



## HAEA in Action December Newsletter!

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### **A YEAR OF ACTION!**

It has been a very active 2017 for the US HAEA and our patient community. As we focused our efforts on the four pillars of **H**Health, **A**Advocacy, **E**Engagement, and **A**Advances in Research, we saw an increase in community participation and a strengthening of mission of lifelong health for all HAE patients. We look

forward to 2018, as we reach more important milestones together. We thank you, the entire HAEA community, for your continued commitment and for taking ACTION to StandUpStrong4HAE!

### Together, this past year, we experienced....

- **Another successful Capitol Hill Day and grassroots campaigns** – we advocated on behalf of patient rights; visited over 55 congressional offices in support of patient legislation that protected patients and wrote impactful letters to legislators.
  - **US HAEA National Patient Summit** – our largest gathering to date of patients and family members, physician experts, pharmaceutical leaders, and specialty care organizations gathered in Bloomington, MN to learn the latest HAE information and enjoy time together.
  - **FDA Public Hearing** – HAEA advocates, heroes, and patients attended the FDA's Patient-Focused Drug Development Meeting to discuss HAE-related challenges.
  - **FDA approved a new HAE Therapy** – the first subcutaneous HAE therapy is approved for patient treatment.
  - **Groundbreaking research** - multiple pharmaceutical companies announced successful studies on new therapies.
  - **Youth Leadership Council** – Teens from the HAEA community joined together to promote peer engagement and interaction to meet the needs of our younger HAE patients.
  - **HAE IN-MOTION® 5K races** – 10 amazing race events were held across the country to help raise funds for three HAEA community resources; HAEA Scholarship Program, HAEA Benevolence Fund, HAE Research.
  - **ER Tool Kits for hae day:-)** – over 1,000 kits were ordered and distributed to local emergency rooms, schools, and work places.
  - **US HAEA Scholarship Program** – awarded nearly 30 scholarships to assist students pursuing higher education.
  - **Brady Club** – added new games and images to the website to further support childhood learning and engagement.
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## THE US HAEA ANGIOEDEMA CENTER CAN NOW SEE KIDS!

ATTENTION PARENTS! The US HAEA Angioedema Center at UCSD is thrilled to announce that the Center can now see children with HAE, ages 8 and up. The Center's expert physicians specialize in the care of patients with all types of angioedema. To learn more about how to arrange a visit for your child, please contact a member of the HAEA Health Team - Heidi Polek at [heidipolek@haea.org](mailto:heidipolek@haea.org) or Troyce Venturella at [troyce@haea.org](mailto:troyce@haea.org).

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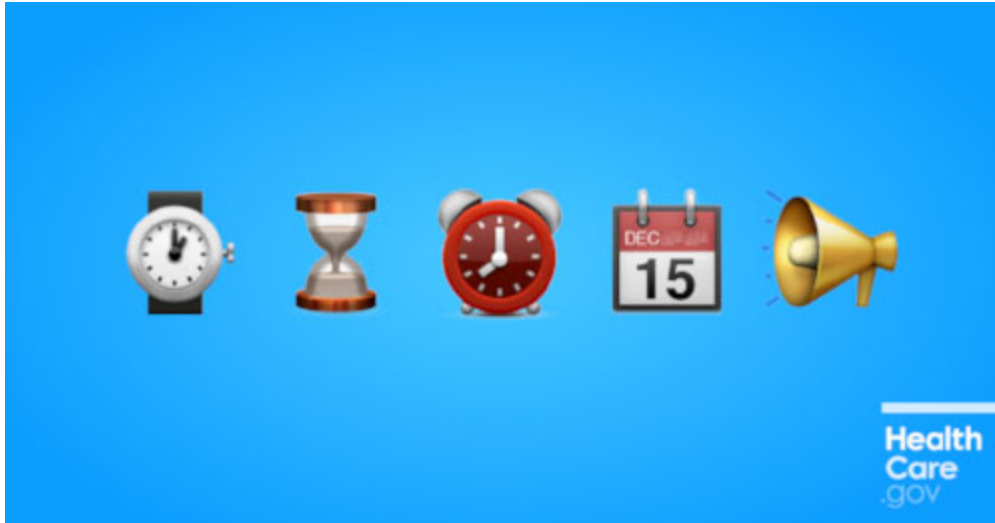
## HAPPY HOLIDAYS!

As the holiday season is upon us, we give thanks for our HAEA family and patient community. We wish you all the very best wishes of the season. May your New Year be blessed with good health, peace, and joy!

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# UPCOMING

# EVENTS



## **INSURANCE ENROLLMENT PERIOD**

**November 1 to December 15, 2017**

The enrollment period for Health Insurance runs for this limited time. Learn what you need to do to secure your coverage! Visit [www.healthcare.gov](http://www.healthcare.gov) or contact your HAE Health Advocates Heidi Polek or Troyce Venturella at: [heidipolek@haea.org](mailto:heidipolek@haea.org) or [troyce@haea.org](mailto:troyce@haea.org).

December 7th is the deadline for Medicare recipients and December 15th for non-Medicare patients - but check with your private insurance or employer for their deadlines.



## **YOUTH WEBINAR**

**January 18, 2018**

Topic: StandUpStrong4HAE - Youth Edition This webinar will explain HAE in easy to understand terms for young people, while comparing the old school vs. new school ways of thinking about HAE.

**Guest Speaker: Dr. Johnston**

**Date: Thursday, January 18, 2018**

**Time: 7:30PM EST, 4:30 PM PST**

Join from PC, Mac, Linux, iOS or Android: <https://haea.zoom.us/j/689442657>

From smart phone one-tap: US: [+16699006833](tel:+16699006833),689442657# or

[+16465588656](tel:+16465588656),689442657#

Or Telephone: Dial US: **+1 669 900 6833** or **+1 646 558 8656** Meeting ID: **689 442 657**

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