Supporting us

HAE UK is a Patient Support Association, focusing solely on the needs of Hereditary Angioedema (HAE) patients and their families in the UK.

Background

HAE UK is a Patient Support Association, focusing solely on the needs of Hereditary Angioedema (HAE) patients and their families in the UK.

HAE is a very rare condition affecting between 1/10,000 and 1/50,000 of the population. It is characterised by huge swelling of the tissues (angioedema). These swellings can occur on any part of the body and they typically last from three to five days. Swelling in the gut can cause severe pain. Airway swellings are life threatening.

Diagnosis

HAE is such a rare condition that most doctors would not see a case in their entire career and misdiagnosis was and is still common. Many patients suffer for decades with inappropriate treatments and unnecessary operations before they receive the correct diagnosis.

Treatment

Treatments now exist that can transform the lives of HAE patients. The frequency of attacks varies from patient to patient and can affect children and babies, some having swellings every week or even more frequently. Without proper treatment patients’ lives can be blighted. They are hindered in their education, unable to function properly in a work environment and their ability to travel safely is limited.

Please support HAE UK in their efforts to achieve early diagnosis, good treatment and practical support for HAE patients. Thank you.
The charity

With your support HAE UK aims to raise awareness of this very rare condition and to work together to ensure better treatment and support for HAE patients and their families, thus transforming their lives. We seek to achieve this by:

- Campaigning for better diagnosis and treatment
- Organising patient days, where leading experts in the field are available to update on research and treatments and address patients questions and concerns
- Maintaining a website to offer particle information and advice
- Providing confidential one to one support

Giving

You can support HAE UK by providing a one off or regular donation, organising a fundraising activity, shopping online or leaving a legacy gift. Please see the reverse of this leaflet for information about how to donate.

Please make any cheques payable to HAE UK.

Meet Izzy

Izzy

Izzy is a mother of two young children and she has Hereditary Angioedema (HAE).

- HAE causes frequent unpredictable huge swellings affecting her gut, back, legs, feet, hands and face.
- It can cause her tongue and throat to swell putting her at risk of suffocating.

If these attacks are untreated they have a major impact on Izzy’s life. Swellings of her feet mean that she can’t get her shoes on or walk. Hand swellings prevent her doing normal every day tasks. Abdominal attacks cause excruciating pain with vomiting and diarrhea. Facial attacks are very disfiguring and they can progress to swelling of the airway which is life threatening.

Izzy started to experience HAE symptoms when she was four years old, but she wasn’t diagnosed until she was twenty one. HAE symptoms had a major impact on her schooling and she left school with very few qualifications.

When Izzy went to work it was very difficult to explain to her employers why she was frequently off sick with such ‘weird’ symptoms. Because of this it was difficult to hold down a job or make progress with her career.

The first time Izzy’s face swelled and spread to her throat she said she was choking on what she was saying and she couldn’t get any words out. It was really terrifying, like something was caught in her wind pipe.

Three things have helped to change Izzy’s life

She got the correct diagnosis.

She was referred to a HAE Specialist.

The HAE specialist developed a personalised HAE management plan that allows Izzy to self medicate at the first symptoms of an attack. The medication stops the attack progressing and allows Izzy to get on with her life.

She was supported by HAEUK.

HAE UK provided lots of information and support about so many practical aspects of living with HAE and it helped Izzy meet and share experiences with other HAE sufferers.

Please give generously to this worthy cause that can help transform lives. Thank you.