



HAEA in Action July Newsletter!



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We're halfway through the summer, and there is still plenty to do! Whether

you're planning your vacation days, moving or organizing homes, searching for fun family activities, or simply taking things a bit slower, this is a great time for you to take care of yourself and enjoy. As July rolls around, we have some helpful suggestions for you to consider for when you're at home or out and about.



Safe Travel with HAE Tips!

Don't let stress ruin your trip! Enjoy the summer with your family and friends by following these 5 great tips when planning for your trip!

1. Carry your emergency contact information with you on your phone.
2. Check with your HAEA Patient Advocate for information on local medical care options.
3. Keep your HAE medication with you in your carry-on bag.
4. Make sure you have enough medicine available for your trip and after.
5. Request a doctor's note or prescription to take with you on your trip.

For more INFORMATION [CLICK HERE!](#)



Youth Support Groups!

Do you have a child 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 about the emotional and physical impact HAE may have on your life. 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.

For more information on HAE youth support groups or to register, please contact Lisa Facciolla at lisa@haea.org.



Getting School Resources Ready for Kids and Teens

Summer is a great time to plan ahead for the school year. Parents of children with HAE often have many questions as the first day of school approaches. How will the school respond if my child misses too many days of school? How will my child make up missed assignments? An HAE school packet can be a great resource for you, your child, and your school. Students function to their maximum potential if their needs are met. With a full HAE management plan, your child can enjoy better attendance, participate in a wider range of physical and special activities (such as field trips), and fewer medical emergencies.

For printable materials that you can use and customize for your child's school [CLICK HERE!](#)

FACEBOOK FUNDRAISER



Birthday Fundraising for HAE!

HAEA is now included in Facebook's fundraising platform. It's never been easier for you to support HAEA programs and raise HAE awareness by creating your own online fundraising campaign via Facebook! Consider making a difference in the lives of HAE patients by starting a Birthday fundraising campaign!

Simply follow these easy steps:

1. Select Hereditary Angioedema Association - HAEA as your charitable organization.
2. Enter how much you want to raise and the period of time you want your fundraiser to run.

Funds raised go to three HAEA patient support programs: HAEA Scholarship Program, HAEA Compassion Fund, and HAE Research. You can start fundraising through Facebook today!

START your Facebook BIRTHDAY FUNDRAISE here!



Wheaton Community Stands Up Strong for HAE IN-MOTION 5K event!

Join Team Luke/PUFFY POSSE, A Swell Bunch, Blood Walkers, and Team Abby during our next HAE IN-MOTION 5K event at Danada Forest Preserve, Saturday, August 4th in Wheaton, Illinois! You can attend with your family and friends, or you can create a virtual team to help raise HAE awareness and fundraise. After the race, there will be fun family activities and breakfast sponsored by Orsini Specialty Pharmacy Services. Please plan to spend some time post-race mingling, eating and meeting other patients and families! 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!



Advance HAE Scientific Registry receives record reports during hae day :-) 2018

In the last few months, the **Advance HAE Scientific Registry** has received the largest number of Quarterly report submissions since 2015! HAE patients from across the country joined our **hae day :-)** campaign in support of HAE scientific research! Let's keep up the momentum! Quarterly Reports for Quarter 2 of 2018 are available to fill out as of July 1! Every single Report submitted to the Registry is incredibly vital to our shared goal of Lifelong Health for all the HAE patients. Visit <http://sr.haea.org> to access the Registry portal where all of your Advance HAE reporting forms are available and where you can track your progress toward a perfect record for the remainder of 2018!

Also, be sure to check out the Advance HAE app now available for both Apple and Android devices! It's the quickest, easiest way to access your Attack Event Reports.

You are making the difference in the drive to Advance HAE!

If you are not already a member and would like to join the Advance HAE Scientific Registry to become part of this powerful drive, please click **HERE!**

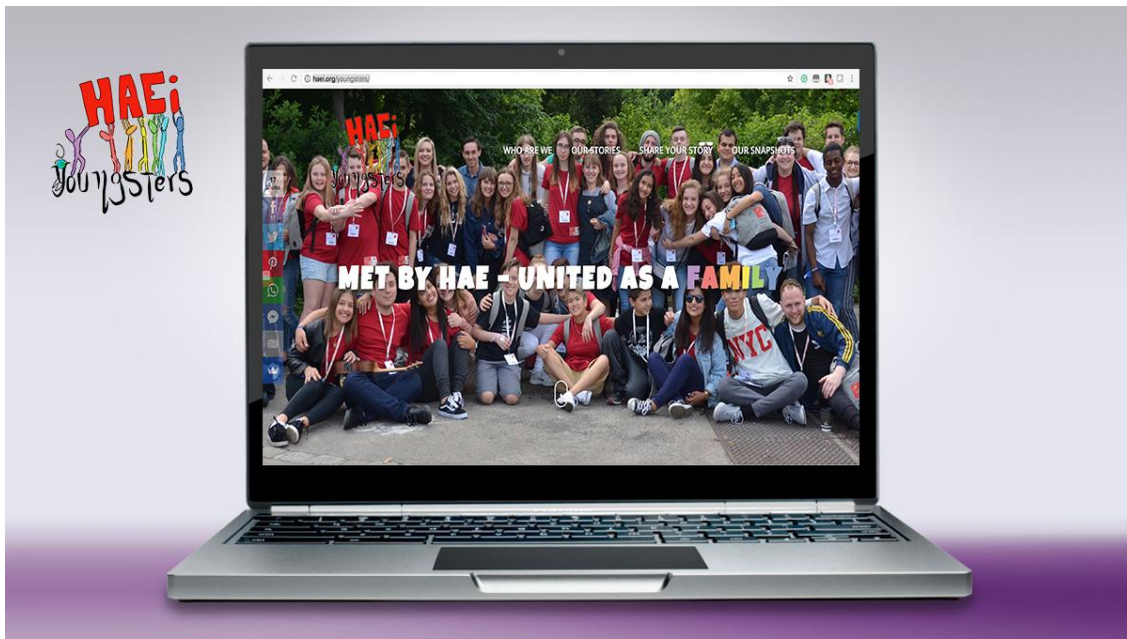


Calling All Kids and Teens!

The HAEA Youth Program members and Youth Leadership Council (YLC) have been very active this year! Kids and teens have been sharing their experiences and ideas on how they can help manage HAE at home, raise awareness in their own communities, and help their peers deal with this rare disease. Whether they are patients themselves or have a family member with HAE, these youngsters are changing how others perceive Hereditary Angioedema. The program brings together kids and teens from across the nation and generates a conversation that is unique to their age group.

For more information on the HAEA Youth Program or to register to join, please contact Lisa Facciolla at lisa@haea.org or

CLICK HERE!



New HAEi Youngsters Website

Check out the NEW HAEi Youngsters Website! Kids and teens can share their stories, and learn some helpful tips on how to manage their HAE. CONNECT with new friends and discover life-changing experiences by learning about different countries, cultures, and traditions! MET by HAE -UNITED as a FAMILY! Designed and created by the HAEi Youngsters!

Learn more [HERE!](#)



Interested in an Upcoming Clinical Trial for HAE?

The US HAEA is currently assisting BioCryst Pharmaceuticals in recruiting patients for their 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](mailto:JohnWilliamson@haea.org) (john@haea.org) for additional information. You may also reach him by telephone by calling (972) 984 - 0621.

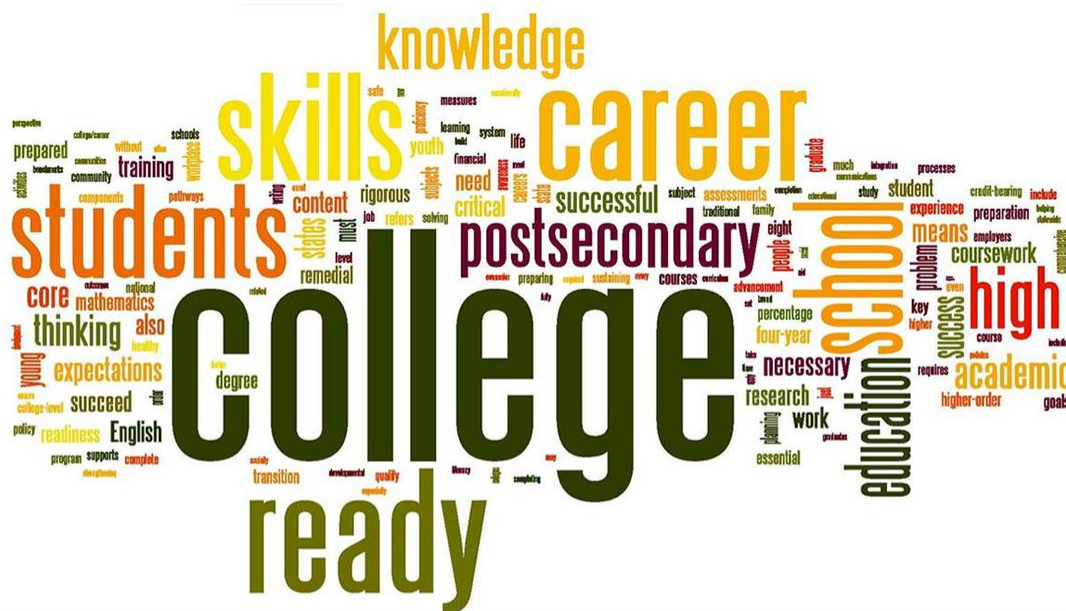




August 4: HAE-IN-MOTION® 5K event at Danada Forest Preserve, in Wheaton, Illinois! JOIN us after the race for great food and fun family activities! All confirmed registrants are entered into a raffle for a Bose® Wireless Speaker! Funds raised go to 3 HAEA patient support programs: HAEA Scholarship Program, HAEA Compassion Fund, and HAE Research. REGISTER or CREATE your VIRTUAL TEAM TODAY: 5k.haea.org!



August 9 at 7:30 PM EST: Fundraising and Advocacy Youth Webinar. As we approach the first annual HAE Youth Advocacy Month, hear from young people who are involved in 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.



HAEA Café Webinar: *Preparing for College*

Date: Tuesday, August 14, 2018

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

Hosted by: Lisa Facciolla

August 14 at 7:30 PM EST: Preparing for College: Are you getting ready for your first semester in college or maybe your returning for another year? Preparing for college can be stressful, especially when you have to create a plan for managing your HAE while you are in a new environment, possibly away from home. Hear from young people with HAE who have been there and done that. This is a webinar that first-year college students won't want to miss!

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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