

## SAMPLE TEACHER NOTE

Dear \_\_\_\_\_

I hope we will be able to meet soon, so that we can get to know one another better. I am excited that \_\_\_\_\_ will have you for his/her teacher this year. I know the beginning of school is always a very busy time, but I would very much appreciate if we could make time to sit down and talk about \_\_\_\_\_

\_\_\_\_\_ is looking forward to the new school year. I wanted to let you know that he/she has a condition of which you should be aware.

\_\_\_\_\_ has been diagnosed with Hereditary Angioedema or HAE.

HAE is a very rare and potentially life-threatening genetic condition.

To give you a bit of the medical background HAE patients have a defect in the gene that controls a blood protein called C1 Inhibitor.

Because defective C1-Inhibitor does not adequately perform its regulatory function, an imbalance can occur that causes the release of fluids into surrounding tissue. This causes swelling in various body parts including the hands, feet, abdomen, face and throat.

Children like \_\_\_\_\_ with HAE may have bouts of excruciating abdominal pain, nausea and vomiting, caused by swelling in the intestinal wall. Throat (airway) swelling is a medical emergency and must be taken seriously. My child may complain of a lump in the throat or difficulty swallowing. You may notice a change in the quality of his/her voice..Throat swelling can lead to death by suffocation.

It is very **important** at the slightest hint of throat swelling, please call 000 (111 NZ) for immediate medical treatment to ensure that my child's airway is not compromised.

\_\_\_\_\_ 's HAE is as well-controlled as possible, but there may be times when his/her HAE attacks are too severe to attend school.

Please understand that days missed from school are not by \_\_\_\_\_ 's choice - he/she would rather be in class. I will be working with you and the school guidance counselor to make arrangements for makeup work so that \_\_\_\_\_ will not fall behind.

We will always make the best effort to make sure \_\_\_\_\_ has the same school experience as any of his/her classmates - to arrive on time, to have a terrific attendance record, to do the best work possible, and to participate in all activities.

\_\_\_\_\_ may be sensitive about how others perceive him/her.

He/she may or may not wish to share information about HAE with classmates. Please talk with my child and me to clarify his/her wishes.

Please take the time to read the HAE materials I have provided. They will help you to understand not only HAE, but also my child's life with this disease.

I also recommend the HAE Association website (<http://www.haeaustralasia.org.au>) – it contains a wealth of information and HAE resources. If you have any questions at all, please do not hesitate to call me.

I appreciate your attention to \_\_\_\_\_'s particular needs. I will also be providing information regarding \_\_\_\_\_'s HAE to the school nurse.

I look forward to meeting with you at your convenience.

Sincerely,

Name,  
Phone number  
email address