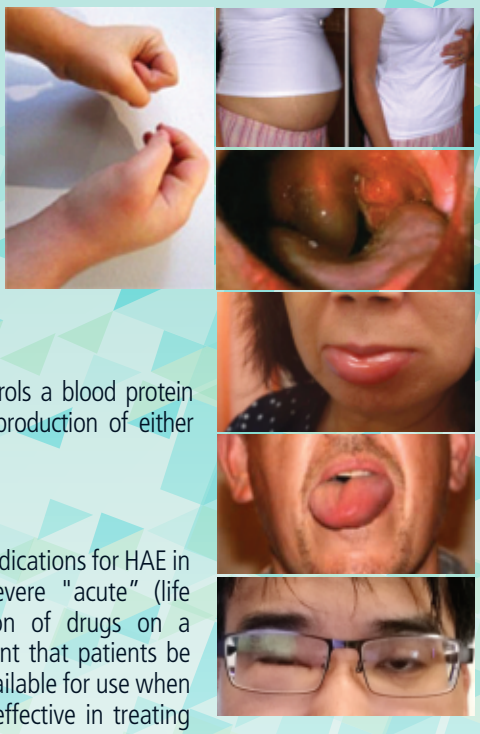
What is HAE?

Hereditary Angioedema (HAE) is a very rare and potentially life-threatening disease that occurs in about 1 in 10,000 to 50,000 people. HAE symptoms include episodes of edema (swelling) in various body parts including the hands, feet, face and airway. In addition, patients often have bouts of excruciating abdominal pain, nausea and vomiting that is caused by swelling in the intestinal wall. Airway swelling is particularly dangerous and can lead to death by asphyxiation.



What is the cause?

HAE patients have a defect in the gene that controls a blood protein called C1 Inhibitor. The genetic defect results in production of either inadequate or non-functioning C1-Inhibitor protein.

Medications

Unfortunately, there are currently no registered medications for HAE in Hong Kong. Patients needing treatment for severe "acute" (life threatening) attacks need individual registration of drugs on a "named patient basis". That is why it is important that patients be diagnosed and registered so that medication is available for use when needed. Known anti-allergy treatments are not effective in treating HAE attacks.

In the event of a severe attack...

Each patient should be prescribed a personal treatment plan by their own immunologist, especially if they are severely swollen (eg, throat, tongue or gastrointestinal swelling) and the patient needs emergency treatment (eg C1 inhibitor replacement therapy). In Hong Kong, patients may need to provide health care providers with emergency letters issued by their immunologists and recommended medications within the treatment plan to ensure proper treatment in a timely manner.

What next?

If you have a family history of HAE, or have suffered from sudden swelling episodes, consider getting yourself checked for HAE at your Immunologist as soon as possible.

About hae hk

The Hong Kong HAE Patient Group Ltd. is the first HAE patient group in Hong Kong formed in 2019 to support HAE patients and their families, to create awareness, provide education, and advocate for access to modern treatments so HAE patients can enjoy a higher quality of life.

hae hk

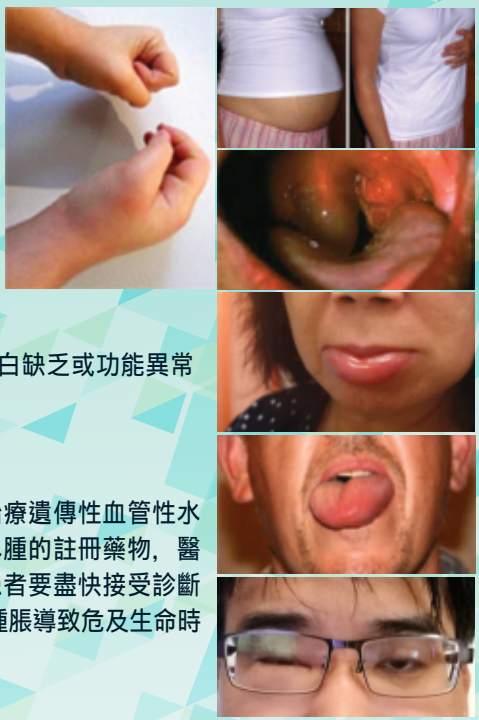
HOW CAN I FIND OUT MORE?

Send an email to: hkhaepatientgroup@gmail.com
Visit our website: http://haehk.haei.org
Follow us www.facebook.com/haehongkong

什麼是 HAE?

遺傳性血管性水腫(HAE)是一種非常罕見且可能危及生命的疾病，約在10,000到50,000人中便有一位個案。病徵是重複發生血管性水腫在身體部位(包括手、腳、面部和氣道)。

此外，患者通常會出現由腸壁腫脹引起難以忍受的腹痛，噁心和嘔吐。氣道腫脹特別危險，可能導致窒息死亡。



原因是什麼？

HAE患者是因血液中的一種蛋白質-C1抑制蛋白缺乏或功能異常引致的免疫疾病。

藥物

一般用於治療過敏性腫脹的藥物是無法有效治療遺傳性血管性水腫，更不幸的是香港現時沒有遺傳性血管性水腫的註冊藥物，醫護人員只能為已登記的患者對症下藥，所以患者要盡快接受診斷並登記到"指定病人名單"上，那麼在發生嚴重腫脹導致危及生命時便能得到更有效的治療。

如果發生嚴重腫脹 . . .

每位患者都應該經自己的免疫科專科醫生處方其個人治療方案，尤其當嚴重腫脹時(例如：咽喉、舌頭或腸胃腫脹)，患者需要接受緊急治療(例如C1抑制劑替代療法)。在香港，患者可能需要向醫護人員提供其免疫科專科醫生簽發的應急信及治療方案內建議的藥物，以確保能及時得到適當治療。

接下來是什麼？

如果您有HAE的家族史或曾有突發性腫脹及類似HAE病徵，請考慮儘快找您的免疫科醫生檢查。

關於 hae hk

遺傳性血管性水腫病人組織(香港)有限公司是香港首家成立於2019年的HAE患者團體，旨在支持HAE患者及其家人，提高對這病的認識，提供教育及倡導現代治療，讓HAE患者享有更高質素的生活。

hae hk

我怎樣才能找到更多？

可發送電子郵件至：hkhaepatientgroup@gmail.com
或到訪我們的網站：http://haehk.haei.org
追踪 www.facebook.com/haehongkong