

DATE: _____

RE: Important health information for _____ [insert child's name]

To all teachers and administrators involved with my child's education,
_____ [insert child's name] _____ has been diagnosed with a rare and potentially life-threatening genetic disease called Hereditary Angioedema (HAE). HAE symptoms include episodes of swelling (edema) in all various parts of the body, including the hands, feet, face, and airway.

Important: All attacks of angioedema involving the upper airway are medical emergencies and must be treated immediately. In addition, emergency department assessment is recommended.

Call 911 immediately if the child reports swelling in the throat, you notice a change in the pitch of his/her voice, or he/she exhibits any difficulty breathing.

On occasion, _____ [insert child's name] _____ may recognize signs of HAE swelling and may need to be excused from school.

_____ [insert child's name] _____ is currently under the care of Dr. _____ [insert physician's last name] _____, who can be reached during office hours at _____ [insert physician telephone number] _____.

If _____ [insert child's name] _____ begins to recognize the symptoms of an HAE attack, immediately contact one of the following people who have been trained to administer their medication:

CONTACT #1 Name: _____
Phone number: _____

CONTACT #2 Name: _____
Phone number: _____

I am happy to answer any questions and I am grateful for your partnership in providing the best care while he/she is at school.

SIGNED: _____

RELATIONSHIP TO CHILD: _____

HAE attacks often occur spontaneously and can be triggered by many things:



PHYSICAL TRAUMA

(e.g., in the school yard or gym class)



EMOTIONAL STRESS

(e.g., social or academic)



INFECTIONS

(e.g., cold or flu)



MENSTRUATION

ABOUT HAE

HAE occurs in about 1 in 10,000 to 1 in 50,000 people. HAE symptoms include episodes of swelling (edema) in various parts of the body, including the hands, feet, face, and airway.

FIVE THINGS TEACHERS NEED TO KNOW ABOUT MY CHILD WITH HAE:

1. Due to their 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) – and I ask for your assistance in monitoring for any trauma-related swelling.
3. They are 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 they report a thickness in his/her throat or difficulty breathing. Then, please call my emergency contact phone number: [insert contact name and phone number(s)]
5. They may or may not wish to share information about his/her HAE with classmates. Please talk with the child and me to discern his/her wishes.

**HAE is not allergic swelling, although it may share a similar appearance.
HAE does not respond to antihistamines or corticosteroids.**

FACIAL SWELLING

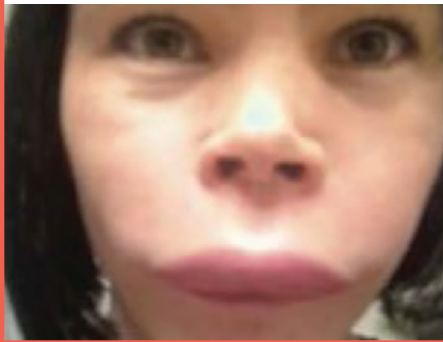


Image obtained from www.haeimages.com.

HAND SWELLING



ABDOMINAL SWELLING



Image obtained from www.haeimages.com.

In addition, abdominal swelling can be accompanied by nausea, vomiting, and excruciating pain.