

HAE BACK TO SCHOOL RESOURCES

Every parent of a child with HAE has questions at the start of the school year, such as - How will the school respond if my child misses too many days of school? or How will my child make up missed assignments? An HAE school packet can be a great resource for you and your child's school. Taking the time to put the packet together ahead of time will help with your stress levels while providing valuable education and insight for your school's staff.

We hope you will find the information below helpful as you meet your child's teacher and school nurse. The information provided is meant only as a guide – you will want to personalize your child's school packet to meet their own particular needs and situation.

Below, are a few items that might be helpful to include in your packet that you present to your child's teacher.

1. Put together an attractive package.

Create a packet that includes your note to the teacher, your child's physician letter, and any printed resources from the HAEA web site (www.haea.org) about HAE. Label the packet and place it in a large manila envelope or clear plastic portfolio.

2. Carefully choose what you will send in your packet.

Sending in too much information all at once may make it seem like an overwhelming task for your child's teacher. You can always offer to send additional resources later.

3. Understanding HAE - Patient Guide

These printed resources provide a brief overview of HAE for your child's teacher. These resources can be obtained from the US HAE Association. Send your request to info@haea.org.

4. Write a note to the teacher.

Your note does not need to be any more than a page long. Be positive about how much you are looking forward to working with the teacher this year. Mention specific things you want the teacher to know about your child and their HAE. Let the teacher know that you can provide more information if they have additional questions. (A sample letter is provided on the following pages)

5. Follow up.

If you don't hear back from the teacher, check back in a few days with a note or a phone call to make sure they received your package and ask if they have any additional questions about the information presented. Repeat your offer to answer any questions and discuss further in person.



TIPS:

1. Create a focused and timely presentation- The start of a school year can be a hectic time for teachers. They may not have a lot of free time to read a large volume of material of material. A package that looks manageable and well-thought out will be more effective. You may wish to allow more time by delivering your HAE school packet in the weeks before school begins.
2. Make an effort to collaborate. In your teacher note to the teacher, provide suggestions specific to your child's HAE health needs.
3. Keep your tone friendly. Remember, it's important to develop a positive relationship with your child's school. Make it clear that you are available to answer any questions, and that you would be happy to do what you can to ensure that the school has everything they need to help your child thrive despite their HAE.
4. Make a copy of all correspondence for your records. Keep a log of when and what you sent to the teacher, and what follow-up outreach you made.

RESPONSIBILITIES:

Reinforce the importance of everyone (student, parent, and school) doing their part to help the child succeed in school.

STUDENT

Learn to communicate when something is wrong

Tell an adult at school when something is wrong or they are experiencing swelling

Do your school work on time

Make the same amount of effort as someone without HAE

PARENT

Communicate about child's condition and needs

Help obtain makeup work

Help child have a positive attitude about school

Work with school staff and nurse to develop a care plan

SCHOOL

Monitor student achievement and notify parent of changes to performance or personality

Notify parent if student reports an HAE attack

Stress the importance of completing assignments

Respect privacy and confidentiality

FIVE THINGS TEACHERS NEED TO KNOW ABOUT HAE

1. Due to my child's low levels of [non-functioning] C1-Inhibitor, a blood plasma protein, he/she can experience episodes of internal or external swelling – often without warning.
2. Swelling may result from trauma – please alert his/her gym teacher(s) - always ask for assistance in monitoring for any trauma-related swelling.
3. My child is very aware of how HAE affects his/her body, but please do not hesitate to contact me immediately if he/she is not asking for help and you feel medical attention is needed.
4. Please call 911 immediately if my child reports a thickness in his/her throat or difficulty breathing. Then please call my emergency contact phone number: ____-____-____.
5. My child may or may not wish to share information about his/her HAE with classmates. Please talk with my child and me to understand his/her wishes.

