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## HAEA in Action July Newsletter

**Get Ready for Back to School!**



Back to school is just around the corner and we know that students with HAE can function to their maximum potential when their needs to meet academic success are addressed. With a full HAE management plan, kids can enjoy better attendance records, fewer restrictions on participation in physical activities, and special activities (such as field

trips), with minimal medical intervention.

School age kids with HAE are not alone; chronic illnesses affect at least 10 to 15 percent of American children. With teamwork, students can successfully navigate their school year with HAE.

A team approach means parents work together with schools, health care providers, and their community to provide a safe and supportive educational environment to ensure that students with HAE achieve their educational goals. Here are a few tips and resources to help you kick off your child's new school year!

- Notify the school of your child's HAE diagnosis and supply school staff with the HAE management plan you have developed with their HAE treating physician - (keep the plan up-to-date).
- Provide authorizations for administering medication and emergency treatment, signed by your child's HAE treating physician.
- Participate in the development of a school plan: 1) Meet with school staff to develop an accommodations plan (504 Plan), if needed, and 2) Authorize contact between school health staff and your child's HAE treating physician.
- Provide an adequate supply of acute HAE therapy, if you have it, in pharmacy-labeled containers, and other supplies to the school health staff. Replace medications and supplies as needed. A dedicated supply should remain with the school nurse.
- Provide school health staff with information on how to administer therapy, per your management plan or instructions on how to call 911 on your child's behalf.
- Provide the school with a way to contact you or another responsible person in case of an HAE attack and/or a medical emergency.
- Promote good general health, nutrition, and physical activity.

# school resources >>>

Many parents of children with HAE are unsure about how to approach school staff. The US HAEA has put together some materials to help you work together with your child's school. The materials are provided only as a general guide. You will want to personalize any materials that you provide to your child's school to reflect his/her own particular needs and situation.

- **How to prepare a school packet:** [Click here to download useful information on putting together a school packet.](#)
  - **You, Your Child and 504 Plans:** What Is a 504 plan? Who is eligible for a 504 plan? Are 504 plans really necessary. [Information can be found here to answer these questions and more.](#)
  - **The School Nurse:** Chances are your school nurse has never heard of Hereditary Angioedema. A letter providing a brief introduction to HAE, an idea of what is needed to help your child if medical intervention is necessary, and your emergency contact information can be a great help to you, your child and your child's school. [Download a sample letter for the nurse at your child's school by clicking here.](#)
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UPCOMING

EVENTS

July 10-14, 2017

**You're invited to the Company  
Sponsored HAE Educational  
Programs**

Want to learn more about HAE  
treatments?

Visit the HAEA Cafe for a list of  
HAE Educational Programs and  
find one near you. Go to:

<http://www.haeacafe.org>

Thursday, August 3, 2017

**Webinar: Getting ready for  
Back to School With HAE**

7:30 pm EST

Join

here: [https://haea.zoom.us/j/302  
512203](https://haea.zoom.us/j/302512203)

Or join by phone:

[+1 \(415\) 762-9988](tel:+14157629988)

Meeting ID: 302 512 203

Sept. 15th-17<sup>th</sup>, 2017

**The 2017 US HAEA National  
Patient Summit** - Registration is  
*Now Open* and spaces are filling  
up fast! The Summit will take  
place in Bloomington, Minnesota  
and will be another exciting  
event for the whole family. You

won't want to miss it!  
Travel grants are available.

**Sign Up Here Today!**

## US HAEA Patient Advocates

MEET YOUR PATIENT ADVOCATES !

Click [HERE](#) to contact your dedicated HAEA Patient Advocate today!



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