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The US HAEA Summit, 2017!

We are excited to share details of the 2017 US HAEA National Patient Summit!

The US HAEA is excited to announce our upcoming National Patient Summit! This 2017 meeting will be held for our entire HAEA community and will feature some familiar offerings, including: educational lectures and one-on-one learning opportunities with HAE expert physician/researchers, the chance to participate in on-site HAE research, a fun evening - dinner and entertainment to enjoy with members of your HAE community, another exciting HAE in Motion 5K walk/run, and more!

Save the Date! September 15-17th in Minneapolis, MN!



HAEA Capitol Hill Day 2016!



In June, the HAEA took 21 participants to Capitol Hill in Washington, DC to meet with congressional leaders there. These patients and family members advocated for congressional action on political issues that benefit HAE patients in the US. Constituents made their voices heard in over 35 Senate and House offices, advocating for more research funding and continued access/reimbursement for HAE medicines.

HAEA volunteer advocate John Harrington and his son Michael join Tony Castaldo in presenting the HAEA Distinguished Public Service Award to Congressman Leonard Lance. Rep. Lance signed a letter to the NIH asking for more HAE research funding and is a member of the Rare Disease Caucus.

HAEA President, Tony Castaldo presented the award to Rep. Lance as well as an award to Sen. Brian Schatz for his outstanding support of legislation that benefits HAE patients and families. Also pictured, HAEA Assistant Vice President of Patient Advocacy, Lois Perry.



HAEA Patient Advocate Sherry Swanson was excited to meet Illinois Senator Dick Durbin, Ranking Member, Defense Appropriations Committee and longtime supporter of the HAE community as she walked the halls of the Senate!

HAEA Patient Advocate Sherry Swanson was also glad to meet with her Congressman Randy Hultgren of Illinois, another fantastic supporter of the HAE community and our current initiatives on Capitol Hill. Also pictured is Janet Long, HAEA Executive Vice President.



[Click here to learn how YOU can get involved on the hill!](#)

HAEA Cafe!



Check out the new look of the HAEA Café! We are working hard to develop even more exciting features to enhance your experience at the café, our unique and private communication platform allowing members to virtually meet one-on-one with HAEA patient advocates, attend fascinating webinar presentations, and reference quick updates and links to important HAE information. The President's Table holds "virtual update" webinars with important information on topics like access and reimbursement, health management and ER education, and much more.

In case you missed it! All of our informative Café webinars over the past few months are now available on the Café Archive! View these important presentations on insurance basics, visits to the Emergency Room, advocacy in the nation's capital, and more.

Not a member yet? Don't miss out! Click on the button below and claim your profile, today!

Click [HERE](#) to Join the HAE Café Today!

Continuing Medical Education

Announcing a new CME program on HAE in the Emergency Room



Marc Riedl, MD

Clinical Director of the US HAEA
Angioedema Center at the UC San Diego.
Professional focus on angioedema
conditions and primary immunodeficiency,
and clinical pharmacology.



Jesse Pines MD, MBA, MSCE

Director of the Center for Healthcare
Innovation & Policy Research at The George
Washington University.
Professor of Emergency Medicine
and Health Policy.

Angioedema in the Emergency Medicine Setting
Optimizing Management for Every Patient

The US HAEA is proud to provide a brand new Continuing Medical Education (CME)

module specific to treatment of HAE in the Emergency Department.

Dr. Marc Riedl and Dr. Jesse Pines discuss angioedema in the ER. These experts review both histamine and bradykinin-mediated angioedemas. They also review appropriate management strategies for both angioedema pathways.

The webinar is produced in cooperation with the American College of Emergency Physicians (ACEP) and may be viewed by doctors, nurses, pharmacists and any others interested in learning more about HAE.

The webinar is FREE and medical professionals who attend will receive 1 CME credit upon completion. The US HAEA is proud to provide another vital educational tool, specific to HAE in the emergency room.

The HAEA Scholarship Program 2016

The US HAEA Scholarship Program demonstrates the HAEA's longstanding commitment in supporting the HAE patient community with lifelong health and personal goals and aspirations.

Please join us in congratulating all of our HAEA Scholarship Recipients for the Fall program of 2016. Stay tuned for information regarding future scholarship opportunities. Visit us on [Facebook](#) to read through all of our scholarship recipients who have shared touching and inspirational testimonials.

Meet Maureen - one of the US HAEA Scholarship 2016 scholarship recipients. "I am honored to have received the HAE Scholarship for the 2016-2017 school year. I will be continuing my education at the University of Connecticut as a mathematics education major. This scholarship will help me in pursuing my dream to become a teacher. I am extremely grateful for the HAEA and its generous contribution towards financing my education."



HAE IN Motion 5Ks



As you've probably heard, the HAEA has created a new national fundraising platform to benefit our HAE community called HAE in MOTION. This program supports patients in hosting 5k walk/run events to raise awareness in their own communities throughout the nation. We have successfully hosted nearly 10 events this year with 12+ events already booked for 2017! Some of our successful latest events this year took place in Omaha, Philadelphia, Chicago, Cincinnati and Rhode Island. These events have been nothing short of inspiring as hundreds of patients participate and set-up teams with family, friends, co-workers and other supporters to drive awareness and take a stand against HAE. [Visit us on facebook for pictures of past events and updates](#)

Another great success was the HAE in MOTION 5k held on the island of Puerto Rico, where nearly 300 runners enjoyed a sun-filled day and a brunch provided for patients after the event finished. We look forward to the next races to be held in Atlanta, GA and San Diego, CA. Each year, these events will grow in number and in the impact they have to raise HAE awareness across the US!

Click [HERE](#) to Register for a 5K event in your area, TODAY!

Patient Meeting in Puerto Rico



The largest meeting of HAE patients to date was held in Puerto Rico on August 7th. Puerto Rico is a small island by population, but the incidence of HAE is the same as everywhere else in the world, so gathering more than 100 patients and family members together was a great success. HAEA Patient Advocate and Puerto Rico resident, Michelle Cuevas introduced the meeting speakers: HAEA President Tony Castaldo, physicians Rafael Zaragoza and Anardi Agosto and HAEA Clinical Nurse Manager, Troyce Venturella. The day closed with a professionally produced slideshow from the recent HAE in MOTION 5k held in San Juan. HAEA Puerto Rico is growing and making great strides for lifelong health for all of those on the island. Mas Salud! Mejor Vida!

Click [HERE](#) to Join our HAEA family, it's free!

World Premier of "Special Blood"



President Tony Castaldo of the US HAEA and other HAEA staff members attended the world premier of Director Natalie Metzger's riveting film, "Special Blood" in San Diego. Natalie is a gifted film maker, and her work serves as a magnificent tribute to HAE patients.

Here is a synopsis: "Special Blood provides provides an absorbing, unfettered view into the world of families whose loved ones are affected by a rare, debilitating, and potentially fatal disease known as Hereditary Angioedema. The film probes the depth of human emotions as families cope with loved ones experiencing wearying chronic symptoms and mothers transform the grief of losing their precious children into purposeful advocacy. Special Blood

provides a front row seat for inspirational stories of survival in the midst of despair and the deep human predisposition for hope and positive action."

A must see for everyone in our patient community! Congratulations to Natalie and her talented team for capturing the essence of what its like to be an HAE patient.

[Click HERE For Special Blood Screening Details](#)

HAEA Scientific Registry Corner



The US HAEA Scientific Registry

Patient Driven Research for a Cure

Thank you again for your dedication to *Patient Driven Research for a CURE!*

[Click HERE to read more about the HAEA Registry!](#)

US HAEA Patient Advocates

MEET YOUR PATIENT ADVOCATES!

Click [HERE](#) to contact your dedicated HAEA Patient Advocate today!

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