



HAEA in Action April Newsletter!



Share

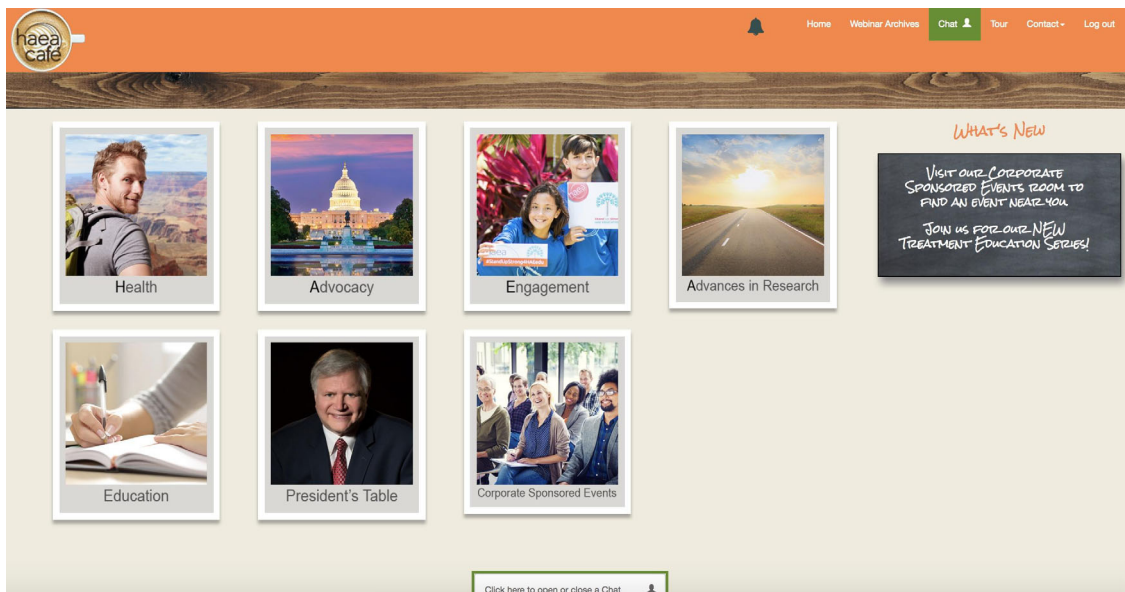


Tweet



Forward

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 our patients and their families, which includes 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.



Join our NEW HAEA Café!

The HAEA Café has a FRESH NEW LOOK! Join TODAY at www.haeacafe.org to enjoy access to HAE exclusive events, news, and webinars! NEW features help you stay connected with the HAE community.

CHECK OUT the enhanced options on the **MENU** and click on all of our 4 HAEA **PILLARS** to learn more about specialty interest areas created just for you!

- Easy navigation allows for everyday interaction and participation
- One-stop shop for the latest info on HAE
- Handy resource for topics and information on your specific interests

CHAT LIVE with other **MEMBERS** and **HAEA PATIENT ADVOCATES!**

- Start or join a conversation with other members or HAEA patient advocates in a private setting
- Ask questions or talk live to others about HAE-related topics

TAKE A LOOK at the Café Bulletin Boards for **EVENTS** and **ACTIVITIES NEAR YOU**

- Patients will be able to find HAEA or corporate events near their home
- Reach out to event coordinators for specific information or details

DISCOVER the latest breakthroughs through the HAEA *Treatment Education Series*

- Our new Education Series includes webinars on available therapies and patient care
- Exclusive access to webinar archives to view at your own time

SHARE your stories and UPLOAD your event PICTURES

- Share your stories and upload your pictures
- Promote your hae day :-) events

PARTICIPATE in HAEA virtual SUPPORT GROUPS for patients and family members

- Talk to other patients and caregivers, and come together to discuss issues that affect you

CLICK HERE to JOIN the NEW HAEA Café!



Get ready for hae :-) day!

On May 16th, 2018, we will celebrate **hae day :-)**. This year, we expect to raise even more HAE awareness by supporting research efforts. Our patient community has

come a long way in having access to therapy, however, there are still a lot of mysteries about HAE that we need to solve. By collaborating on, and supporting research efforts, we can help create a future that includes better care, earlier and more accurate diagnosis, and greater awareness that HAE patients can lead a normal life.

Together, we can drive the research needed to resolve the remaining scientific questions of HAE, and accelerate the advancement of future therapies. We encourage HAE patients, and family members to join, and actively participate in the US HAEA Scientific Registry. Because HAE is a rare disease with a very small number of patients, the greater the community participation, the faster we can collect a sufficient amount of data to ensure scientific validity.

Join your fellow HAE patients in the nationwide movement that is driving HAE research. Together let's Advance HAE.

REGISTER to the Scientific Registry [HERE!](#)



Making a difference in HAE patients' lives!

As you already know, HAE is often overlooked and misdiagnosed. The HAE IN-MOTION® 5k events supports the Hereditary Association in its mission to improve

the lives of people who suffer from HAE. All proceeds raised in these events go to three of the following main 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 specialist.
- **HAE Research** - supports expert researchers in their efforts to solve the remaining scientific mysteries of HAE.

There are many ways for you to participate, you can register to run, walk, cheer, or simply start your own virtual team to help raise awareness and funds that will make a difference in patients' lives. Regardless of how you choose to participate, the HAE IN-MOTION® 5k events will bring together patients, families, caregivers, friends, and neighbors to support each other and those living with this rare and potentially life-threatening genetic disease.

How to Fundraise 101

Step 1: Set a Goal

Establish a fundraising goal and a deadline for reaching that goal.

Step 2: Make a list

Make a list of everyone in your network (friends, family, co-workers, etc.)

Step 3: Share information

Tell everyone about the HAE IN-MOTION® 5k event, and why it is important to you.

Step 4: Ask!

Don't be shy! Asking people to donate to a cause is an honorable request. The #1 reason people don't donate is because no one asks them!

Step 5: Say, Thank you!

Follow-up with people, and thank them personally for their contribution!

2018 INCENTIVE PROGRAM

TO REGISTER FOR A 5K VISIT 5K.HAEA.ORG



EARN PRIZES FOR FUNDRAISING!

Awards are based on individual fundraising amounts, not team amounts

\$100 IN FUNDRAISING

* Stand Up Strong Cotton Baseball Cap



\$200 IN FUNDRAISING

*Stand up Strong Cotton Baseball Cap

*Pair of Custom Logoed HAE IN-MOTION Socks



\$300 IN FUNDRAISING

*Stand up Strong Cotton Baseball Cap

*Pair of Custom Logoed HAE IN-MOTION Socks

*HAE IN-MOTION Custom Logoed Nalgene Water Bottle



\$500 OR MORE IN FUNDRAISING

*Stand up Strong Cotton Baseball Cap

*Pair of Custom Logoed HAE IN-MOTION Socks

*HAE IN-MOTION Custom Logoed Nalgene Water Bottle

*HAE IN-MOTION Custom Logoed Picnic/Beach Blanket





Calling all HAE Youth!

Are you interested in connecting with other young people with HAE, participating in youth focused events, and learning about more ways to get involved? Join the HAEA Youth Leadership Council (YLC)!

[JOIN the YLC HERE!](#)



HAEA Scholarship Program UPDATE!

We are excited to announce that over 40 students applied to the 2018 HAEA Scholarship program. All applications will be reviewed by the Scholarship Committee, an independent adjudicatory board. Scholarships will be awarded based on a combination of financial need, academic effort, and individual goals. We wish all applicants the best of luck, and will be sending out award announcements by the end of April.



April

Saturday, April 21, 2018 - Strasburg Hobbies, VA

Support Luci Toman on her 2nd Annual Slot Car Drag Race to raise Awareness for HAE. For more information about this fun event VISIT <https://bit.ly/2Jzw35X> or contact our Patient Advocate, Jenny Barnes at jennybarnes@haea.org.



Monday, April 23, 2018 - HAEA Café: Treatment Education Series

TUNE IN to our next EXCLUSIVE Café Webinar

Webinar: Learn about a preventative subcutaneous therapy option for Hereditary Angioedema (HAE)

Sponsored by: CSL Behring

Date: Monday, April 23

Time: 8:00PM EDT, 5:00PM PDT

Speakers: Dr. Raffi Tachdjian & Machel Pecoraro, Patient Advocate

JOIN the FREE Webinar with this LINK <https://haea.zoom.us/j/327571137> or by

PHONE +1 669 900 6833 (Webinar ID: 327 571 137)

ADD the WEBINAR to your CALENDAR here!

HAEA Café -Youth Edition Webinar: Dealing with and Managing Stress

Date: Thursday, April 26, 2018

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

Link: <https://haea.zoom.us/j/808146671>

Phone: +1 669 900 6833 (Meeting ID: 808 146 671)



Thursday, April 26, 2018 - HAEA Café - Youth Edition Webinar: Dealing with and Managing Stress

Young people face unique challenges as they learn to navigate stressful situations. Finding ways to manage stress is important, especially for people with HAE. Join us for this youth-focused webinar as we talk about different kinds of stress and provide tips on how to find ways to manage stress in your life.

Date: April 26, 2018

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

Link: <https://haea.zoom.us/j/808146671>

Phone: [+1 669 900 6833](tel:+16699006833) (Meeting ID: 808 146 671)

ADD the WEBINAR to your CALENDAR here!



HAE IN-MOTION® 5K' near you - MAKE IT A FAMILY DAY!

Join us for the HAE IN-MOTION® 5K events! Register today to run, walk or cheer! There will be food, games and crafts for the whole family following the 5K race! You can also buy a raffle for a chance to win a Bose® Wireless Speaker. Learn more at: 5k.haea.org

-
Sunday, April 22, 2018 - Hopkins Park, DeKalb, IL

Saturday, April 28, 2018 - Winding Trails, Farmington, CT

REGISTER for the HAE IN-MOTION® 5K events [HERE!](http://5k.haea.org)



***GLOW** and Day Golf!*

*Raising Awareness for Abby
and RESEARCHING for a CURE!
Saturday, May 5, 2018*

Saturday, May 5, 2018 - Cincinnati, OH

Register today for Abby's Glow & Day Golf event! Don't miss this fun family event on at Tri County Golf Ranch in Cincinnati, OH!

REGISTER or DONATE HERE!

Saturday, May 12, 2018 - Cullman, AL

First stop on "Lyndon's Walk Across America". If you donate \$12 to the US Hereditary Angioedema Association for research in memory of Lyndon, you will receive a Team Lyndon shirt and bracelet. For more information contact Jenny Barnes at jennybarnes@haea.org!

CLICK HERE for EVENT details!

Our mailing address is:

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

Want to change how you receive these emails?

You can update your preferences or unsubscribe from this list.