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US Hereditary Angioedema Association

US HAEA TODAY

FALL 2013 Newsletter

A Message from the President

Dear HAEA Friends,

I hope everyone in our HAE community had a pleasant summer that included lots of restful vacation time!

It has been a busy summer for the HAEA, and this newsletter provides details on our

- work to ensure that the September 27-29 Patient Summit in Orlando, FL provides our community with a memorable, fun, and information-packed experience,
- fundraiser for HAE research featuring the sailboat Bodacious IV (with the HAEA logo displayed on one of the boat's huge sails) as it made a two week journey across the Pacific Ocean during the bi-annual Transpac Race, and
- launch of a Spanish version of the HAEA web site.

In addition, the HAEA continued its work on the myriad details required to get the US HAEA Angioedema Center at the University of California at San Diego ready for its late fall opening.

Please keep in mind that the sailboat race fundraiser for

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HAE research was an unqualified success, but as noted below, it is not too late to contribute! Likewise, there is also time to sign up for the Patient Summit!

I am very excited about having the opportunity to see all of you at the US HAEA National Patient Summit later this month!

Warm regards to all,

Anthony J. Castaldo
President, US HAEA

Your US HAEA Patient Services Team

US HAEA National Patient Summit - Register TODAY!

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2013 US HAEA
National Patient Summit
September 27–29, 2013
Orlando, Florida

The 2013 US HAEA National Patient Summit is coming up soon! If you have not done so already, please be sure to register to attend!

Only a few spots are left and we want to see EVERYONE there!

The National Patient Summit will feature a completely new format - one in which you and your family can participate in a powerfully interactive way!
* Being part of data collection for new HAE research
*Making your voice heard on Capitol Hill
*Gaining knowledge about Healthcare Reform and what the Affordable Care Act
*Visiting exhibit tables
*Joining the Scientific Registry - for a CURE!
*Meeting new and old HAEA friends

*Kids Program - ages 4 - 13
*Teen Chat Group - ages 14-19

Please go to:
2013-us-haea-national-patient-summit/registration
to register today!
You can find the Summit agenda there, too!

See you on September 27-29, in sunny Orlando, FL!

Building A Better Future Together

Transpac Race Fundraiser Sails to Success!

Friends of the HAE community, Pam King, Chris Pike, Gaye Hill, Jeff Urbina and the crew of Bodacious IV joined forces recently to help raise awareness and funds in support of the HAEA Research Program and Patient Benevolent Fund. The monies collected will be dedicated to increasing HAE awareness, education, diagnosis and fostering research that includes finding a cure.

On Thursday, July 11th, 2013, the crew of Bodacious IV departed on a 2225 nautical mile sail, the Transpac race from California to Hawaii, proudly raising their custom made

sail
with the US HAEA logo!

Everyone was able to track the progress of Bodacious IV in real time by going to
http://yb.tl/transpac2013
and Pam King provided a blog to provide daily posts of the ship's progress.

You can still read the blog to learn about the trip at
http://www.haea.org/donate/race/transpac-race-blog/
AND
you can still contribute to the fundraiser by going to
https://www.haea.org/donate/race/

Thank you

to the HAEA patient community and friends of the HAEA
who were energized by this great fundraiser not only to donate funds,
but to also distribute flyers to raise HAE awareness
in their own communities, work places and schools!

Thank you

to Pam King, Chris Pike and all of the Bodacious crew
for making this fundraiser possible - so many patients will benefit
from your selfless dedication to this rare disease.

Looking forward to Transpac 2014 already!

US HAEA Angioedema Center at UCSD

In our Spring/Summer Newsletter, we introduced the medical staff of the new Angioedema Center to you. Dr. Bruce Zuraw, Dr. Marc Riedl and Dr. Sandra Christiansen are eager to welcome you at the Center!

As we await the announcement of Opening Day, we wanted to introduce our Center

Patient Liaison, Michelle Williamson, to you.

You may already know Michelle from her many years as a US HAEA Patient Services Team member.

It will be Michelle's job to work with angioedema patients who wish to visit the Center. Michelle will be able to provide information on travel and accommodations, as well as assist you with any documentation required for your appointment at the Center before you arrive.

The HAEA is pleased to assist you in making your appointment at this comprehensive center for patient care, clinical trials and research.

Michelle can be contacted at michellewilliamson@haea.org

A Quick Reference Guide to Publications from your HAEA

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US Hereditary Angioedema Association

Did you know the US HAEA authors and publishes articles to bring greater awareness of

HAE

to the medical community and general public and to increase interest in new

angioedema research?

The US Hereditary Angioedema Association: An Important Partner in a Longstanding Effort to Improve Patients' Quality of Life Journal of Angioedema Fall 2013

Lay Organization Spotlight: US Hereditary Angioedema Association The Journal of Allergy and Clinical Immunology: In Practice. **Fall 2013**

US HAEA Medical Advisory Board 2013 Recommendations for the Management of Hereditary Angioedema Due to C1 Inhibitor Deficiency
The Journal of Allergy and Clinical Immunology: In Practice   Fall2013

Hereditary angioedema with normal C1 inhibitor function: Consensus of an international expert panel
Allergy and Asthma Proceedings, Volume 33, Supplement 1, November/December 2012 , pp. S145-S156(12)

HAEA Spotlight   Plasma Protein Therapeutics Association (PPTA) - The Source (Quarterly Magazine)   Fall 2013

The US Hereditary Angioedema Association: An Important Partner in a Longstanding Effort to Improve Patients' Quality of Life
Poster presented at the 8th C1 Inhibitor Deficiency Workshop in Budapest, Hungary 2013

The humanistic burden of hereditary angioedema: Impact on health-related quality of life, productivity, and depression
Allergy and Asthma Proceedings, Volume 31, Number 5, September/October 2010 , pp. 407-414(8)

New US HAEA Spanish Language Web Site

The US HAEA web site serves as an online portal to authoritative and unbiased information on all things HAE. We are proud to announce our we site is now available in Spanish (*¡En español!*)

As you may know, the HAEA has recently begun making strides for HAE patients in Puerto Rico where access to FDA-approved medicines is still often difficult.

This web site will help not only patients and families in Puerto Rico, but all Spanish speakers in our community to better understand their HAE, to learn about HAE medicines and to advocate for the most optimal healthcare for themselves.

You can just go to http://www.haea.org and click on the language selector at the top of the page and there's another in the footer.

¡Muchas gracias e salud!

The US HAEA Scientific Registry Report

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

Thank You!

Your response to our mailed *First Quarter report* was outstanding!
We really appreciate the time and effort each of you took to complete your reports and return the vital research data they contain!

Just around the Corner - The New Online System!

Very soon we'll be updating you about our new streamlined and simplified reporting system, designed with you, the HAEA user in mind, because every minute that you contribute to research is so incredibly valuable to the future of all who have HAE!

Can I join the Registry in at the Patient Summit in Orlando?

Absolutely! Just come by the Scientific Registry Room at your convenience and you can learn more about the Registry, sign up, and then contribute a blood sample -all in just a few minutes with the help of our friendly staff and volunteers.

Prizes!

Recognizing your dedication is very important to the Scientific Registry!
If you are:
  *a new Registry member,
  *attended the original Orlando patient conference in 2008,
or
if you have:
  *have submitted at least 6 Quarterly Reports
please join us at the Orlando Summit and receive your award!
  There's even a prize for providing your second blood draw!

Contact us at any time for Registry assistance at 866-798-5598
and ask for a Scientific Registry Administrator -
sharongrina@haea.org
susanfinley@haea.org

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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