



US HAEA TODAY

Spring 2014
Newsletter

A Message from the President

Dear HAEA Friends,

Significant change always causes at least some uncertainty and that may turn out to be the case with the implementation of the Affordable Care Act (ACA). The HAEA has already started working with a coalition of patient advocacy organizations to carefully monitor the ACA's impact on insurance coverage for medicines prescribed to treat rare diseases, including HAE. The coalition is prepared to make its collective (and loud) voice heard in Washington, DC and State Capitols should we detect any potential adverse impact on access to and reimbursement for rare disease therapies.

Speaking of legislation, HAEA friends have reason to congratulate themselves on a recent highly successful advocacy effort! During the September 2013 HAEA Summit, our patient community wrote letters to their congressional representatives that highlighted the importance of Federal support for HAE research. These letters asked that HAE stay on a limited list of conditions eligible for a large pot of research money provided by the Department of Defense (DOD). Not only did Congress keep HAE on the list, but we were recently informed that a

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research proposal submitted by Professor Bruce L. Zuraw-- US HAEA Endowed Chair and Director of the US HAEA Angioedema Center at the University of California at San Diego--was one of the very few chosen to receive funding under this DOD program.

Please keep in mind that May 16th is HAE day and, as noted in this newsletter, it is not too late to organize an event in your community. Contact your Patient Services Team member to learn how you can help to make hae day :-) a success!

Also, remember that the HAEA is available 24/7 to help you problem-solve your HAE-related issues. Visit our web page www.haea.org for the latest information on all things HAE and for the number of our emergency line and patient services team members.

Warm regards to all,

Anthony J. Castaldo
President, US HAEA

US HAEA Angioedema Center at UCSD



The US HAEA is proud to announce the Center is beginning its build out. A brand new office suite is being constructed, tailored to provide state of the art care for all angioedema patients. The Center's physician experts will work with each patient to diagnose, create an individualized treatment plan and work with their local physician for follow-up care.

Stay tuned for more information on the date of the Grand Opening for the US HAEA Angioedema Center at UCSD. And if you are interested in being one of the first to visit the Center, please register your interest at www.haea.org by clicking on the Angioedema Center TAB or just click this link: <http://www.haea.org/angioedema-center/>

How HAEA Advocacy Makes a Difference!



In past HAEA Newsletters or emails, you have read about the public policy program the HAE Association has put in place to advocate for HAE patients and families. You may have wondered just how does this program make a difference in *YOUR* life?

The US HAEA partners with the Health and Medicine Counsel of Washington, a political advocacy firm that specializes in working with rare disease patient organizations.

In September of last year, attendees at the US HAEA National Patient Summit wrote letters to their congressional leaders asking for their support of legislation that affects the lives of HAE patients.

The letters which the HAEA delivered to congressional offices made a huge impression.

A group of HAE patients also traveled to Washington, DC in December of 2013 to make more

than 55 visits to government offices on Capitol Hill. Both US Senate and House leaders heard powerful stories of living with HAE. In specific, HAEA advocates asked that congressional leaders keep HAE on a select list of only 22 diseases eligible for federal research funding from the Department of Defense (DOD).

These advocacy efforts succeeded!

HAE was again listed as eligible for DOD research funds. Dr. Bruce Zuraw, chair of our

HAEA Medical Advisory Board, submitted a research proposal and was awarded a grant from these very same DOD funds! His research will help to solve some of the many lingering mysteries of Hereditary Angioedema.

The US HAEA stands at the forefront of HAE advocacy on your behalf - making a difference in your life.

HAE DAY 2014! Coming SOON!!! May 16, 2014



May 16, 2012, was the *first* hae day :-) - a global event to raise awareness of Hereditary Angioedema among the general public and the medical community.

This year we celebrate our *third* annual hae day :-) and we hope you and your family will help us to make it the best one yet!

Every year our HAE awareness events and fundraisers have grown. Can we top last year's 22 events created by YOU, our HAEA community?! We are already on our way with more than 8 events planned - be inspired by these events, as well as events from past years, at <http://www.haea.org/hae-news/hae-day/fundraiser-events/>

As you will see when you browse the 2014 events list, you don't need to hold an event on the exact date of May 16. *Every day* is a day to spread awareness! Every day can be hae day! So plan your 5k walk in July or hold a fundraiser in September - every event will be key to raising HAE awareness!

This year, Patient Services Team member Jenny Barnes will provide dedicated hae day :-) event assistance. Please contact her at jennybarnes@haea.org with any hae day :-) event help you might need - including arranging your own free web site to promote your event!

Please note: our hae day :-) web pages have been revised to make it easier to find everything you need to know about hae day :-) and organizing your event. Get started by clicking on the News & Events tab or just click here: <http://www.haea.org/hae-news/hae-day/>

Big or small, bake sale or stadium billboard, join in the effort

to make a difference with *your* hae day :-) event! **hae day :-) 2014 !!!**

HAEi - HAE Global Conference to be held in US in 2014

HAEi - International Patient Organization for C1 Inhibitor Deficiencies - cordially invites you to attend the 2014 HAE Global Conference which will take place in Washington DC, 15 - 18 May 2014. (Patient sessions to be held May 16-18). To learn more, please go to www.haei.org and scroll down on the landing page to the information listed under EVENTS.

The first HAE Global Conference was held in Copenhagen, Denmark in 2012. Those who were able to attend agreed it was an invaluable experience - meeting other HAE patients from around the world, learning more about the state of HAE treatment in other countries, and about global HAE research efforts. Not to mention the time to socialize and have some fun!

Registration for the conference is now open! Registration will take place on a first come, first served basis. Please be sure to visit www.haei.org . Hope to see you in DC!

The 2013 HAEA Year in Review is here!



HAEA President, Anthony Castaldo, sums up the 2013 **Year in Review** well in his message to the HAEA community on page 3:

" During 2013, the US Hereditary Angioedema Association (HAEA) made great strides in fulfilling its mission of increasing HAE awareness, education, and diagnosis while empowering patient access to an optimal therapy and fostering groundbreaking research."

The **Year in Review** features a look back at the US HAEA National Patient Summit, successful public policy advocacy program, and the work of the HAEA Patient Services Team. Of greatest importance is the

ground-breaking *2013 Recommendations for the Management of HAE* document written by the US HAEA Medical Advisory Board. (Be sure to print your own copy of the Recommendations - you can find it on [haea.org](http://www.haea.org) or click here: <http://www.haea.org/resources/2013-recommendations/>)

Your **2013 Year in Review** should have already arrived in the mail! And an easy to read online version is available as well at www.haea.org - just like a magazine, but it's electronic! Flip the pages with a click or print it!

As we look forward to all that is ahead of us as an HAEA community in 2014, be sure to go to: <http://www.haea.org/DOCS/2013/> and read through the many pages of all that *you*, our HAEA community, accomplished in 2013!

Building a better future together!

The US HAEA Scientific Registry Report

**...providing you with updates about our Scientific Registry (SR)
and the new HAE research it supports.**

We appreciate everyone's time and effort in making the Scientific Registry a success!

Our new online report system is working better than ever and our 4th quarter Quarterly Report response has been outstanding!!!

Please remember that 1st Quarter Reports will be available online on April 1st.

We're looking forward to

another great Quarter - Thank You to all of our US HAEA Scientific Registry members! Not yet a member and want to join this effort for better HAE treatments and... a cure?

It is easy and free! (Please note: Even if you are a current member of the HAEA, you must register *again* specifically for participation in the Registry...)



To learn more and to join, please go to

<http://www.haea.org/get-involved/us-haea-scientific-registry/>

Every member helps the US HAEA Scientific Registry achieve its goal:

Collect a robust cohort of participants, so that qualified HAE researcher/scientists will be able to
1) present a ground-breaking research proposal for the US HAEA's Medical Advisory Board to review
and 2) then have access to data and clinical samples maintained by the Registry to facilitate that research.

To contact the HAEA Scientific Registry staff with any questions you may have, please email scientificregistry@haea.org or call the HAEA toll free number at 866-798-5598.

Make 2014 your year to join the HAEA Scientific Registry - and invite your family members to join, too!

Together, we can make a brighter future for HAE generations to come!

US HAEA Scientific Registry - Patient Driven Research for a Cure

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Your Patient Services Team by Region



Your
US HAEA
Patient
Services
Team

Find your region and your Team Member at

<http://www.haea.org/contact/patient-services-representatives/>

The US HAE Association publishes its newsletters to ensure everyone in our HAE family is informed about important clinical developments and all HAE Association activities.

We hope you have enjoyed this issue!

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