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Official e-mail from HAEA



HAE in Action!

HAEA focuses on Health, Advocacy, Engagement and Advances in Research

A Call to Action

Changes to the US Health Care System are Likely in 2017! **Sign up now to be Part of the HAEA Team that Fights to Maintain Access to HAE Therapies!**

This is the time to become active and you can make a difference by joining our grassroots efforts as an HAEA Patient Rights Advocate and speaking out in favor of quality and affordable healthcare.

The HAEA has built a strong presence on Capitol Hill and maintains a prominent role within several important rare disease patient coalitions. Given the looming changes, our patient community must be ready to vigorously “take on the fight” for robust healthcare insurance coverage and, if and when an “access to therapy” public policy challenge arises.

Our community must be ready to unite in order to send a clear, consistent, and strong message to our elected representatives about HAE patient rights. For more information on how you can become an HAEA Patient Rights Advocate contact John Williamson at john@haea.org.

Changing to Better Meet the Needs of HAE Patients

As we continue to grow together, we want to always be sure that we are meeting the needs of you, our HAEA members. With this in mind, the HAEA will soon announce how we will strengthen our mission through the realignment of our work teams and a more focused approach to **Health, Advocacy, Engagement and Advances in Research (HAEA)**. We are committed to our HAEA community and look forward to helping each one of you achieve lifelong health. Watch for more information on the new HAEA and ask us how you can get involved!



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

Continuing Medical Education



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 pleased to partner with the American College of Emergency Physicians (ACEP) to provide a brand new Continuing Medical Education (CME) module specific to treatment of HAE in the Emergency Department. The ACEP is the national association with a reach to all emergency doctors in the US. Dr. Marc Riedl and Dr. Jesse Pines discuss angioedema in the ER in this new CME that is available on www.haeedu.com. These medical experts review both histamine and bradykinin-mediated angioedemas. They also review appropriate management strategies for both angioedema pathways. The CME module on HAE and the Emergency Department is another important initiative of the US HAEA that will make inroads into education for emergency physicians. The module may be viewed by doctors, nurses, pharmacists and any others interested in learning more about Hereditary Angioedema.

The US HAEA also attended the ACEP national conference in Las Vegas, NV in October to educate the thousands of ER physicians on Hereditary Angioedema.

[Click HERE For More Information](#)

Get Involved in HAE Events!



The US HAEA will have a full agenda for 2017 and we are looking forward to seeing you! Whether you plan to host an HAE in Motion 5K race, attend one of the many health and wellness webinars, go to the Special Blood Documentary Film screenings, celebrate HAE Day, or gather for our National Patient Summit

in Minneapolis, there are many ways for you to participate!

2017 will be an active year for HAE patients and engagement and awareness will be key in helping to educate the general public about this rare condition. The HAE in motion 5K races will take place in multiple cities across the nation. The HAE IN-MOTION® 5K is projected to serve as our largest HAEA national fundraising event. We're encouraging all patients and members of the HAEA community to host their own HAE IN-MOTION 5K events throughout the country to raise awareness and help HAE patients achieve lifelong health. For more information on how you can host or participate in a race go to: <http://events.haea.org>

Special Blood Cinema Screenings



The documentary film by Natalie Metzger follows four patients with a dramatic, rare disease fighting to live normal lives. Faced with a life-threatening condition, they join together to conquer adversity, finding strength in each other and their small but strong community.

Special Blood is an intimate look into the personal lives and struggles of rare disease patients in America. Filmmaker Natalie Metzger uncovers stories of inspiration, struggle, and death come too early. As she enters the community which they have created around their shared disease, she shows us how these brave underdogs are changing the future for rare disease patients on a global scale. The film has been recognized repeatedly.

- Official Selection – Awareness Film Festival
- Winner – Best Woman Filmmaker Chandler International Film Festival
- Official Selection – Mosaic World Film Festival

For more information about screenings in your area go to:
<http://www.facebook.com/specialbloodmovie>

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

The US HAEA Summit, 2017!

The US HAEA is excited to announce our upcoming National Patient Summit on **September 15-17th in Minneapolis, MN!** 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!



US HAEA Patient Advocates
MEET YOUR PATIENT ADVOCATES !

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

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