



HAEA in Action November Newsletter!

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Happy Thanksgiving!

Thanksgiving is only a few weeks away and this is the time to reflect on those unique moments when we experienced successes or had challenges to overcome. Whether we triumphed or failed in our plans, we showed that as a HAE community, there is great resolve and compassion amongst us. By

embracing the US HAEA call to Stand Up Strong, together we've demonstrated an unbeatable spirit. Let us celebrate this Thanksgiving that our patient community is more passionate, resilient, united and stronger than ever! We wish you and your loved ones a peaceful and joyful Thanksgiving Season!



About the medicine shortage survey

We recently conducted a survey among HAE patients using the Cinryze therapy. The survey revealed that over 50% of respondents ran out of medicine during the recent shortage. Over half of the patients who ran out of medication experienced 5 or more attacks and many patients experienced HAE attacks that resulted in an emergency room visit and in some cases emergency intubation.

The HAEA continues to monitor the medicine shortage issues and is engaged in ongoing discussions with the FDA, therapy manufacturers, and our Medical Advisory Board to help mitigate patient challenges. Keep in mind that HAEA's Health and Patient Advocates are here to help. If you need assistance, don't hesitate to reach out to your advocate.

[CLICK HERE](#) to MEET your Patient Advocates!



We want to know what you think!

Looking forward to 2018, the HAEA asks that you provide feedback so we can better serve our patient community by expanding our existing programs and developing new and exciting initiatives. We kindly ask you to fill out two (2) surveys that will inform our future strategy.

1. 2017 National Patient Summit Survey – We are already making plans for our 2019 National Patient Summit and we hope to make it the best one yet! If you attended this year's National Patient Summit in Minnesota, we would like to know about your experience. Please fill out this quick survey - it only takes a few minutes to help us plan an unforgettable 2019 event!

Complete the SUMMIT Survey here!

2. Patient Interest Survey – Our Patient Interest Survey is brand new! As our HAEA community continues to grow, we want to make sure that we are in tune with what you want and need! This survey will help us personalize services for you and your family. Please fill out this important survey today!

Complete the Interest Survey here!



Open Insurance Enrollment Period

The enrollment period for Health Insurance has already started and runs ONLY from November 1 to December 15, 2017. Learn what you need to do to secure your coverage! Learn more about what is required to get your coverage in place for 2018! Visit www.healthcare.gov or contact your HAE Health Advocates Heidi Polek or Troyce Venturella at: heidipolek@haea.org or troyce@haea.org

#GIVINGTUESDAY

A Time for Giving

#Giving Tuesday is scheduled for November 28th and celebrated on the Tuesday following Thanksgiving. #Giving Tuesday kicks off the charitable season, when many focus on their holiday and end-of-year giving. At the HAEA, 100 percent of every dollar donated by individuals is allocated to one of our major activities:

1. HAEA Scholarship Program
2. HAEA Benevolence Fund
3. HAE Research

We encourage everyone to take part in #GivingTuesday and donate to the HAEA or another charity you hold dear. Whether you come together with your family, your community, your company or the HAEA, consider a way to give back and make a difference on GivingTuesday.

Make your DONATION here!



Tis' the season to start Christmas shopping!

Black Friday and Cyber Monday are just around the corner and you're probably planning your shopping strategy! Christmas is a time for giving and Amazon has created a charitable program called AmazonSmile through which the Company donates 0.5% of the price of your eligible purchases to the charitable organization of your choice.

This is a wonderful way for you to not only quickly and easily take care of all of your holiday shopping, but to also contribute to the US HAEA. It's easy to support the HAEA:?

- o Log in to smile.amazon.com
- o Select Hereditary Angioedema Association as your charity of choice
- o Start shopping!

Don't forget to tell your friends and family to sign up as well. Giving back has never been easier!

For more information visit:

smile.amazon.com

UPCOMING

EVENTS

Don't miss our last HAE IN-MOTION® of the year. Help us cross the fundraising finish line Strong! Come run, walk, volunteer or cheer! Or, you can start your own virtual team and help raise funds. If your TEAM reaches \$100, each MEMBER will receive our OFFICIAL SHIRT and BAG! For more information contact Sherry Swanson at: sherryswanson@haea.org

Don't miss it!

- Saturday, November 18, 2017 - Camp Mabry, Austin, TX



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