

# HIDRADENITIS SUPPURATIVA

THE SKIN DISEASE NO ONE TALKS ABOUT

# SHH...

Break the taboo! Let's talk about HS

# HS THE SKIN DISEASE NO ONE TALKS ABOUT

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.



Neel De Place is 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".

# THIS IS WHAT WE WANT TO CHANGE



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

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**It typically takes eight years before HS is diagnosed**



**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.

## Case 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.

## The patient's journey with HS

- the current journey from symptom to diagnosis and acceptance



# LET'S TALK ABOUT HIDRADENITIS SUPPURATIVA



**HS is a dermatological disease, and it is a dermatologist, who decides the course of treatment for the patient**



**The word most HS patients associate with the disease is pain**

## **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 find it difficult to distinguish HS from ordinary boils, leaving patients without a diagnosis 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.

## **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 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.

## **You are not alone**

You can do something about HS. 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. It gives you energy to talk to others in the same situation.

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## **Standing strong in the patient association**

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. Join the Patient Association HS Denmark and the Facebook group "Alle os der lider af HS".

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