

# One-of-a-kind virtual medical centre launches in Cape Town

An innovative new virtual medical support centre offering expert advice on, and treatment of angioedema and hereditary angioedema (HAE), has launched.



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The Sinovuyo South African Virtual Angioedema Centre in Cape Town is the first of its kind in Africa and the second of its kind in the world.

The centre is named after seven-year-old Sinovuyo, who had hereditary angioedema but tragically died during an HAE attack. Unfortunately, hereditary angioedema is often misdiagnosed by medical practitioners who are unaware of the disease and its symptoms. Many sufferers (and their families) don't know that they even have HAE, or how to go about seeking ongoing treatment and medications.

The centre aims to correct this through an expert independent specialist team that offers advice and support for patients; their families and carers; medical practitioners, as well as nurses caring for angioedema patients.

## What is angioedema?

Angioedema refers to sudden swelling that is often caused by an allergic reaction.

There are various types of angioedema and although the symptoms may appear the same, hereditary angioedema (HAE) is not an allergic reaction and does not respond to conventional allergy treatments.

Those with HAE have a problem with a gene that produces a protein in the blood called C1-inhibitor. Lack of this protein causes fluid from small blood vessels to leak into, and under, the surrounding skin resulting in localised swelling and pain.



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Katja Hamilton 23 Feb 2023



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Various body parts may be affected, including the hands, feet, face, gastrointestinal tract, throat, and genitals.

Swelling in the throat is the most dangerous aspect of HAE because the airway can become constricted and, without treatment, can cause death by suffocation. Swelling in the abdominal wall causes excruciating abdominal pain, nausea, and vomiting.

There are various types and causes of angioedema, and most cases of angioedema are not HAE.

## Access to expert medical care for all

According to Henrik Balle Boysen, HAE International executive vice president and chief operating officer, the Sinovuyo South African Virtual Angioedema Centre will quickly connect people with chronic swelling disorders to specialist doctors.

“This is of huge benefit to sufferers who may live in remote areas or otherwise cannot travel and need medical assistance and information.”

The Sinovuyo South African Virtual Angioedema Centre is the virtual arm of the UCT Lung Institute, Allergy & Immunology Unit, under the leadership of Jonny Peter. “Sinovuyo’s story is a heartbreaking one with an avoidable outcome. Sinovuyo’s life and death is a call to action for us as healthcare workers and patient advocates.

“Her story highlights the ongoing need for education, awareness, and treatment access for all affected by this life-threatening but treatable condition. The need is even greater in places with fragile healthcare systems,” Peter said.

## Knowledge is essential

According to Janice Strydom, chief executive officer of HAE SA and an HAE sufferer herself, patients living with chronic swelling often go undiagnosed or misdiagnosed for many years and suffer unnecessarily.

“In some instances, such as Sinovuyo’s, patients have died due to a lack of correct treatment as doctors were unaware of the underlying cause.



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“We are frequently contacted by patients suffering from unexplained bouts of swelling and are excited to have a virtual centre dedicated to assisting South Africans in getting an accurate diagnosis, advice, and suitable treatment - whether they have HAE or another form of angioedema.”

## How the centre’s services work

Appointments with an angioedema specialist can be set up by means of the centre’s online system for a secure video-based consultation.

“We provide family-member information and education as well as information on screening, the importance of early diagnosis, information about clinical trials and access to advice from a geneticist,” says Peter, who is also head of the division of allergology and clinical immunology in the department of medicine at UCT.

“We are very pleased that this groundbreaking new centre has been launched. It is a fitting way for us to honour the legacy of Sinovuyo, and to shine a spotlight on all forms of angioedema in order to strengthen the call for improved diagnosis, and consistent access to lifesaving therapies for everyone,” concludes Peter and Strydom.

“Sinovuyo in Xhosa means “we have happiness”, and we hope that this virtual angioedema centre will lead to increased happiness for South Africans of all ages affected by angioedema, and their loved ones.”

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