**Dear Emergency Medical Professional,**

DRAFT

My patient, \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ , has asked me to tell you about his/her diagnosis of a rare, but potentially life-threatening, genetic medical condition called hereditary angioedema (HAE).

***About HAE***

HAE is a rare inherited disease that can cause considerable swelling in various body tissues. People with HAE are missing a blood protein called C1 esterase inhibitor (C1-INH). When the body’s need for C1-INH overwhelms its ability to keep up with demand, a sudden attack can occur.

***What causes an HAE attack? What are the triggers?***An HAE attack occurs when the demand for C1 esterase inhibitor exceeds the amount of available functional C1 esterase in the body.  C1 esterase is like a key that turns off the immune response (in the complement and contact systems). Therefore, deficiency in functional C1 esterase means that there will not be enough of this protein available to turn off this immune response, leading to increased bradykinin levels. Since bradykinin increases vascular permeability, fluid continues to leak into the surrounding tissues, causing the swelling or edema

***Not an Allergic Response***

During an attack, the edema may appear to be allergic in nature; however, HAE is **not** an allergic condition, and the patient typically will not respond to antihistamines or corticosteroids.

***Life-threatening Symptoms***

***Please note that if an HAE patient experiences a swelling attack in the face or in the mouth, throat, or airway, this can be a serious and potentially life-threatening condition requiring immediate emergency care.***

***Potentially life-threatening symptoms in HAE attacks:***

* Extreme dizziness or fainting
* Hoarse voice or laryngitis
* Significant lip or facial swelling
* Shortness of breath
* Swollen tongue
* Throat swelling
* Whistling or wheezing when breathing

Some patients may experience symptoms in advance of an attack, such as fatigue, nausea and flu-like feelings, bowel movement changes, urticaria, non-itchy rash, and tingling. Individual patients often are aware of specific symptoms that herald the onset of their attacks.

***Treatment for Attacks***

My patient is being treated with **BERINERT®** (C1 Esterase Inhibitor) for HAE.

His/her dose is \_\_\_\_\_\_\_ UNITS and s/he has 1 dose with him/her. S/he has been instructed on how to store this product so that it is acceptable to use in this emergency. If necessary, a 2nd dose may be administered after \_\_\_\_\_\_ minutes if symptoms have not subsided. Contact the Blood Transfusion Lab to request the 2nd dose.

Instructions for reconstitution and administration are in the product insert.

Here is some additional important information you should know about it: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

***Contact Information***

I am available for a consultation and can be reached at the following number(s):

Office: \_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

 In emergencies, please call: \_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

If you’d like to learn more about HAE, please visit: [www.allaboutHAE.ca](http://www.allaboutHAE.ca).

Thank you for your interest in HAE and our shared commitment to the patient’s healthcare.

Sincerely,

**Physician’s Name**: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ **Date**: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**Signature**: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_