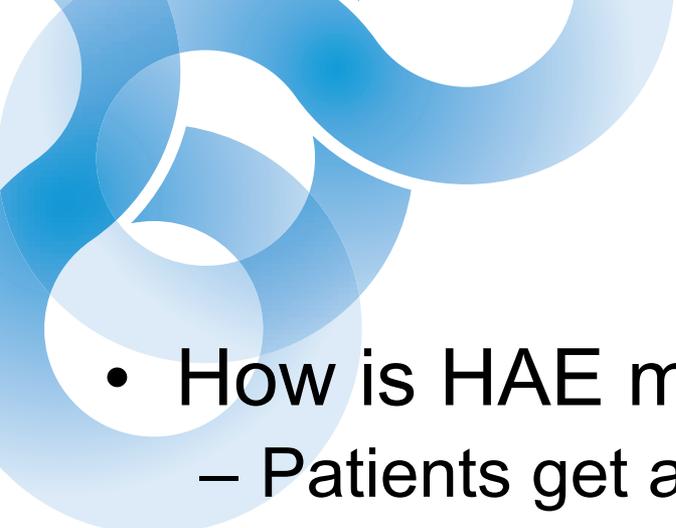
- US Population = 322,762,018
- HAE patients in the US = 10,759  
(using 1:30,000)
- Total HAE patients = 3904  
(Type I and II)



# 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



USA



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**

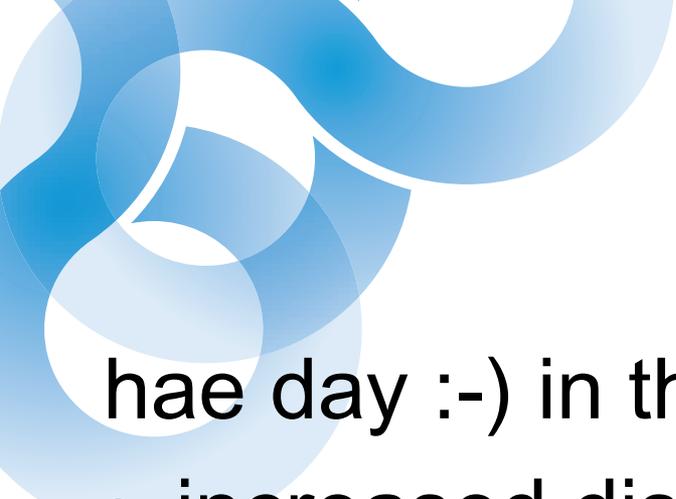
<http://5k.haea.org/>



# 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](mailto:info@haea.org)
- Organization contact details
  - Web site [www.haea.org](http://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