



## HAEA in Action August Newsletter!



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**In Memoriam - Pam King**

It is with heartfelt sadness we inform you that Pam King, who worked with the HAEA for the past 10 years as a consultant and most recently as our Chief Operating Officer, passed away from metastatic breast cancer on June 16th, surrounded by her family and friends.

Pam fought a valiant battle since her initial diagnosis of metastatic breast cancer, and true to the Pam we know and love, she could not sit back and just be a patient. She became a staunch metastatic cancer advocate and paved the way for greater awareness and increased research funding.

Pam possessed a unique understanding of the HAE patient community's needs and used that knowledge to become a driving force behind the HAEA's growth and development. There is so much to be said about Pam's enduring effect on the HAEA and all of us individually, but I don't have the words at my disposal to even come close to describing the full scope of her magnificent impact.

Our thoughts and prayers are with Pam's immediate and extended families. It's just not enough to say that we will all miss her.

Pam is survived by her beloved husband, Chris Pike; her mother, Pat King; and her brother, Don King. A service will be held Saturday, August 4<sup>th</sup> at 1:00 pm, at St. Mark Church in Jamestown, Rhode Island, with a Celebration of Life to follow at 3:00 pm at the Conanicut Yacht Club.

**Tony Castaldo, HAEA President**



[Click here to read Pam King's obituary.](#)

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## **HAEA Volunteer Advocates Descend on Capitol Hill**

The HAEA's 2018 Capitol Hill Day was a great success as 100 dedicated members of the HAEA community visited over 75 Senate and House offices to advocate on behalf of all HAE patients. Our volunteer advocates delivered a vitally important message requesting continued support for HAE patients that includes expanded research, access to charitable assistance programs, and research funding. Clearly, our legislative leaders are listening to the HAE awareness-raising stories and patient-driven agenda that were presented. Already, four members of Congress whose offices we visited have agreed to co-sponsor H.R. 3976—the bill that aims to eliminate restrictions on charitable assistance for insurance payments. The HAEA has also received positive feedback on our requests for additional HAE (and NIH) federal research funding. HAEA Volunteer Advocates requested that policy makers specifically address the following issues:

1. Additional funding for National Institutes of Health (NIH)
  2. Maintain HAE on the Department of Defense (DOD) Peer Medical Review Program
  3. Support for H.R. 3976 which supports Charitable Assistance Programs
  4. Expand awareness of HAE related legislative and healthcare issues
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## Congressmen Stand Up Strong for HAE during Capitol Hill Day Special Briefing

The HAEA hosted a Congressional Luncheon Briefing in which key House of Representative members and legislative staff were invited to participate in a panel discussion focused on the Critical Importance of Charitable Assistance Programs to the Healthcare Safety Net. Congressmen Kevin Cramer (South Dakota), David Young (Iowa), and Gerry Connolly (Virginia) attended and spoke at the briefing. HAEA President Tony Castaldo started the meeting by emphasizing the need and value of charitable assistance programs and their impact on HAE patient quality of life. Congressman Cramer—author and sponsor of H.R. 3976 —“Access to Marketplace Insurance Act”—spoke about the importance of this bipartisan bill and the need for other legislators to co-sponsor the project in order to allow charities to be charitable. Tony then presented the 2018 HAEA Distinguished Public Service Awards to Congressman Gerry Connolly from VA and David Young from IA for their commitment to advocating for medical research and public health funding. Both Congressmen spoke about the importance of patient advocacy and how much they appreciate hearing from their HAE patient constituents. The briefing ended with a special thanks to Senator John Cornyn from Texas, who commended the HAEA on its efforts to protect and defend patient rights.



## HAEA YLC get a close-up look at Washington D.C.

The HAEA Youth Leadership Council (YLC) and youth members joined the legislative advocacy efforts during Capitol Hill Day on July 19 and demonstrated how they, too, Stand Up Strong for HAE. Members of the YLC spent a few extra days learning about the legislative process, how to advocate for themselves, and the history behind some of Washington, DC's national monuments. Dozens of HAEA kids and teens had an opportunity to speak during the legislative visits that took place during Capitol Hill Day, sharing their own HAE stories. As part of their special youth program, the HAEA hosted workshop sessions that included an Intro to Capitol Hill Day, a patient advocacy chat with Tony Castaldo, how to use social media as an advocacy tool, legislative advocacy training from the Health & Medicine Council of Washington, how to weave advocacy into your lives with YLC member Sydney Peel, and more. Participants also enjoyed the President's Dinner and a Trolley Tour through D.C. The exciting week came to a close on Friday with a Scavenger Hunt on the National Mall and a fun mixer in the evening. YLC members have posted and shared their experiences, and expressed their excitement over advocating on behalf of HAE patients like themselves, on social media.

**CLICK HERE to SIGN UP for our Youth Leadership Council!**

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## Get Tested!

Great advances have been made in the diagnosis and treatment of HAE. Today, our patient community has access to six (6) FDA-approved therapies for preventing and treating HAE attacks. It is important to note that most cases of angioedema or swelling are not HAE. The path to obtaining an accurate HAE diagnosis involves laboratory analysis of blood samples and the interpretation of the results by an expert HAE physician. Genetic testing may be a valuable tool when blood tests are borderline or otherwise inconclusive.

The HAEA highly encourages you and everyone in your family to get tested for HAE. Physicians recommend testing children as early as one year of age. If you, or someone in your family has tested positive for HAE, it is imperative that other members of the family get tested as well. The earlier you get tested, the faster you can seek treatment that can help you lead a normal life.

**If you need help finding an HAE expert physician in your area, [CLICK HERE!](#)**

**For more information on diagnosing HAE visit [HERE!](#)**

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## Ready, Set, GO!

Summer is winding down, and now is the time to start planning your fall HAE fundraising/awareness event. Thanks to your kind and generous support, we are able to increase the HAEA's overall commitment to improving the lives of HAE patients through the following three programs:

- **HAEA Scholarship Program** - provides financial support for HAE patients who are entering or attending college and seeking to improve their lives through academic achievement.
- **HAEA Compassion Fund** - offers financial assistance for patients in need who must travel to see an HAE medical specialist.
- **HAE Research** - supports expert researchers in their efforts to solve the remaining scientific mysteries of HAE, in partnership with the US HAEA Angioedema Center at UCSD.

If you're interested in hosting an event, or if you need help with ideas, please contact Jenny Barnes at [jennybarnes@haea.org](mailto:jennybarnes@haea.org).

**FILL OUT the EVENT form HERE!**

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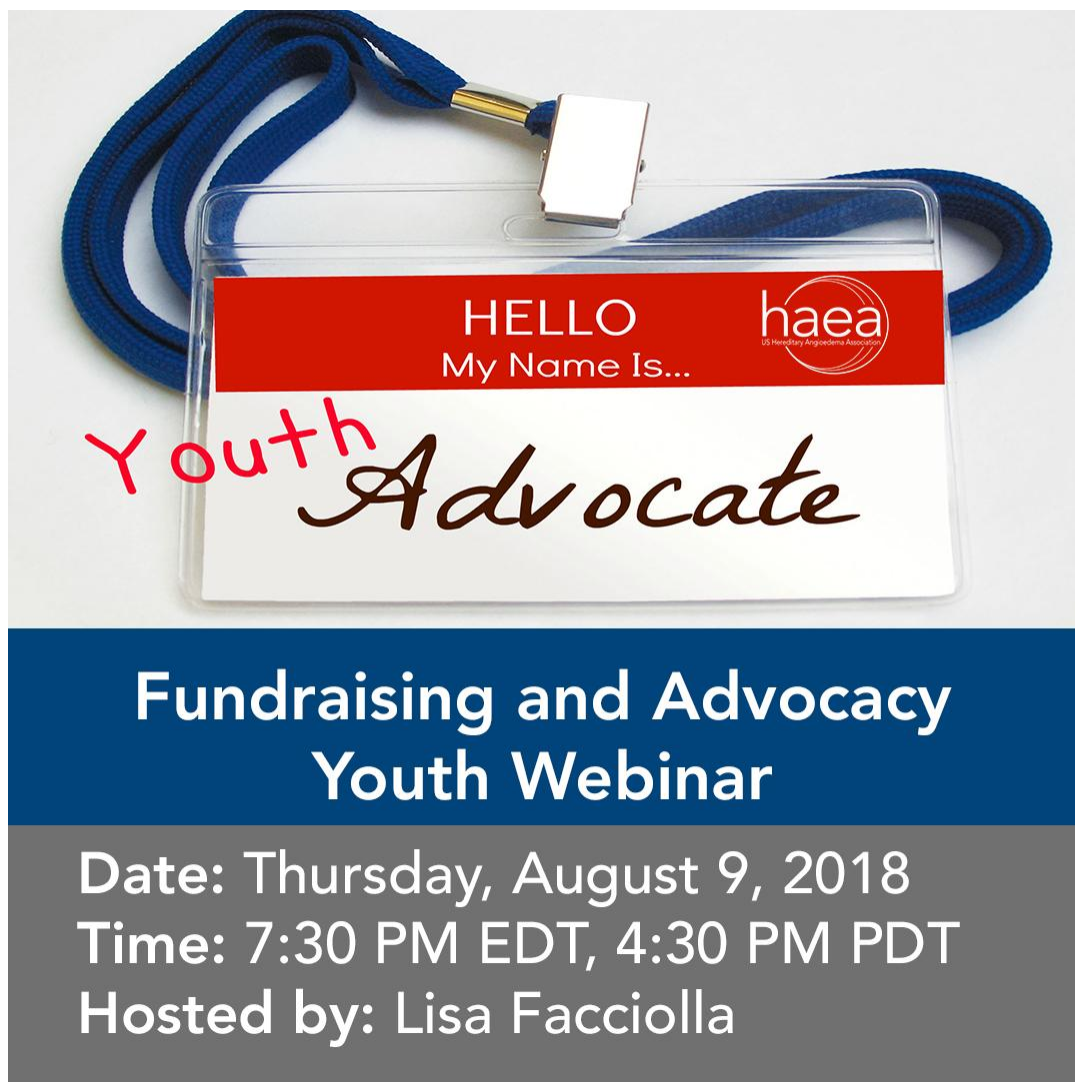


**August 4 HAE-IN-MOTION® 5K event at Danada Forest Preserve, in Wheaton, Illinois**

JOIN us after the race for great food and fun family activities! All confirmed registrants are entered into a raffle for a Bose® Wireless Speaker! Funds raised go to 3 HAEA patient support programs: HAEA Scholarship Program, HAEA Compassion Fund, and HAE Research.

**REGISTER or CREATE your VIRTUAL TEAM TODAY here!**





**Date:** Thursday, August 9, 2018  
**Time:** 7:30 PM EDT, 4:30 PM PDT  
**Hosted by:** Lisa Facciolla

**August 9 at 7:30 PM EDT: Fundraising and Advocacy Youth Webinar.**

As we approach the first annual HAE Youth Advocacy Month, we invite you to hear from young people who are involved in HAE fundraising and advocacy in their local communities. Learn about the strategies they use to host successful events. We will provide tips and guidance on simple and easy ways that our youth can raise awareness about HAE.

**Time:** 7:30 PM EDT, 4:30 PM PDT

**Hosted by:** Lisa Facciolla

**Link:** <https://haea.zoom.us/j/390104465>

**Phone:** +1 669 900 6833 (Webinar ID: 390 104 465)

CLICK that you're GOING here!





# HAEA Café Webinar

A preventative subcutaneous  
therapy option for Hereditary  
Angioedema (HAE)



W • E • B • I • N • A • R

**Date:** Thursday, August 16, 2018

**Time:** 7:00 PM EDT, 4:00 PM PDT

**Speakers:** Dr. Doug Johnston & Shari Starr (Patient Advocate)

**Sponsored by:** CSL Behring

**August 16 at 7:00 PM EDT: HAEA Café Webinar: A preventative subcutaneous therapy option for hereditary angioedema (HAE)**

**Time:** 7:00 PM EDT, 4:00 PM PDT

**Sponsored by:** CSL Behring

**Guest Speakers:** Dr. Doug Johnston & Shari Starr, Company Patient Advocate

**Link:** <https://haea.zoom.us/j/729877384>

**Phone:** +1 646 558 8656 (Webinar ID: 729 877 384)

**ADD this WEBINAR to your CALENDAR here!**

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The HAEA is a patient advocacy and research organization committed to actively engaging our community in a wide variety of grass roots activities that promote disease education and awareness. We provide personalized services



to address the unique needs of HAE patients and their families, which include helping them secure access to and reimbursement for modern HAE medicines. Our great success in supporting clinical research has resulted in a variety of FDA-approved therapeutic options. We work closely with expert physicians to continuously upgrade patient quality of life through improving diagnosis and knowledge of the disease, and encouraging a tailored, patient-focused use of available therapeutic options. The HAEA is product neutral and continues to enthusiastically support drug discovery research aimed at the next generation of HAE therapies.

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