



HAEA in Action June Newsletter

Learn More About How to Treat Your HAE

Continuous communications and engagement with our community has led us to observe that far too many HAE friends, for one reason or another, do not have the opportunity to adequately control their HAE.

With this in mind, the US HAEA is launching our HAE On the Horizon Quarterly Update which will provide vital information about current and future HAE therapies, scientific publications, and clinical research and trials. Below is a list of FDA-approved therapies that help patients prevent and/or treat HAE attacks. Please consult your doctor to discuss these HAE medications and to determine which therapy would work best for your individual needs.

Expert physicians cite two approaches to HAE therapy;

1. On-Demand – treatment when a patient is having an acute attack. Current on-demand therapies, particularly when taken as soon

as the patient feels symptoms, are highly effective in reducing the severity and duration of symptoms.

2. Prophylaxis

- Ongoing prophylactic treatment should be considered for patients whose HAE is not sufficiently controlled to maintain suitable quality of life with on demand therapy.
- It is important to prevent HAE attacks when a patient is most susceptible due to trauma from surgery or dental procedures.

Keep in mind that HAE swelling does NOT respond to drugs used to treat swelling caused by allergic reactions-- antihistamines, epinephrine, and corticosteroids.

FDA Approved Therapies for HAE treatment:

Cinryze™ is an FDA-approved C1-inhibitor concentrate for preventing HAE attacks in teenagers and adults. Cinryze™ is delivered intravenously and is approved for home infusion.

Berinert® is an FDA-approved C1-inhibitor concentrate for treating acute HAE attacks in adults and pediatric patients. Berinert® is delivered intravenously and is approved for on-demand treatment through self-administration.

Kalbitor® is an FDA-approved kallikrein inhibitor for treating acute HAE attacks in patients 12 years of age and older. Kalbitor® is delivered by subcutaneous injection and must be administered by a healthcare professional.

Firazyr® is an FDA-approved B2 bradykinin receptor antagonist for treating acute HAE attacks in patients 18 years and older. Firazyr® is delivered by subcutaneous injection and is approved for self-administration.

Ruconest® is an FDA-approved plasma free recombinant C1-inhibitor concentrate for treating acute HAE attacks in adults and adolescents. Ruconest® is delivered intravenously and is approved for self-administration.

The 2017 US HAEA National Patient Summit Registration is Now Open

The US HAEA is excited to announce that registration for the National Patient Summit is now open! The Summit will take place from September 15th through 17th in Bloomington, Minnesota. This year's theme, "Stand Up Strong", is a unifying call to action for the HAE community and a celebration of work being done by HAE heroes who make a difference every day by raising HAE awareness within their communities.



The 2017 meeting is open to the entire US HAEA patient community and will feature programs for the entire family! Don't miss the opportunity to; learn about breakthrough therapies on the horizon, get your questions answered by our world-class HAE expert physician/researchers, hear first-hand from Washington insiders the latest on healthcare legislative issues; and be the first to gain insights into never previously disclosed data from the HAEA's Scientific Registry. You'll end the day with an incredibly fun evening that includes dinner and entertainment with the entire HAEA community. On Sunday morning, we'll close out the 2017 Patient Summit with another exciting HAE-IN-Motion® 5K walk/run!

Also, this year's Youth Programs offer special events organized just for children and teens attending the conference. There will be a variety of engaging activities as well as plenty of time to get to know other kids

and teens in the HAEA community. A super fun off-site TEEN trip for ages 12-17 is planned for Saturday, September 16, while KIDS 5-12 will enjoy their time together on-site at the SUMMIT venue.

Click [HERE](#) to Register!



Saturday, June 10, 2017 - Lake Zorinsky Park, Omaha, NE

Look for the Digital Release of the HAE documentary Special Blood. A percentage of the proceeds from DVD sales will be donated to the US Hereditary Angioedema Association! For details go to: <http://www.moviezyng.com/818522018249.aspx?microstoreID=75>

About Special Blood:

This poignant, heartfelt documentary chronicles the lives of four patients with a dramatic, rare disease. Due to the rarity of Hereditary Angioedema, Ava, Noah, Kelsie, and Lora face misdiagnosis, improper treatment, and preventable tragedy in the emergency room all as they fight to live normal lives. Struggling to be heard by an often, uninformed healthcare system, they join their voices together to face challenges and encourage others with HAE.



US HAEA Patient Advocates

MEET YOUR PATIENT ADVOCATES !

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