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US Hereditary Angioedema Association

US HAEA TODAY

SPRING/SUMMER 2013 Newsletter

A Message from the President

Dear HAEA Friends,

We are very excited that our dream of having a comprehensive care and research center dedicated to patients with swelling problems is about to become a reality. The US HAEA Angioedema Center at the University of California at San Diego will be open and begin seeing patients later this summer.

The fundamental mission of the US HAEA Angioedema Center is to provide our patient community with access to internationally respected expert angioedema clinicians and researchers in a warm and caring environment.

The Center is available for any patient who experiences problems with swelling and will offer a full range of diagnostic services

- the opportunity to work with an expert physician to prepare a comprehensive care/management plan,
- post-visit coordination and consultation with the local physician to help implement that plan

The Center will also serve as an international leader in setting the standard for angioedema diagnosis and care and conducting groundbreaking angioedema research. In addition, the HAEA will be fully integrated into the Center's operations and will be responsible for working closely with patients to

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- set up appointments,
- coordinate insurance determination and travel arrangements, and
- stay in touch during and after their trip to San Diego.

The US HAEA Angioedema Center is a trail blazing endeavor and marks the first time that a rare disease patient organization has been responsible for establishing and helping to fund such an all-encompassing care center.

Above all, we believe that the Center will have a major impact on angioedema diagnosis and care and will bring us closer towards meeting our strategic vision of helping patients achieve life long health.

Warm regards to all,

Anthony J. Castaldo
President, US HAEA

Your US HAEA
Patient Services Team Members

US HAEA Angioedema Center at UCSD - Meet the Center's Physician Experts

Bruce Zuraw, MD

Dr. Zuraw has been a practicing allergist/immunologist for more than 30 years, and specializes in all types of non-histaminergic angioedemas,with particular attention to Hereditary Angioedema. He is Professor of Medicine and Director of the Allergy & Immunology Training Program at the University of California School of Medicine, San Diego.

Dr. Zuraw is board-certified in allergy/immunology. He chairs the US HAEA Medical Advisory Board, is an international thought leader in angioedema and has been a driving force behind HAE research in the US.

Dr. Zuraw has been proposed as the first US HAEA Endowed Chair at UC San Diego.

Marc Riedl, MD

Dr. Riedl will join the Center on July 1, 2013 as Associate Professor of Medicine and Clinical Director of the US HAEA Angioedema Center at UC San Diego.

Dr. Riedl received his medical degree from the University of Chicago-Pritzker School of Medicine, trained in internal medicine at Washington University/Barnes-Jewish Hospital, St. Louis, and completed fellowships in Allergy/Immunology and Clinical Pharmacology at UCLA. He also received a Master's degree inClinical Research at UCLA.

Dr. Riedl directs the clinical services of the Angioedema Center and leads the Center's active clinical research program. Dr. Riedl is board-certified in allergy/immunology and sits on the US HAEA Medical Advisory Board. He is an international thought leader in all angioedemas and has been a driving force behind HAE research in the US.

Sandra Christiansen, MD

Dr. Christiansen is Clinical Professor of Medicine at UC San Diego and a volunteer faculty member at the Angioedema Center.

Dr. Christiansen received a medical degree from Loyola University Chicago Stritch School of Medicine in Maywood, Illinois, trained in internal medicine at UC Los Angeles and UC San Diego, and completed her fellowship in Allergy & Immunology at the Scripps Clinic and Research Foundation.

Dr. Christiansen is a member of the Department of Allergy at Kaiser Permanente in San Diego, where she is Director of the Allergy training program. She serves as a member of the US HAEA's Medical Advisory Board and has played an active role in angioedema research. Dr. Christiansen is the recipient of numerous research grants and awards and is an internationally respected allergy and angioedema expert.

US HAEA National Patient Summit - Register Today!

2013 US HAEA National Patient Summit
September 27-28, 2013 in Orlando, FL

Registration is now OPEN!

The National Patient Summit will feature a ***completely new*** format - one in which you and your family can participate in a powerfully ***interactive*** way!

* Be part of exciting and unique opportunities to contribute to medical science and the understanding of HAE! HAE scientists will be conducting interactive (anonymous) HAE data research and plan to use this important data to prepare a medical journal article.
*Learn how to make your voice heard on Capitol Hill - work with the HAEA's public policy experts to write your Congressional leaders and mail your letter right from the Summit!
*Learn how Healthcare Reform and insurance reimbursement apply to you!
*Talk one-on-one with physician/researchers, experts in all areas of angioedema
*Meet new HAEA friends!
*Visit with representatives from the companies who make FDA-approved HAE medicines!
*Join the US HAEA Scientific Registry - help find a *cure*!
*Ask your HAE questions to a panel of world renown physician experts
*Enjoy Saturday night's dinner and entertainment!

Register TODAY at http://www.haea.org/hae-news/2013-us-haea-national-patient-summit/registration
You can find a Summit agenda there too.
And watch for more details to follow in the coming weeks!

Building a Better Future Together!

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

john@haea.org Why are Clinical Trials Important?

The HAE patient community's willingness to participate in clinical trials has led to FDA approval of 4 HAE treatments that allow patients to both treat and prevent HAE attacks. The exciting news is that further improvement in HAE patients' quality of life is on the horizon! Clinical trials are either underway or planned for testing

- subcutaneous administration of current IV medicines, and
- completely new medicines to prevent attacks including a once a month subcutaneous injection, and a therapy in pill form.

HAEA friends already know that participating in clinical trials requires effort and can be a bit inconvenient, but there can be some great benefits - such as free treatment during the course of the trial. Four FDA-approved HAE therapies since 2008 provides compelling evidence that our community is always ready to step up and participate! After all, clinical trials provide the only path available for FDA approval of better treatments that will enable an even healthier and happier future for us, our children, and all affected family members.

Anyone interested in participating in a clinical trial should contact HAEA Patient Services Team member John Williamson at 972-984-0621 or at john@haea.org

HAE DAY 2013 A Second Successful Year!

How did YOU mark the day on May 16?

US HAEA members held more than 17 events around the country - from a heartfelt report to classmates, to dinners, to Walks, to percentages of sales donated, to providing HAE information at local medical facilities, and more.

Be sure to check out all of the 2013 events listed at http://www.haea.org/hae-news/hae-day/fundraiser-events/ Some events are still to come in 2013, so if you see one in your area, please plan to attend! J

HAEA President, Tony Castaldo, was able to attend the Lyndon Brooke Stidham Memorial Walkand was featured in television interviews that reached thousands with HAE information.

HAEA Executive VP, Janet Long, was able to raise HAE awareness in the Commonwealth of Puerto Rico, with a media tour following the Puerto Rican governments passing of a resolution declaring May 16 HAE DAY there. Puerto Ricans are US citizens and there are an estimated 130 HAE patients on this island.

A big THANK YOU to everyone who organized an event to mark hae day :-) this year - you can be proud of your efforts to raise HAE awareness. You have made a difference for all HAE patients ,caregivers and families!

It's never too early to start planning your hae day :-) 2014 event. And there are still great products you can purchase to show your hae day :-) pride all year
http://www.haea.org/hae-news/hae-day/fundraiser-products-available/

Spreading HAE Awareness within the Medical Community

In February 2013, your HAEA executive staff attended the largest national conference of allergy/immunology specialists in the US (AAAAI, for short). With our HAEA exhibit, more than 4200 physicians and other healthcare professionals who may have never heard of HAE before, learned about HAE. They received information on the new FDA-approved medicines available and on the power of the US HAEA as a community where patients can find compassionate support and a strong advocate.

In late May, HAEA staff also attended the Eastern Allergy Meeting of allergy/immunologists in the country. More thousands of physicians learned about HAE there. More meetings will be attended in the Fall on behalf of our community as the
US HAEA continues to educate the medical community on this large scale as well as one-to-one in our on-going awareness efforts on behalf of our members.

The US HAEA Scientific Registry Report

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

What's New?
The Scientific Registry is enhancing its communication to its members and, as always, inviting *everyone* to participate in the US HAEA's vital work - toward a ***cure!***

Recently, SR members received a paper version of the 1st Quarter report in the mail while the new SR online system is completed. The plan is for the new online system to be ready for 2nd Quarter reporting.

The SR Administrators and your HAEA have listened carefully to your input and this new reporting system will streamline your time and effort, because every minute that you contribute to research is so incredibly valuable to the future of all who suffer with HAE!

Can I join the Registry in Orlando?

We would like to welcome YOU as a new member!
And it's easy to join the Registry at the upcoming US HAEA National Patient Summit in Orlando.
You can complete the entire first phase of the Registry in one quick step - your paperwork plus your blood donation right at the hotel! We will set you up for your online HAE reporting and award you with a Scientific Registry member pin!

Already an SR member? If you attend the Summit in Orlando, you'll be eligible to receive additional recognition for your participation.
Were you at the first Orlando HAEA National Patient Conference? There's a prize for you!
Have you submitted 6 or more Quarterly reports - there's a prize for you, too!
We'll also announce a new 5-year award - everyone will become eligible for this award starting in Jan. 2014! Learn more in Orlando! See you there!

Contact Us

Remember, your SR Administrators are available to answer any questions and assist with any SR issues.
If your last name begins with the letter A - J, Sharon Grina is here to help you - sharongrina@haea.org
If your last name begins with the letter K - Z, Susan Finley is here to help you - susanfinley@haea.org

Your Patient Services Representatives by Region

Your US HAEA Patient Services Team

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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Find your region and your Team Member at
http://www.haea.org/contact/patient-services-representatives/