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US Hereditary Angioedema Association

US HAEA TODAY

Summer 2014 Newsletter

A Message from the President

Dear HAEA Friends,

The HAEA's longstanding dream of having a comprehensive care and research center devoted to HAE patients will become a reality in August of 2014!
The US HAEA Angioedema Center at the University of California at San Diego (Angioedema Center) is unique in that a patient advocacy organization was the driving force behind its establishment and has been deeply involved in all phases of pre-opening planning. Our objective is to provide patients who are seen at the Angioedema Center with a positive experience that features exceptional care by expert HAE physician/scientists in a friendly and supportive environment. We are confident that the Angioedema Center will establish a model, patient-friendly standard of care for the HAE community in the US and around the world.
See the article and associated links below to learn more about the Angioedema Center and stay tuned for more information coming soon about making an appointment.

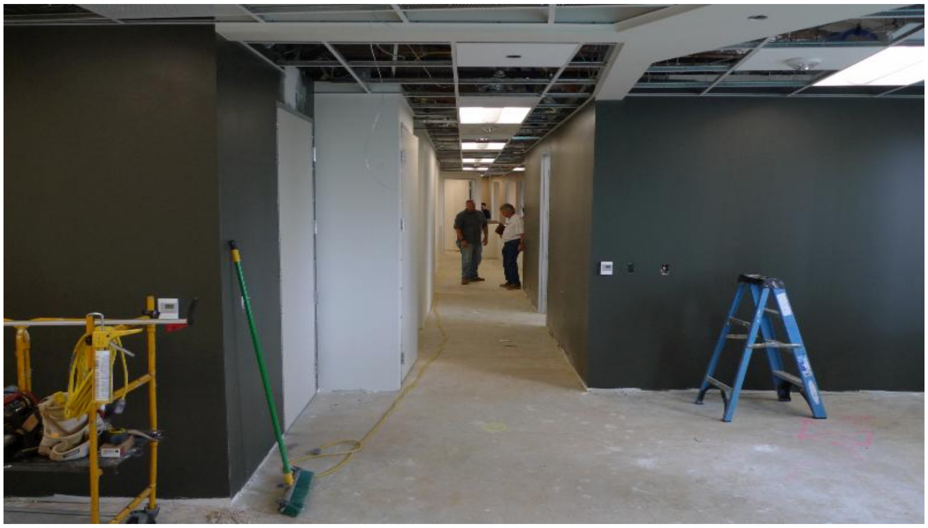
I wish everyone a happy and healthy summer,

Warm regards to all,

In This Issue

Anthony J. Castaldo
President, US HAEA

US HAEA Angioedema Center at UCSD - Update



Construction of the Center is in full swing! The brand new office suite is 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.

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/

HAEi - Global HAE Conference held in Washington, DC

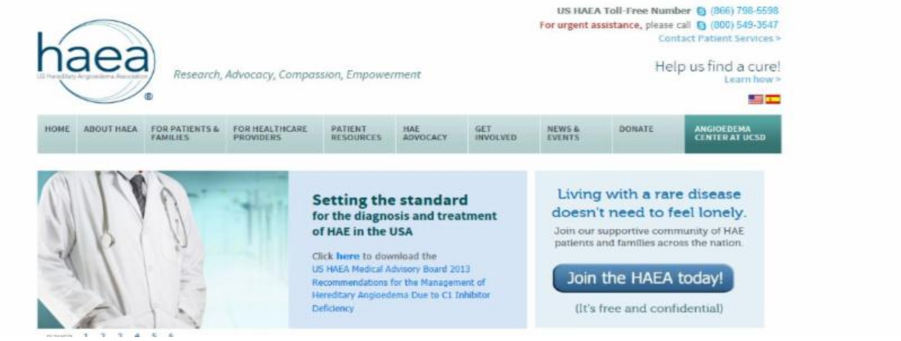
HAEi - International Patient Organization for C1 Inhibitor Deficiencies - welcomed more than 450 attendees to the 2014 HAE Global Conference which will took place in Washington DC, 15 - 18 May 2014. Check out www.haei.org for photos from this amazing event that gathered HAE patients from around the world.

The first HAE Global Conference was held in Copenhagen, Denmark in 2012 and everyone who was able to attend the DC meeting agreed it was an even more exciting and powerful meeting - talking with other HAE patients from around the world, learning more about the state of HAE treatment world-wide, and about global HAE research efforts.
About 100 HAE patients and caregivers attended this international event where HAEA President Anthony Castaldo and HAEi Director Henrik Boysen directed the days' sessions.

We will look forward to hearing where the 2016 HAEi Global Conference will be held!

HAEA staff attending the 2014 HAEi Global HAE Conference

What's New at HAEA.ORG



US HAEA Toll-Free Number (866) 798-5598
For urgent assistance, please call (800) 549-3547

Research, Advocacy, Compassion, Empowerment

Help us find a cure!

Setting the standard for the diagnosis and treatment of HAE in the USA

Click here to download the US HAEA Medical Advisory Board 2013 Recommendations for the Management of Hereditary Angioedema Due to C1 Inhibitor Deficiency

Living with a rare disease doesn't need to feel lonely.

Join our supportive community of HAE patients and families across the nation.

(It's free and confidential)

Have you noticed? The HAEA web site is now available in Spanish! Just click on the flag icon and read all of the great HAE information en espanol!

Dr. Marc Riedl, member of the HAEA Medical Advisory Board, has contributed an expert Q & A on Hereditary Angioedema. Be sure to read through it for the concise and knowledgeable help provided. http://www.haea.org/patients/expert-physician-hae-qa/

And if you have not read it already, be sure to read the ground-breaking *2013 Recommendations on the Management of HAE,* written by the US HAEA Medical Advisory Board. Print it out for family, colleagues, or your local physician as well. The authoritative HAE information you need is contained in the pages of this consensus document. http://www.haea.org/resources/2013-recommendations/

In the Patient Toolbox, don't miss the information on the *Genetic Counseling Program* from Dyax Corp. - in partnership with Informed DNA. The program includes an assessment of risk factors for family, genetic testing, treatment barriers and available solutions, and possible psycho-social impact of HAE. Be sure to check it out at http://www.haea.org/resources/patient-toolbox/

AND...

A contest offered by Salix in conjunction with hae day :-) 2014 has opened for voting. As you may remember, the contest offered **the opportunity to tour the new US HAEA Angioedema Center at UCSD**. You can support those who submitted their entries by voting for your favorite at www.haeanswers.com

Voting ends on July 7 - so vote today!

The US HAEA Scientific Registry Report - Research for a Cure

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

Thank You to all of our US HAEA Scientific Registry members for a great start to 2014!

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 your new Quarterly Report is available ANY time now online!!!

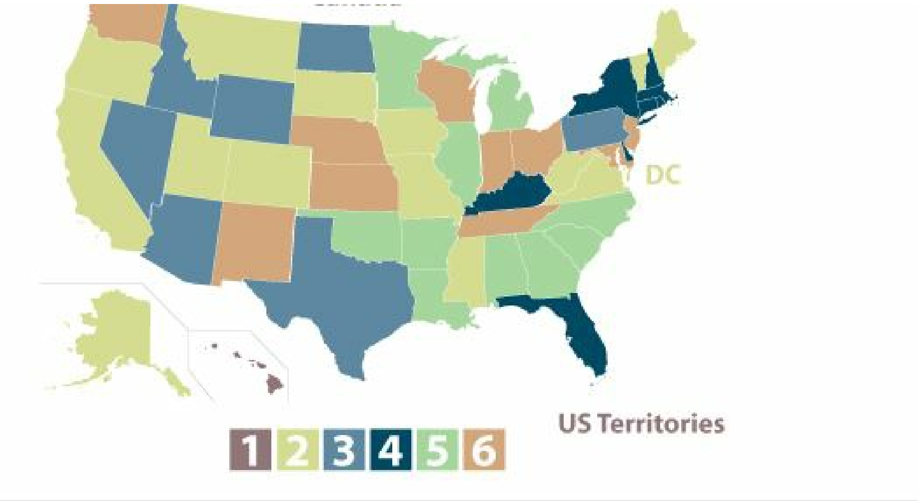
***Do YOU* want to be a vital member of this effort for better HAE treatments and... a cure?**
To learn more and join today, please go to http://www.haea.org/get-involved/us-haea-scientific-registry/

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.

Join the HAEA Scientific Registry today- 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

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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