This is Sian Harding. To all appearances Sian is a healthy and happy 18 year old – but in fact she suffers from a very rare genetic condition called Hereditary Angioedema (HAE).

HAE patients have a lack of an essential blood component C1 Inhibitor (C1 INH ).

C1INH controls the flow of fluid from the capillaries into the tissues; HAE patients have frequent attacks of huge swellings of arms, legs, gut, face, and throat swelling which is life threatening. Without treatment each attack lasts from 3 to 5 days and causes severe pain and disruption to normal life.

Sian has coped courageously with HAE for most of her life. She gives herself intravenous injections of C1INH whenever she has an attack, and in this way she has managed to hold down a job and have a reasonable quality of life.

Life can be very difficult for Sian, but thankfully she does have her medication to treat her condition. Many patients suffer for many years with an incorrect diagnosis, and many others have difficulty accessing the treatment they need. Most HAE patients have never met anyone else with their condition.

HAE – UK is the Patient Association for HAE Patients. We are trying to raise funds to build a web site that will offer support and information to help HAE patients to get the support and treatment that they need so badly.

Please give generously to help build the web site that will support Sian and others like her who are living with this debilitating and life threatening condition.