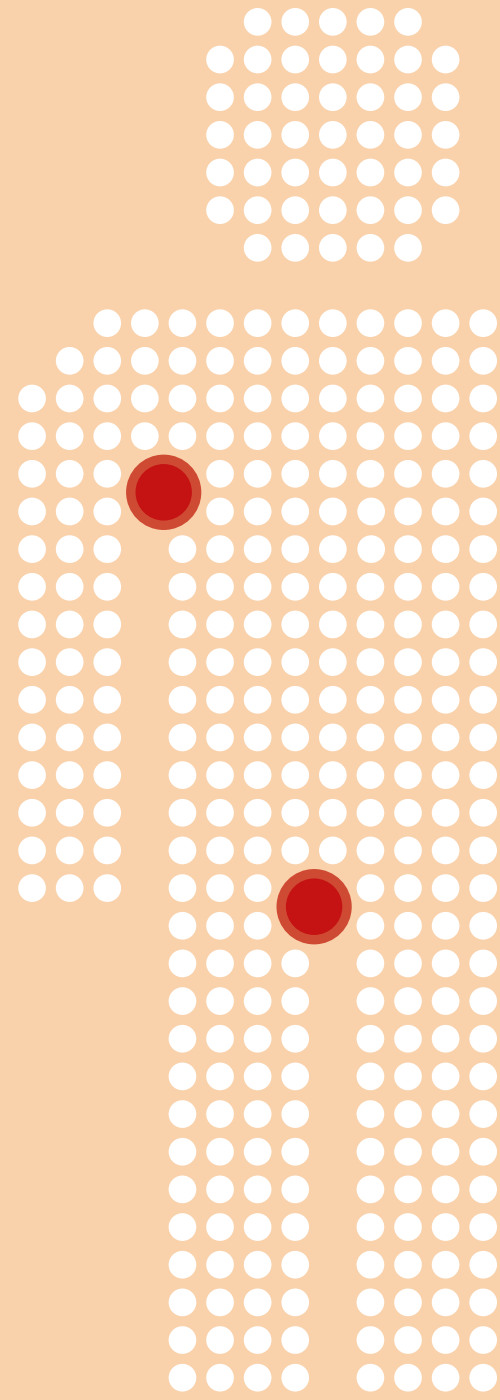




HS

THE SKIN DISEASE NO ONE TALKS ABOUT

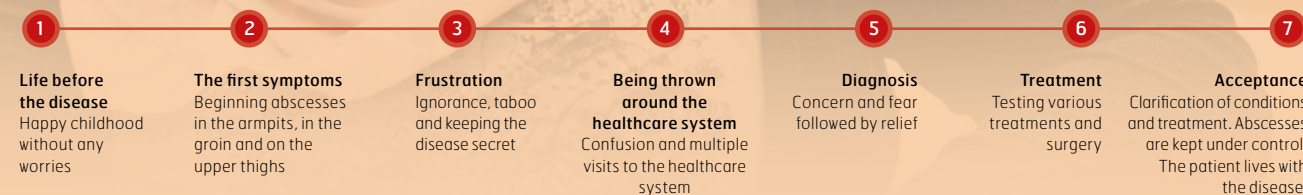


THIS IS WHAT WE WANT TO CHANGE

Hidradenitis suppurativa is a tabooed disease that most people do not know about. This is partly due to the nature of the disease with suppurating and foul-smelling abscesses in sensitive parts of the body. There is no cure, but the disease can be controlled and relieved if diagnosed early.

The patient's journey with HS

- the current journey from symptom to diagnosis and acceptance



Neel De Place 38 years old. When she first discovered abscesses in her armpits she was 13 or 14, but she did not see a doctor until she was 17. By that time the abscesses had spread to her groin. Then the hunt for a diagnosis began. The doctors were generally ignorant about the nature of the abscesses. At the age of 30 and after 15 years of being bounced around the healthcare system she was finally diagnosed with Hidradenitis Suppurativa at Roskilde Hospital.

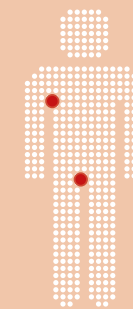
Today, Neel suffers from both HS and fibromyalgia. She gets regular check-ups for HS and frequently has her abscesses surgically removed. Neel has tried many different kinds of medication over the years. This often helped, but when resuming treatment after an interruption, she would sometimes find that the medication no longer had the same effect.

After her diagnosis with HS, Neel feels that it is important to raise awareness about the disease, and she is currently active in the patient association as well as in the Facebook group "Alle os der lider af HS".

It typically takes eight years before HS is diagnosed

8
YRS

HS occurs in areas where skin touches skin. The disease is often seen in the armpits and the groin area



Symptoms of HS

Hidradenitis suppurativa, usually referred to as HS, is a disease causing abscesses, nodules or cysts in areas of the body, where skin touches skin. The disease is caused by inflammation of the hair follicles and is most frequently seen around the armpits, in the groin, under the breasts and on the buttocks. When the abscesses form, the area around them swells and reddens.

HS is often very painful. At times, fluid drains from the abscesses, and may smell bad. After breakouts, the abscesses often turn to scars.

HS is a disease that may have serious impact on patients' daily lives. During breakouts, the pain, the suppurating abscesses and the smell make it a real challenge to live a normal life – therefore patients with HS often need welfare support and healthcare assistance. The disorder is made worse by the fact that other diseases often coincide with HS, e.g. rheumatism or the intestinal disease Morbus Crohn.

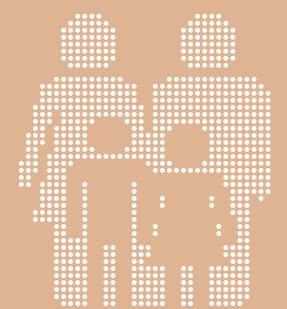
Cause unknown


The cause of HS is unknown. In some families the disease is hereditary. It is a skin disease, but also a disorder associated with the immune system. Some factors are presumed to contribute

to or aggravate the disease. These include smoking, obesity, physical stress and tight clothing.

HS is not a contagious disease. It often occurs during or just after puberty. Recent studies indicate that approx. 2% of the Danish population suffers from HS to varying degrees.

HS is often hereditary; 44% have family members with HS





HS is a dermatological disease, and it is a dermatologist, who plans the patient's course of treatment

find it difficult to distinguish HS from ordinary boils, leaving patients without a diagnose for far too long.

HS leads to social challenges

Because of its nature and appearance, HS may quickly lead to social challenges, as patients isolate themselves from social events. In some cases the disease may ruin friendships and make it hard for patients to socialise with other people, because they are concerned about, what people will think of their abscesses.

of creams or ointments and through medical or surgical treatment. It is important to diagnose HS as early as possible, so that the correct treatment can be initiated.


If you have doubts as to whether you have HS, you should see your GP and get a referral to a dermatologist.

No one talks about HS

Although the disease is widespread, few people know of HS. This is true of the population in general, but also of doctors, healthcare professionals and social workers. The lack of knowledge is partly due to the fact that the nature of the disease makes it hard to talk about. As a consequence many patients wait far too long before they see a doctor. In addition, many doctors

A disease you learn to live with

HS is a chronic disease, which may change over time. For some patients it may disappear, while others may go into temporary remission before they relapse. There is no cure, but you can learn to live with it, as it is possible to keep the disease under control or relieve the discomfort through the use



The word most HS patients associate with the disease is pain

Standing strong in the patient association

In addition to seeing your GP or a dermatologist, you can join the Patient Association HS Denmark. Here you can share your experiences with peers and get advice and guidance on how to cope with the disease.

Talking to others, who are in the same situation may give you comfort and energy to make the most of your life.

The patient association was established in 2013 with the mission of making a difference for people with HS. JOIN us and help us increase the focus on and awareness of HS among politicians, doctors and patients. You will find answers to many of your questions and also obtain information about research and developments regarding the disease.

Get more information at www.hidrosadenitis.dk