US HAEA TODAY

Summer/Fall 2015 Newsletter

A Message from the President

Dear HAEA Friends,
I sincerely hope that everyone enjoyed a summer season full of vacation time and relaxation!

Have you signed up for the US HAEA National Patient Summit that will take place in Denver on October 9 -11?

As you will read below, the 2015 Summit will offer HAEA friends with a fun environment to learn about the latest information on HAE research and treatments. Attendees will also have plenty of time to interact with fellow patients, the nation's top HAE physician/scientists, and companies who manufacture and distribute HAE therapies.

Adding to the excitement, for the first time ever, we are sponsoring a 5k Run/Walk called "HAE IN- MOTION" to benefit the HAEA Scholarship Fund.

For more information and sign up details see the SUMMIT registration page at www.haea.org

My sincere best wishes to all HAEA friends!

In This Issue

Tony

US HAEA 2015 National Patient Summit - Denver, CO

The US HAEA is excited to announce its 2015 National Patient SUMMIT in Denver, CO on Oct. 9-11!
This meeting is filled with opportunities designed just for you!

The 2015 National Patient Summit will feature completely new HAE content, up-to-date information, and inventive ways for you and your family to participate in Shaping the Future Together!
** Contribute to medical science and furthering the understanding of HAE! Data collected by HAE researchers at the Summit will benefit all HAE patients!*
** Make your voice heard on Capitol Hill - learn about the HAEA's public policy work and how you can help to influence legislation that affects HAE patients and families!*
** Learn about the HAE therapy Access and Reimbursement expertise the HAEA has to offer!*
** Talk one-on-one with physician/researchers, experts in all angioedemas!*
** Meet new HAEA friends!*
** Stop by the exhibits from all of the companies who make your FDA-approved HAE medicine!*
** Visit the US HAEA Scientific Registry - help find a cure!*
** Enjoy amazing entertainment at Saturday night's dinner!*

Everyone, whose travel schedule allows, is invited to join the HAEA's very first

*HAE Awareness 5k Walk/Run on Sunday morning called **HAE IN-MOTION**!*

You can walk, run, or simply cheer from the sidelines. Raise awareness and shape the future together one step at a time! More information will be provided to you on the HAE IN-MOTION race after you submit your Summit registration.

Please contact your Patient Services Team member for hotel discount information. Limited travel assistance available.
The Summit agenda, registration page and a printable flyer are available at www.haea.org

Register today - seats are nearly filled !

Premiere HAEA 5k Walk/Run

Did you know? HAE can take up to 10 years on average to diagnose?
1 in every 10,000 to 30,000 people in the US have HAE?

We are Shaping the Future together in Denver, CO with the first ever US HAEA 5k Walk/Run called **HAE IN-MOTION** !

In conjunction with the HAEA Year of the Youth, all proceeds go toward future academic scholarships for HAEA youth and other developing programs for our kids with HAE.

JOIN US - to run, to walk, to cheer others on! See the Race registration information when you register for the HAEA National Patient Summit at haea.org

We hope to see you at BOTH!

Why Are Clinical Trials Important?

Simply put, clinical trials hold the key to our future as HAE patients! All new medicines are required to undergo rigorous testing for safety and effectiveness before the FDA will consider granting an approval for use in the United States. The HAEA community has always met the challenge and signed up for clinical trials - that is precisely why, in 2015, we have our choice of 5 medicines that treat HAE.

The willingness of HAE patients to participate in clinical trials also explains, in part, why pharmaceutical companies are investing heavily in next generation HAE treatments - they know the HAEA community will once again step up and enroll in one or more clinical trials!

On-going and planned clinical trials are focused on preventing HAE attacks.
The list of companies testing HAE therapies is impressive and includes:
* CSL Behring (Berinert) - a subcutaneous formulation of C1 Inhibitor concentrate
* BioCryst - a pill that inhibits kallikrein,
* Shire (Cinryze) - a subcutaneous formulation of C1 Inhibitor concentrate, and
* Dyax (Kalbitor) - a long acting subcutaneously injected kallikrein inhibiting monoclonal antibody.

On July 7, 2015, the FDA granted *Breakthrough Therapy* status for Dyax's new medicine. According to the FDA, the Breakthrough Therapy designation is considered when preliminary clinical evidence indicates the drug may demonstrate substantial improvement over available therapy. The designation is intended to (1) expedite the development and review of potential new medicines with early indications of clinical benefit in serious or life-threatening conditions and (2) helps make sure that patients have access to them as soon as possible.

We urge you to consider signing up for a clinical trial in your area.

For more information, please call HAEA Patient Services Team Member
John Williamson at (972) 984- 0621

Patient Focused Drug Development - US HAEA to Meet with FDA Officials

FDA
U.S Food and Drug Administration

The US HAEA is pleased to announce that HAE has been chosen for one of the highly coveted day long meetings with FDA reviewers under the aegis of the Patient Focused Drug Development (PFDD) initiative. The HAEA and its Medical Advisory Board worked diligently to convince the FDA that HAE be chosen from the long list of disease states vying for a PFDD meeting with the FDA. Needless to say, this hard work paid off!

The meeting, which will take place sometime in the 2016- 2017 timeframe, provides patients and other interested stakeholders with an opportunity to help FDA understand HAE, its impact on patients' daily lives, the types of treatment benefit that matter most to patients, and patients' perspectives on the adequacy of available therapies.

We look forward to the providing more information in the future on this important meeting to benefit our HAE community.

Introducing the myACT app

Access to Continued Therapy (ACT) app
Introducing the myACT app!

Jane Sorensen
GENDER Female YEAR OF BIRTH 1968
HAE TYPE Type 1
John Smith at 858-555-1212
FATHER
Dr. Judy Chen at 858-222-1111
MY HAE TREATING PHYSICIAN
For urgent assistance
(800) 549-3547

If you are looking for a handy electronic diary for your HAE attacks, this is the app for you! Among the many features of the app, you can easily:
* set up automatic treatment and therapy refill reminders
* create unique reports that detail your life with HAE over 3 months, 6 months or a year
* email your attack reports directly to your physician
* store your emergency contact information

Remember, the information you store in your myACT app is yours alone. Unlike some other HAE logs or diaries, your myACT information will never be seen by anyone unless you choose to share it.

Read more at http://www.haea.org/resources/introducing-the-access-support-record-asr/

Look for the MyACT app in the Google Play store and download it for your Samsung or other android device.

And watch for the iOS version for iphone, ipad, etc. - *coming very soon!*

US HAEA Angioedema Center at UCSD

The Center-which officially opened in January-is enjoying great success. Hundreds of HAE patients have received state of the art HAE care by the physician/experts at the only clinic in the United States dedicated to HAE patients.

Financial assistance for travel and other costs is available, based on need. If you are interested in being seen by one of the Center's caring and compassionate expert physicians, go to www.angioedemacenter.com where you will find all the information needed to set up an appointment.

HAEA Expanded Social Media Reach

As the electronic era continues to grow and evolve, the HAEA is working hard to make sure our patient community has all of the latest real-time information and updates related to HAE right at their finger tips!

http://www.angioedemacenter.com
This web site is your introduction to the US HAEA Angioedema Center at UCSD. The Center offers comprehensive care for patients with all types of angioedema, state-of-the-art diagnostic tests and techniques, the latest available therapeutic modalities, a full range of patient support programs, and cutting-edge research in angioedema. The Angioedema Center, in partnership with the US HAEA, aspires to improve the lives of angioedema patients in the USA and throughout the world.

https://instagram.com/us_haea/
For those of you who are avid Instagram users, the HAEA is now on Instagram! You can now view photos of HAEA events, partnerships and other efforts on behalf of our community. Like or Comment today!

www.twitter.com/TonyJCastaldo
www.twitter.com/US_HAEA
Follow the HAEA President and all of the HAEA news at these Twitter accounts. Real time news for our HAEA community - feel free to favorite and retweet our HAE posts!

http://www.haea.org/get-involved/social-media/
There are now four official HAEA Facebook (FB) pages available to you! You can access them all at this link.

The US Hereditary Angioedema Association is the official FB page for our community. It is a closed group - which means you must ask to join. (Please note: you must have the Message feature enabled on your personal FB page so that we can contact you.) It is a closed group so that you can feel safe in posting your personal triumphs and challenges, your HAE stories.

US HAEA Teen Facebook Group is the official FB page for our community's teenagers. It is also a closed group for privacy and membership is limited to teens so they can feel free to share personal messages of struggle and triumph and their HAE journey.

Hereditary Angioedema Association - HAEA is a Facebook resource page for the HAEA community to keep up with all the latest HAE and HAEA news

Within the first few days of launch, this page was accessed by thousands of viewers. There are many Facebook pages out there, but only one that brings you the unbiased and authoritative news on all things HAE - be sure to check

Hereditary Angioedema Association - HAEA often to see what is new.

US HAEA Angioedema Center at UC San Diego is the Facebook resource and information page for the Center. Here you can find out what is the latest Center news, read the Question of the Week and learn about making appointments with the HAE physician experts there. Photos and news are added each week so check back often!

hae day :-) May 16, 2015

hae day :-)
MANY FACES
ONE FAMILY

May 16 was a great day for HAE awareness! Almost 2 dozen patient events were held this year to raise awareness and funds for HAE research.

Three events were repeated from previous years with even bigger participation - Walk the Square, Lyndon Walk, Show Your Swell Walk.

HAEA youth created educational events and fundraisers were advertised through special web sites with the help of hae day facilitator Jenny Barnes (HAEA).
hae day :-) events can be held throughout the year!

If you have a great fundraiser or awareness event in mind, please see www.haea.org/hae-news/hae-day/about-hae-day-2/ to check out this year's events and to learn more! We look forward to an even greater HAE awareness in 2016 with many hae day :-) events !!!

US HAEA Scholarship Program Launched

In support of our HAEA younger generations and in conjunction with the Year of the HAEA Youth, the HAEA was proud to launch the HAEA Scholarship Fund.

The HAEA is dedicated to helping our young community achieve their lifelong goals and aspirations. The Scholarship Program provides financial support for young HAE patients seeking to improve their lives through academic achievement. Scholarships are available to US citizens with a confirmed HAE diagnosis (letter from a licensed physician) who will be enrolled in an undergraduate educational institution.

All applications are reviewed by the Scholarship Committee, an independent adjudicatory board with no HAEA affiliation. A number of scholarships were awarded for Fall 2015 based on a combination of financial need, academic effort, and individual educational goals.

Congratulations to our HAEA youth!

US HAEA Scientific Registry Report - Research for a Cure

2015 is shaping up to be the ***best year yet***
for Attack Event and Quarterly Reporting!

Thanks so much to all of our dedicated members who have submitted reports during the 1st and 2nd Quarters along with Attack Event questionnaires. Your dedication to the Registry is amazing and so very much appreciated!

Are you a member of the US HAEA Scientific Registry?
Your unique experience living with HAE provides crucial information for researchers, including:

*DNA from your blood sample
*data on HAE therapies you may use
*and how you manage your disease day-to-day

Online reports bring us closer to a cure! And reporting is fast and easily accessible via the Internet.

We invite you to go to http://www.haea.org/get-involved/us-haea-scientific-registry/ and sign up to be a Scientific Registry member!

IMPORTANT Upcoming Opportunity:
If you are planning to attend the US HAEA National Patient Summit in Denver on October 9-11, you will have the perfect opportunity to donate your Scientific

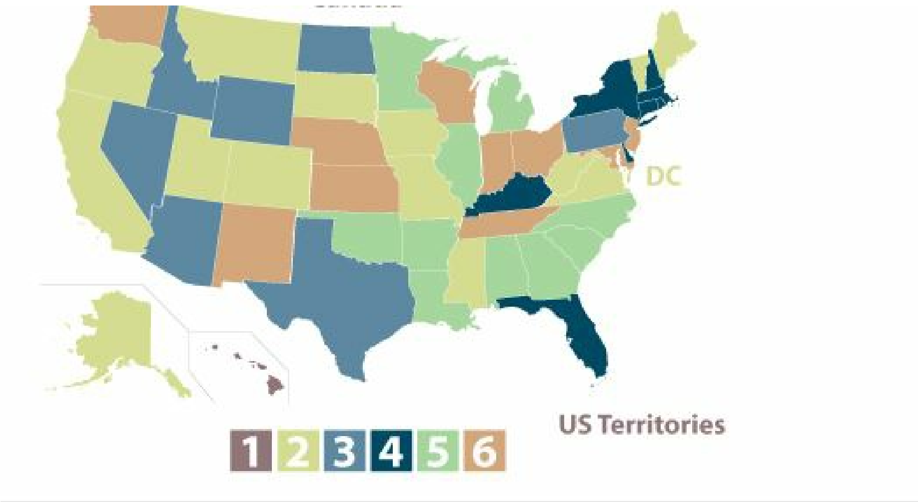
Registry blood sample *free of charge*.
Come and meet us there - whether old friend or new!

Lastly, a couple changes we want to let you know about - Susan Finley has moved on to a new position at the end of July. We wish her all the best. And Anna Long has changed her name to Anna Chenoweth - congratulations to her on her recent marriage! Anna will now serve as your full-time Scientific Registry Administrator.

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

Thank you again for your dedication to *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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