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HAEA in Action October Newsletter

A message from US HAEA President, Tony Castaldo - Remembering Chris Whalen

Dear HAEA Family,

It is with great sadness that we announce the passing of our beloved friend, Chris Whalen. Chris is a founding member of the HAEA Board of Directors and also served our patient community with great passion and distinction for the past 17 years. He had a significant role in shaping the HAEA's programs and activities. As a professional engineer and owner of his own company, Chris's systematic thinking and inherent understanding of how to manage risk put the HAEA on a solid path, that resulted in six FDA approved products for



our HAE patients. A beloved husband, father, and friend, we are heartbroken and will miss him terribly.

Click here to read Chris Whalen's obituary: <http://www.klaassenfuneralhome.com/notices/Christopher-Whalen>

Spectacular Memories of our 2017 US HAEA Patient Summit!



“Thank you to ALL who participated in this year's 2017 US HAEA National Patient Summit! Hundreds of attendees helped to make this year's 3-day conference an unforgettable one! The SUMMIT was a fantastic opportunity for our community to raise awareness and #StandUpStrong4HAE. I'm thrilled about all the incredible memories that we shared this year. The SUMMIT is always an exciting opportunity for attendees to forge new friendships and I enjoyed the chance to talk with everyone in our patient community.

The SUMMIT was a great time for the HAEA to share how we continue to provide a variety of essential services aimed at helping our community achieve lifelong health. We premiered at the SUMMIT how we are strengthening our mission by aligning our staff and operations along four major high priority areas of

focus (pillars) that, coincidentally, match the HAEA acronym; **H**ealth, **A**dvocacy, **E**ngagement and **A**dvances in Research. The focus remains on you, the patient/caregiver, and we are excited to move forward with our ambitious plans to continue serving the HAE community with robust programs within each of our four pillars.” – Anthony Castaldo (US HAEA, President)



This SUMMIT included fun and exciting activities for HAE Youth. We had an amazing room for our Scientific Registry (#AdvanceHAE); educational conferences; the screening of the compelling documentary Special Blood; and an exhilarating Lip Sync Battle. The weekend ended with a sensational HAE IN-MOTION 5K event at Normandale Park. These are only some of the special events enjoyed at the 2017 SUMMIT.

The US HAEA hopes you enjoyed the 2017 SUMMIT as much as we enjoyed providing it for you, our community. We look forward to another amazing gathering for our community in 2019. Until then – remember, Together we Stand Up Strong for HAE!

Your feedback is very valuable to us. Please take some time to fill out our 2017 National Patient Summit Survey and provide your thoughts on the Summit!

(If you missed it, check out and make sure to "LIKE" all of our different SUMMIT sessions & events videos and photos on Facebook [@hereditaryangioedema](#) and Twitter [@US_HAEA](#) [#StandupStrong4HAE](#))

US HAEA Family #StandUpStrong4HAE at The FDA Meeting



Many patients and family members from the US HAEA participated in a Patient-Focused Drug Development (PFDD) meeting for Hereditary Angioedema with the FDA this past Monday, September 25 on the FDA's Silver Spring, Maryland campus. The PFDD program is part of the FDA's performance commitment under the fifth authorization of the Prescription Drug User Fee Act (PDUFA V). This public meeting was held to allow the FDA to hear HAE patients' and caregivers' perspectives on the impact of Hereditary Angioedema (HAE) on daily life. The FDA was also interested in patients' views on treatment approaches for HAE.

"Hello! My name is Stephanie, and I have type 3 Hereditary Angioedema (HAE). No one in my family has been diagnosed with

HAE before. When you have an attack, you feel the limitations. HAE limits your life when you have an attack or not. Anytime, I get a common cold it's not normal, because I know I'm going to get a swell. Thanks to the US HAEA and the FDA for giving us the opportunity to SHARE our testimonials with the COMMUNITY!" Stephanie (Patient).

"With the patients, FDA, physicians and pharmaceutical companies working together to get things done, we now have products that transform lives. We've heard about incredible stories from our HAE patients, but we still need better therapies and ultimately a cure. We stand up here for our PATIENTS! Thanks to our PATIENTS and ADVOCATES for being here with me TODAY. You make a DIFFERENCE!" Anthony Castaldo (US HAEA, President).



Save The Date!

- Saturday, October 7, 2017 - Roger Williams Park - Carousel Village, Providence, RI **online registration will close on 10/5/17**
- Sunday, October 22, 2017 - Chatfield State Park, Littleton, CO
- Saturday, November 18, 2017 - Camp Mabry, Austin, TX

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Survey!

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