



HAEA in Action June Newsletter!



May was an exciting month as our patient community came together in so

many different ways to raise awareness for **hae day :-)**. Every event to raise HAE awareness, drive research, and raise funds to benefit **HAEA** programs for our community moves us closer to living healthier, happier, and normal lives. The following are just some of the amazing events that took place and that showcase how the HAEA continues to **Stand Up Strong for HAE!**

HAE Day Event	Participants	Organizer	Details
HAEi Global Conference	700+	HAEi	Vienna, Austria Over 154 patients, family members, and caregivers from the US attended the 2018 HAEi Global Conference in Vienna, Austria where they joined more than 730 delegates from 57 countries to learn more about how to "Take Control of HAE". (View the video here: https://bit.ly/2kFAnFz)
Man Cave Show	500+	Abby & Ollie Mallory	Hamilton, Ohio A show dedicated to outdoor activities. Ollie & Abby set up a booth to create awareness and promote their golf outing.
Elda Elementary Mom's Night Out	400+	Stephen Mallory	Elda Elementary, Ross, Ohio Movie night at an elementary school. Stephen set up a booth to spread HAE awareness and promote his upcoming golf outing.
Cincinnati Reds Opening Day Parade	45+	Mike Mallory	Cincinnati, Ohio 99 th annual parade to celebrate the first Red's home game and the official kickoff to the baseball season. The parade float included several members of the HAE Youth Leadership Council as well as local HAE patients, caregivers, and friends.
HAE Ribbon t-shirt sale	200+	Dakota Thompson	Kernersville, NC Over 200 HAE t-shirts sold and shipped in time for hae day :-) - May 16 th .
HAE Awareness Race	50	Luci Toman	Strasburg, VA Electric Slot car Drag Race event to fundraise and increase HAE awareness.
HAE Abby Glow golf	65+	Mike & Missy Mallory	Tri-County Golf Ranch, Cincinnati, Ohio Fun-filled night golf outing to fundraise and raise HAE awareness.
Lyndon's Walk across America for HAE	70+	Lora Moore	Cullman, Alabama 7 th annual event to raise HAE awareness and funding for research in memory of her daughter, Lyndon Brooke Stidham. Cullman was the first stop on Lyndon's Walk Across America for HAE.
Show your swell 5K	100+	Chris Koeppe	Liverpool, NY Annual 5k Organized by Chris Koeppe in memory of his father, who passed away from HAE.
Medical Group Presentation	125 ICU Critical Care Nurses	Crystal Lewis	Mobile, AL Presented a 60-minute talk on acute pharmacologic management of non-allergic angioedema at the American Association of Critical Care Nurses National Teaching Intensive Conference.
Fundraising and Spreading Awareness for HAE	50+	Maude Devine	Alpharetta, GA Created a personal fundraising page to share with family, friends, and co-workers to raise awareness and funds for HAE.
Wear Jeans for Rare Genes	200+	Carlie Dalgo	Luling, LA Held event at her school and a bake sale to raise awareness and funding for HAE.
Wouldn't it be swell to find a cure	100+	Maddie F.	Pittsburgh, PA Tables set up during her school lunch break to spread HAE awareness.
Brooks Life Sciences Services Town Hall Meeting	200+	Tina Agnew	Indianapolis, IN HAE awareness event at her place of employment.

You can raise awareness and funds for the HAEA's programs for those living with HAE. Creating and hosting an event is a fun way to build new

relationships, educate others about HAE, and strengthen your HAEA community's voice. If you're interested in hosting an event, please contact Jenny Barnes at jennybarnes@haea.org or complete and submit the form below.

CLICK HERE to HOST a HAE AWARENESS EVENT!



Raising awareness and supporting HAE research one kit at a time

Hundreds of patients throughout the nation have ordered the ***Advance HAE Scientific Registry Info. Kit*** and ***HAE ER Tool Kit***! These FREE resources separately provide important information on how you can drive the research needed to resolve the remaining scientific secrets of HAE, and quick facts on HAE that you can share with your local ER, school, or place of work.

All HAE patients and their family members are encouraged to join and actively participate in the ***Advance HAE Scientific Registry***. The Registry is a confidential database created to obtain uniform, long-term, complete, and accurate disease information. ***Advance HAE*** supports expert researchers in their efforts to learn more about HAE.

Order your **FREE Advance HAE info kit** here and help make a difference in the lives of HAE patients.

Or get your **FREE HAE ER Tool kit** here to distribute and share with others.

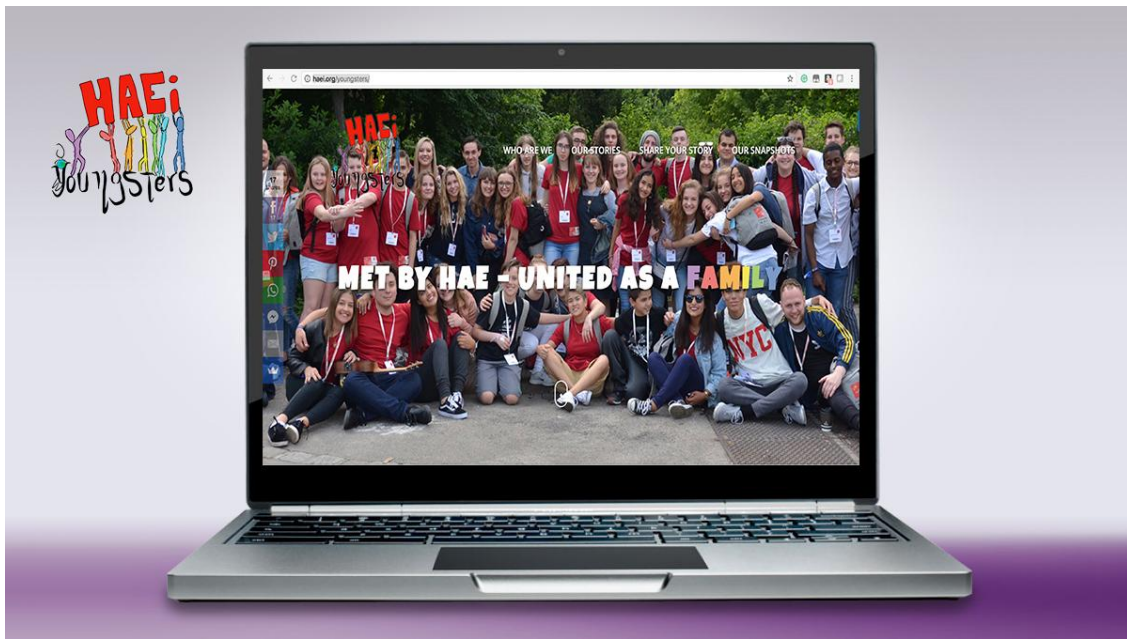


Kids and Teens Support Groups!

Do you have a kid or teen who would be interested in participating in an HAE support group?

Support groups offer a safe space to talk with peers and discuss your feelings and experiences regarding the emotional and physical impact of HAE. Often times peer support groups can provide an opportunity to address questions or situations in an open forum, and receive support or feedback from peers who are going through similar experiences.

Contact Lisa Facciolla at lisa@haea.org, if your child or teen is interested or would like more information about HAE youth support groups.



Inspired and Empowered Youth!

Kids and teens from the US joined their peers from around the world during the HAEi Global Conference, May 17-19, where they participated in the creation of a new Website and Magazine designed and created by HAEi Youngsters. You, too, can connect with new HAE friends and discover life-changing experiences by learning about different countries, cultures, and traditions. Check out ***MET by HAE -UNITED as a FAMILY!*** Designed and created by the newly formed HAEi Youngsters! Check out the HAEi YOUNGSTERS inspired and empowered website and magazine today!

VISIT the HAEi Youngsters WEBSITE [here!](http://haei.org/youngsters)



HAPPY father's DAY

2018/2019 HAEA Scholarship Awards



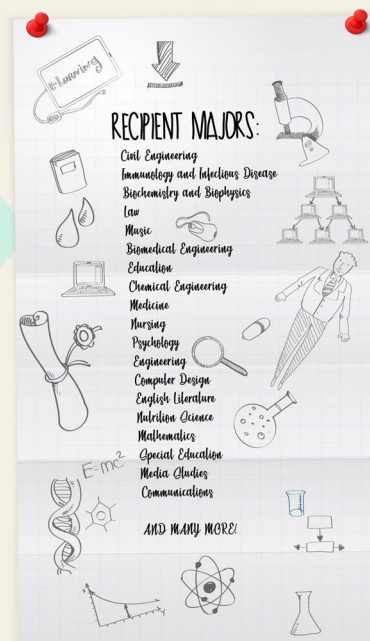
The HAEA is proud to announce the outcome of the **2018-2019 HAEA Scholarship Program**. Dedicated to helping our patient community achieve their lifelong goals and aspirations, the Scholarship Program provides financial support for HAE patients seeking to improve their lives through academic achievement.

2018 was a record breaking year for the HAEA Scholarship program, awarding a total of \$94,500 to 42 students from across the United States.

SCHOLARSHIPS
AWARDED TO
42 STUDENTS

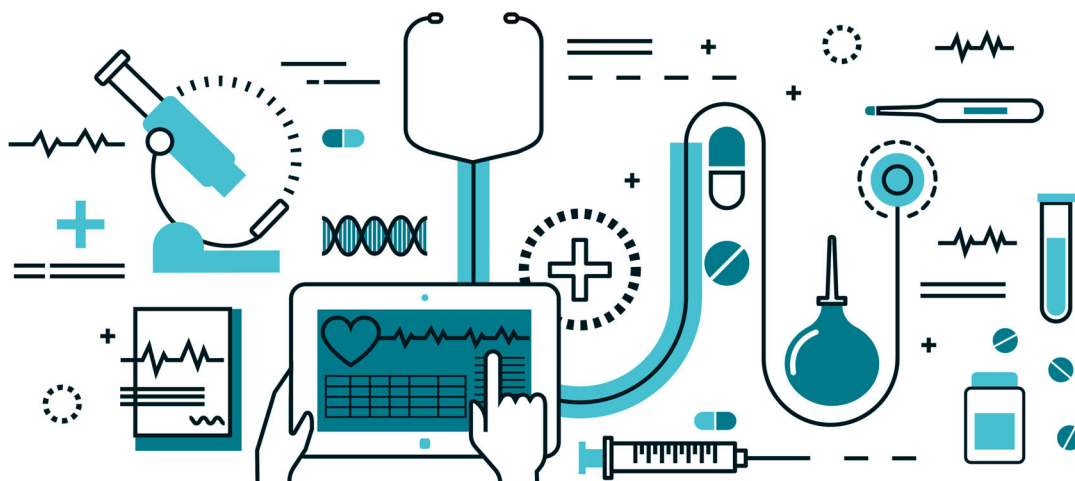


RECIPIENT STATES: Alabama, Illinois, New Jersey, Puerto Rico, California, Maryland, New York, Tennessee, Colorado, Massachusetts, North Carolina, Texas, Connecticut, Michigan, Ohio, Vermont, Florida, Mississippi, Oklahoma, West Virginia, Idaho, Missouri, Pennsylvania, Wyoming



Recipients received awards of \$2000+ for the 2018/2019 academic year.

First time applicants include 16 college freshmen. ALL awardees are HAE patients. Scholarships are prioritized based on financial need.

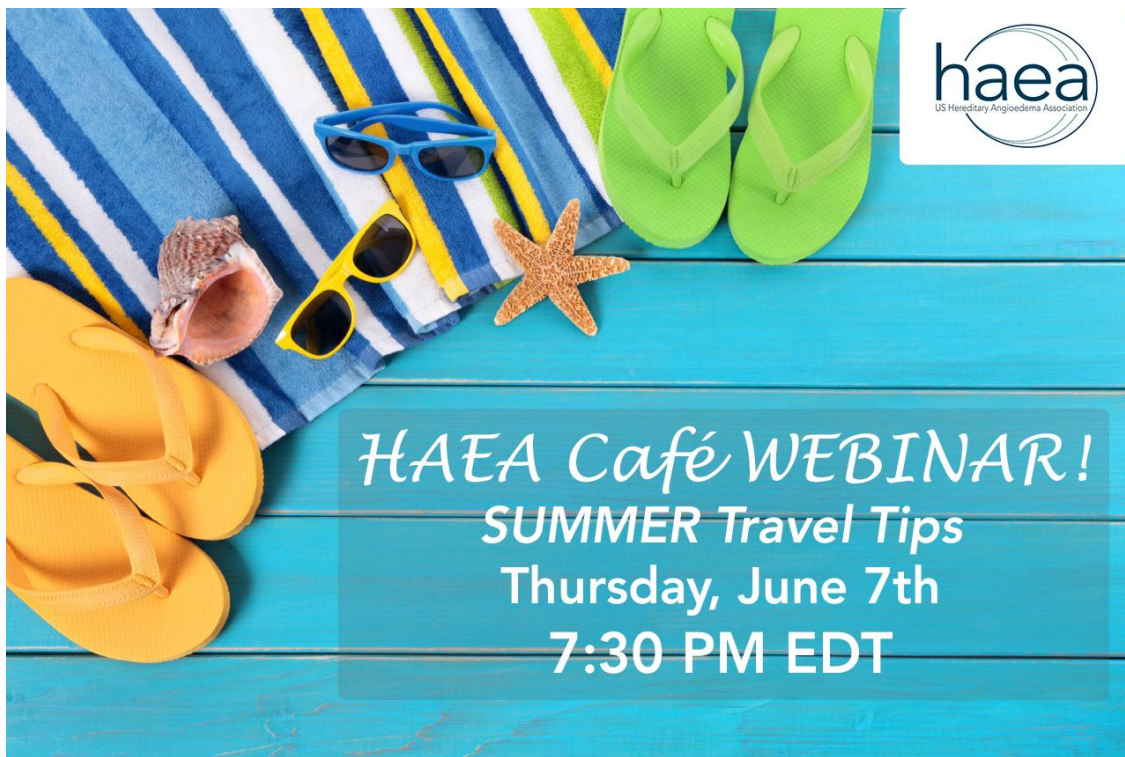


UPCOMING Clinical Trial!

The US HAEA is currently assisting BioCryst Pharmaceuticals in recruiting patients to be enrolled in the APeX-2 study, a worldwide clinical research study to investigate the safety and effectiveness of an investigational oral medication to prevent Hereditary Angioedema (HAE) attacks.

If you have Type I or II HAE, have regular attacks, and are interested in learning about an oral medication that could become an alternative to injections or infusions to prevent attacks, please contact **HAEA Patient Advocate, John Williamson (john@haea.org)** for additional information. You may also reach him by telephone by calling (972) 984 - 0621.





Thursday, June 7, 2018 – HAEA Café® Webinar: SUMMER Travel Tips!

Don't let summer travel stress you out! Connect with us this Thursday, June 7th at 7:30 PM EDT for our next HAEA Café® Webinar: SUMMER Travel Tips! Planning ahead can help limit the impact that HAE could have on your summer travel. <

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

Hosted by: Troyce Venturella

Link: <https://haea.zoom.us/j/752393222>

Phone: +1 (415) 762-9988 (Meeting ID: 752 393 222)

Click that you're GOING here!

HAEA Café Webinar: Families Living with HAE



Date: Thursday, June 21

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

Speaker: Dr. William R. Lumry, MD

Sponsored by: Pharming (RUCONEST)



Thursday, June 21, 2018 - HAEA Café® Webinar: Families Living with HAE

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

Sponsored by: Pharming (RUCONEST)

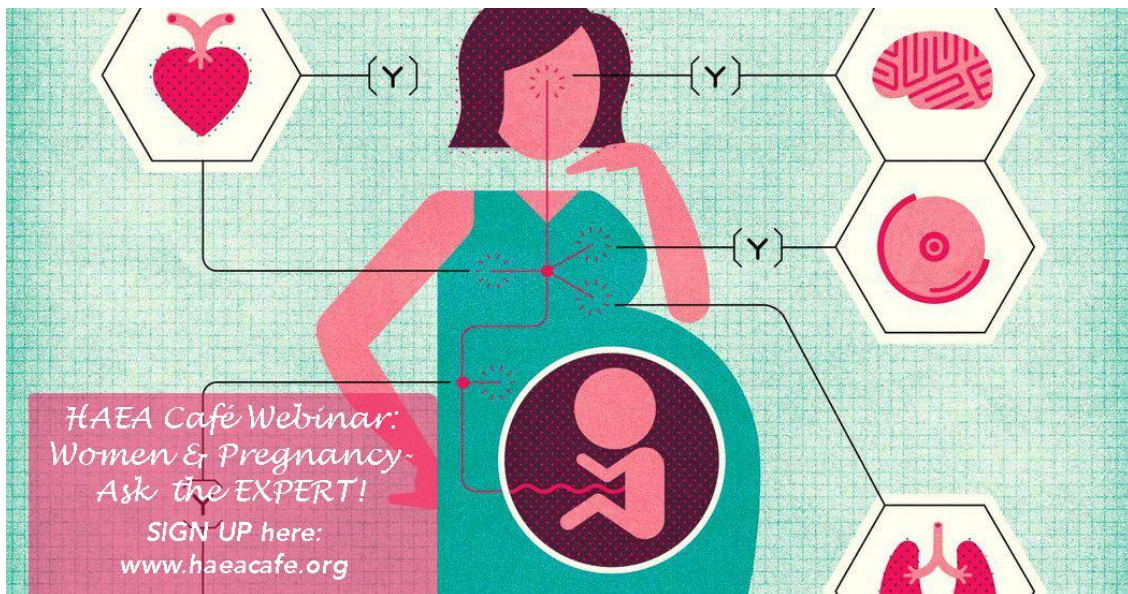
Link: <https://haea.zoom.us/j/568565236>

Phone: +1 (646) 558-8656 (Webinar ID: 568 565 236)



Speaker: Dr. William R. Lumry, MD

Add to your CALENDAR HERE!



IN CASE YOU MISSED IT!

Check out our **HAEA Café® WEBINAR: Women & Pregnancy – Ask the expert**, with **Dr. Sandra Christiansen**! To SIGN UP to the NEW HAEA Café®, and to view this EXCLUSIVE webinar, go to: www.haeacafe.org!
#HAEApregnancy #HAEAwebinars

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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www.haea.org

Our mailing address is:

The US Hereditary Angioedema Association
10560 Main Street, Suite PS40
Fairfax City, VA 22030

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