



## HAEA in Action May Newsletter!



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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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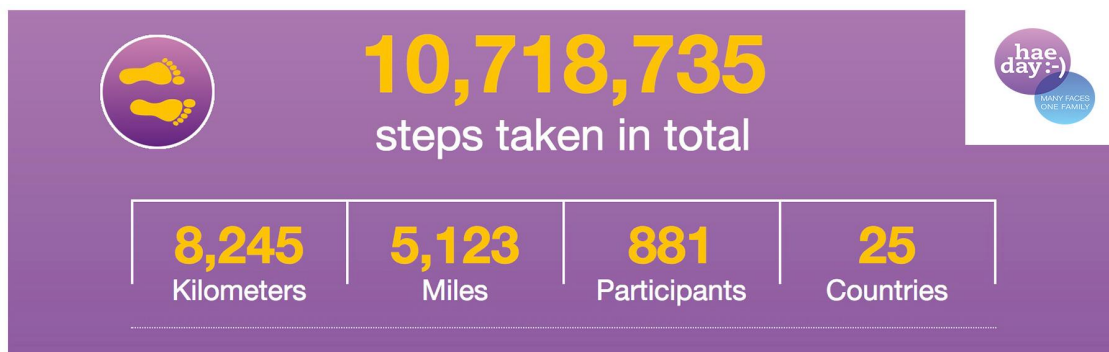
## Support Research on May 16th hae day :-)

Get ready to support research efforts for **hae day :-)**! As we gear up to raise awareness about HAE on this important day, we carefully reviewed how far our patient community has come in terms of having access to therapy. However, there is still much more we need to understand about this ultra-rare disease that could help with better diagnosis, care, and treatment. This month, we would like to encourage you to get involved and drive the research that could lead to new HAE discoveries! By collaborating on, and supporting HAE 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.

This hae day :-) we encourage HAE patients, and family members to join and actively participate in the Advance HAE Scientific Registry. Because HAE is an ultra-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. Your regular participation is needed to achieve important HAE scientific efforts.

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

REGISTER to join or for a FREE Scientific Registry INFO KIT  
[click here!](#)



## HAEi Promotes a Global WALK

On and around **hae day :-)** 2018 a group of HAE patients, relatives, caregivers, doctors, nurses, people from HAE organizations, and industry will walk four stages of the Jakobsweg through Vienna, Austria, right before the HAEi Global Conference takes place.

Jakobsweg is German for "The Way of St. James", the pilgrimage route through the Austrian capital and connected to other pilgrimage routes leading to Santiago de Compostela in Northern Spain.

Mindful that many people would like to take part in this walk but are not able to do so, the HAEi has arranged the HAE Global Walk 2018, allowing everyone to participate no matter where they live. The HAEi will be running a campaign from April 1<sup>st</sup> to May 31<sup>st</sup>, 2018 in order to raise awareness of the rare disease, HAE. All you have to do is add your name, country where you walked, date of your walk, and distance. With your participation, you will be joining thousands around the world committed to raising HAE awareness!

Enter your STEPS for the HAEi Global Walk 2018 [HERE!](#)





## Happy Mother's Day!

Every Mother is amazing in her own special way! Wishing all our HAEA community moms a beautiful, happy, and healthy Mother's Day!

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## Connect through a Support Group!

Try a little self-care! Join other HAE patients, caregivers and family members as they share their day-to-day life experiences. We all need time to process and reset. A support group can help you cope better and feel less isolated as

you make connections with others facing similar challenges. For more information or to join a group, please contact HAEA Health Advocate, Troyce Venturella at [troyce@haea.org](mailto:troyce@haea.org).

**Groups are currently meeting every other week (all are listed in Eastern Time)**

**Tuesday 12:00 PM**

**Tuesday 9:30 PM**

**Wednesday 7:30 PM**

**Thursday 11:00 AM (mostly parent caregivers) & 7:30 PM**

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## **Don't miss our NEW Treatment Education Series!**

The graphic features a dark blue header with the HAEA logo on the left and white text on the right. The text includes the event title, date, time, and speakers. Below the header is a light blue illustration of a desk with a laptop, a coffee cup, a book, a plant, and a tablet. The Shire logo is in the bottom right corner.

**haea**  
US Hereditary Angioedema Association

**HAEA Café WEBINAR: HAE Champions**

Date: *Thursday, May 3*  
Time: *7:30PM EDT, 4:30PM PDT*  
Speakers: *Tanya Bloker (Patient Marketing Shire)*  
& *Alex West (HAE Patient)*

Sponsored by:  
**Shire**

### **Thursday May 3, 2018 - HAEA Café Webinar: HAE Champions**

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

**Sponsored by:** Shire

**Speakers:** Tanya Bloker (Patient Marketing Shire) & Alex West (HAE Patient)

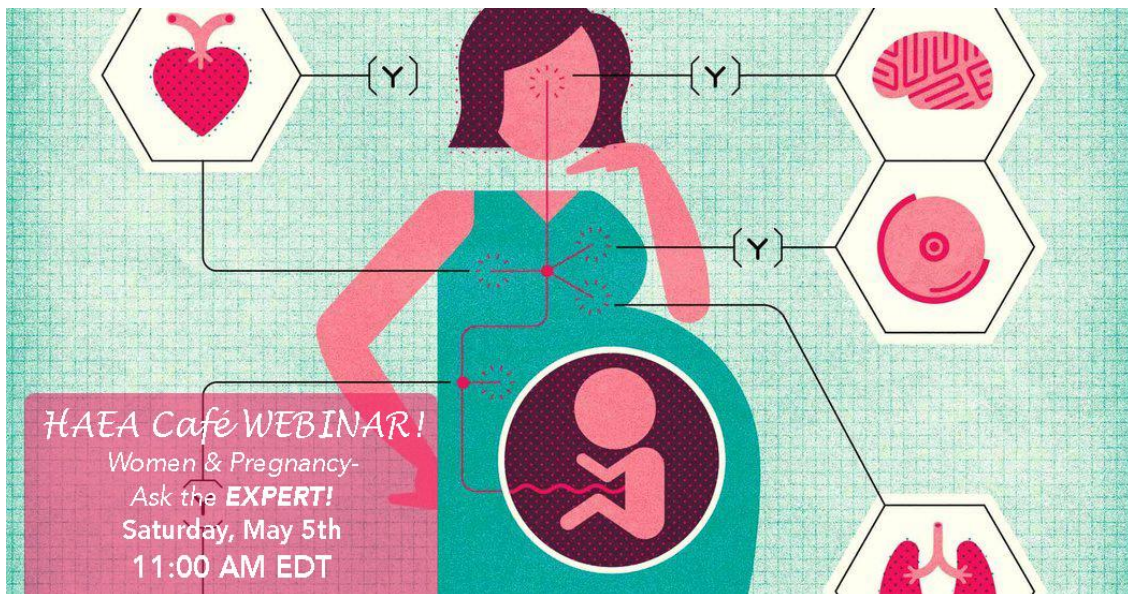
**Link:** <https://haea.zoom.us/j/743376993>

**Phone:** +1 669 900 6833 (Webinar ID: 743 376 993)

**Add to your CALENDAR HERE!**

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**Saturday, May 5, 2018 - HAEA Café Webinar: Women & Pregnancy - Ask the Expert!**

**Time:** 11:00 AM EDT, 8:00 AM PDT

**Link:** <https://zoom.us/j/9585616941>

**Phone:** +1 646 876 9923 (Meeting ID: 958 561 6941)



**Speaker: Sandra Christiansen, MD**

Professor of Medicine at UC San Diego  
and a faculty member of the US HAEA  
Angioedema Center in San Diego

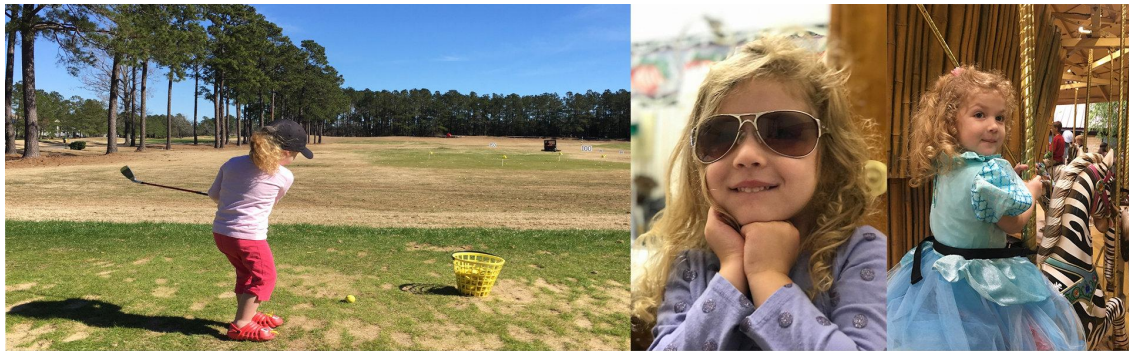
**CLICK that you're GOING here!**

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**May 2018**



**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!**

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# Lyndon's Walk Across America for HAE

Raising awareness of Hereditary Angioedema  
one state at a time in **Lyndon's** sweet memory!



- Onsite  
cooker
- BBQ plate sales  
(\$10 ea)
- Tie dye station
- Talent show
- Special Blood movie  
(after dark)
- Balloon release *in  
memory of Lyndon Brooke  
Stidham, who passed away  
from Hereditary  
Angioedema at the  
age of 12.*

**Saturday, May 12, 2018**  
**11:00 AM**

**Sportsman's Lake**  
1544 Sportsman Lake Rd NW,  
Cullman, AL 35055

Join us for the FIRST STOP on  
Lyndon's Walk Across America  
TOUR! PARTICIPATE in this exciting  
fun DAY event with the whole family!

For more information CONTACT:  
Jenny Barnes [jennybarnes@haea.org](mailto:jennybarnes@haea.org)  
**[www.haea.org](http://www.haea.org)**



**@LyndonswalkacrossAmerica4HAE**

## 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](mailto:jennybarnes@haea.org)!

**CLICK HERE for EVENT details!**

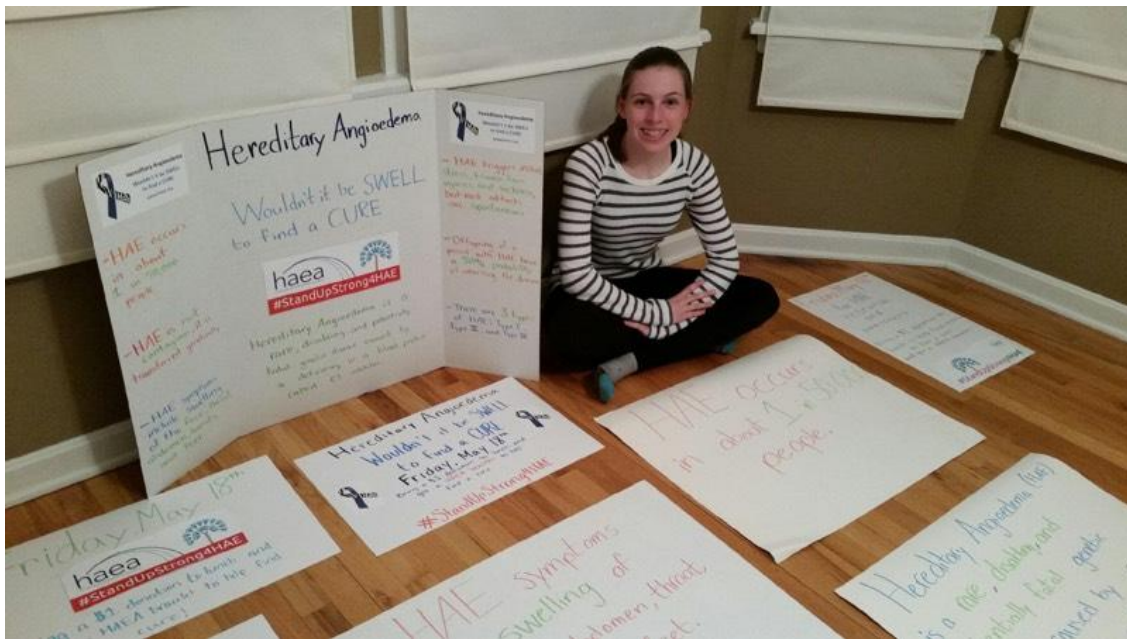




[Sunday, May 13, 2018 - Syracuse, NY](#) GET READY NEW YORK! Come out and JOIN US for the 5th annual "Show Your Swell 5K" event on May 13th at Long Branch Park, Syracuse!

For more information [CLICK HERE!](#)

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### Friday, May 18, 2018 - Pittsburgh, PA

Wouldn't it be Swell to find a CURE! HELP Maddie Fitzgerald in her JOURNEY to RAISE HAE AWARENESS this May 18<sup>th</sup> at her SCHOOL in Pittsburgh, PA! To learn how to create your own awareness event contact HAEA Patient Advocate, Jenny Barnes ([jennybarnes@haea.org](mailto:jennybarnes@haea.org)).

For more information about this awareness event [CLICK HERE!](#)





### **Thursday, June 7, 2018 - HAEA Café Webinar: SUMMER Travel Tips!**

Don't let summer travel cause you any stress! Planning ahead helps limit the impact that HAE has on your summer travel. Join the discussion on ways we can have a safe and stress-free vacation.

**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!



### **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! Each event offers unique family-friendly activities, and all confirmed registrants are entered into a raffle for a Bose® Wireless Speaker!

### **Saturday, June 2, 2018 - Holmes Lake Park, Lincoln, NE**

REGISTER HERE!



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[www.haea.org](http://www.haea.org)

**Our mailing address is:**

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