FAMILY TESTING FOR HEREDITARY ANGIOEDEMA (HAE) DUE TO C1 INHIBITOR (C1-INH) DEFICIENCY

A letter from your relative



I have recently been diagnosed with hereditary angioedema (HAE) due to C1 inhibitor (C1-INH) deficiency. HAE is a genetic disorder, so other members of my family may have the disease.

HAE is characterized by painful, unpredictable, recurrent attacks of swelling and/or edema affecting the hands, feet, face, abdomen, urogenital tract, and the larynx (part of the throat). Symptoms often begin in early childhood; however, some patients experience their first attack later in life and some do not experience any symptoms.

Attacks can significantly limit a patient's ability to perform daily activities, and the impact on quality of life can be considerable.

Undiagnosed HAE and unmanaged swelling attacks can have serious consequences. Attacks occurring in the upper airway (throat) can cause severe breathing difficulties.

It is important that you are tested for HAE, because you may have the disease even if you have not experienced any symptoms.

You may want to ask your doctor to contact my HAE clinician (see contact details below).

They can arrange for you to be tested and address any queries or concerns you may have.

HAE clinician



Name:	
Address:	
Sel:	

The idea of getting tested for HAE may seem daunting; however, there is support available from specialist doctors and HAE patient support groups. In the event of a positive diagnosis, an HAE clinician can help you manage your symptoms and minimize the impact of the disease on your life. The results of your test will remain confidential between you and your doctor.

Best wishes,

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