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HAEA in Action May Newsletter

Celebrate HAE Day :)

On May 16th, hae day :-)) was established by Congressional Resolution to raise awareness of HAE among the general public and medical community in order to support better care, increase earlier and more accurate diagnosis, and spread the knowledge that HAE patients can achieve lifelong health.



This year, the US HAEA has created an **HAE ER Tool Kit** with important information that HAE patients and family members can share with their local hospital or emergency facility. The Tool kit contains educational materials that can help medical personnel identify HAE symptoms and attack triggers, that provides information about CME accredited programs, and more.

Already hundreds of HAE ER Tool Kits have been ordered and people are posting their photos on social media with

#StandUpStrong4HAEedu! Order your own ER Tool Kit and you, too, can share important information that will support HAE patients in your community and ultimately help save lives. Celebrate hae day :-) and help make a difference!

If you need help planning your own hae day :-) event, please contact Jenny Barnes at jennybarnes@haea.org.

Click [HERE](#) to Order your HAE ER Tool Kit TODAY!

Brady Club, New and Improved!



Thanks to your overwhelming support and valuable feedback, Brady has gone international! Have you visited the new and improved International Brady Club? Check out this educational resource for children ages 4-12 which includes even MORE games, puzzles from around the world, and a dedicated space to submit your own stories! The Brady Club makes learning about HAE fun! We value your feedback as we work to improve your experience as a Brady Club member. You can contact Lisa Facciolla if you have any questions at lisa@haea.org.

Click [HERE](#) to visit Brady today!

US National Summit Registration Opens on June 1st

Get ready for the 2017 US HAEA National Patient Summit!

Summit registration will open on June 1st! Mark your calendar and save the date since you won't want to miss this year's Patient Summit. This year's event will take place from September 15-17 in Bloomington, Minnesota. The theme, "Stand Up Strong", is a unifying call to action for the HAE community and a celebration of work being done by HAE Champions who make a difference every day by raising HAE awareness within their communities.

The 2017 conference is open to the entire US HAEA patient community and will feature multiple sessions and panels, one-on-one learning opportunities with HAE expert physicians and researchers, a fun evening that includes dinner and lively entertainment to enjoy with members of your HAE community, an HAE IN-MOTION® 5K walk/run, Youth Programs with exciting events for children and teens, and much more. On June 1st, be the first to register!



Friday, May 12, 2017 - HAEA Scholarship Winners will be notified via

email and announced!

Saturday, May 13, 2017 – Sportsman Lake Park, Cullman, AL
The Lyndon Brooke Stidham Memorial Walk FOR HAE will also help commemorate hae day :-). Join Team Lyndon during this HAE IN-MOTION special event to support HAE patients and families.

Saturday, May 13, 2017– HAE Glow Golf Tournament at Tri Country Golf Ranch in Cincinnati, OH

This special event to help raise HAE awareness will include dinner, an HAE Swag Bag, Live Band, and Silent Auction. For more information or to register please email: mike.mallory3@gmail.com

***Tuesday, May 16, 2017** – hae day :-)

Saturday, May 20, 2017 – HAE IN-MOTION 5k at Danada Forest Preserve, Wheaton, IL

Look for the Digital Release of the HAE documentary Special Blood on May 16th. **You can pre-order today by clicking on the link below!** A percentage of the proceeds from DVD sales will be donated to the US Hereditary Angioedema Association! For details go to:

<http://www.moviezyng.com/818522018249.aspx?microstoreID=75>

About Special Blood:

This poignant, heartfelt documentary chronicles the lives of four patients with a dramatic, rare disease. Due to the rarity of Hereditary Angioedema, Ava, Noah, Kelsie, and Lora face misdiagnosis, improper treatment, and preventable tragedy in the emergency room all as they fight to live normal lives. Struggling to be heard by an often, uninformed healthcare system, they join their voices together to face challenges and encourage others with HAE.



US HAEA Patient Advocates

MEET YOUR PATIENT ADVOCATES !

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



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