



HIDRADENITIS SUPPURATIVA TABOOED AND NEGLECTED

In Denmark a lot of people – girls and boys, women and men – are living with a chronic skin disease. Some do not know what it is, others do not dare to talk about it. They are unaware, embarrassed and frustrated. The disease causes a great deal of pain and social challenges. They feel neglected, because no one talks about the disease, and no one knows what it is, how it occurs or how it is diagnosed.

But they are not alone. Close to two percent of the Danish population – amounting to approximately 110,000 Danes – are suffering from the disease. The majority, however, are not aware of which sickness they suffer from. Therefore, they carry the pain in silence – without getting help, treatment or a diagnosis.

Do you have abscesses and pain in your armpit, groin or other sensitive parts of the body? Are the abscesses recurring? Do they leave scars? If so, it is possible that you are among those suffering from the chronic skin disease with the peculiar name hidradenitis suppurativa – also known as HS.

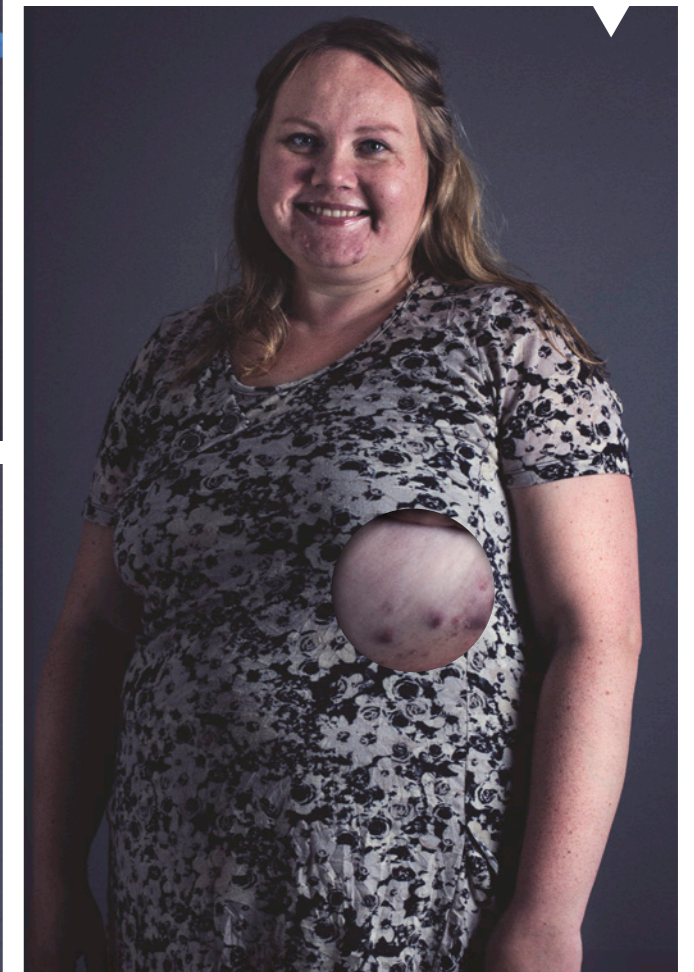
“Men are generally reluctant about visiting their doctor and acting on symptoms. I believe that there are more men suffering from HS than what the statistics show. So if you experience abscesses that are recurring to a greater or lesser extent, I would recommend getting a referral to a dermatologist.”

Mikkel, 30 years old, Webdesigner and photographer.
Seven years from the first abscess to a diagnosis.



“Getting the diagnosis was a great relief, because it confirmed that it wasn’t just me. At the same time I figured out that there were experts, who actually knew something about the disease. Even though I’m still undergoing surgery every six months for recurring abscesses under my arms and in my groin area – and there is no cure for this disease – it helps to know that something is being done to make more people aware of HS and to get proper help.”

Anna Louise, 29 years old, blogger on skriveri.com.
Nine years from the first abscess to a diagnosis.



“I was 18 when I got my first big abscess, but it already started when I was 11. So I have been living with HS for about 22 years now. I got the diagnosis in April this year, so 21 years had to pass before I knew for certain about my torments.”

Rikke, 32 years old, Housewife.
21 years from the first abscess to diagnosis

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. Unfortunately, that only happens for a minority.

Facts about HS

- HS usually occurs where skin touches skin.
- The cause of HS is unknown and there is no treatment that can cure the disease, but there are multiple treatments that can relieve the discomfort and keep the disease under control.
- HS is not a contagious disease.
- It typically takes eight years before HS is diagnosed.
- HS is often hereditary. That is the case for almost half of the HS patients.
- HS is a dermatological disease, and it is a dermatologist, who determines the course of treatment for the patient
- The word most HS patients associate with the disease is pain.
- HS is a disease that may have serious impact on patient's daily lives. During breakouts the pain, the suppurating abscesses and the smell makes it a real challenge to live a normal life.
- It is important to diagnose HS as early as possible, so the optimal treatment can be initiated.

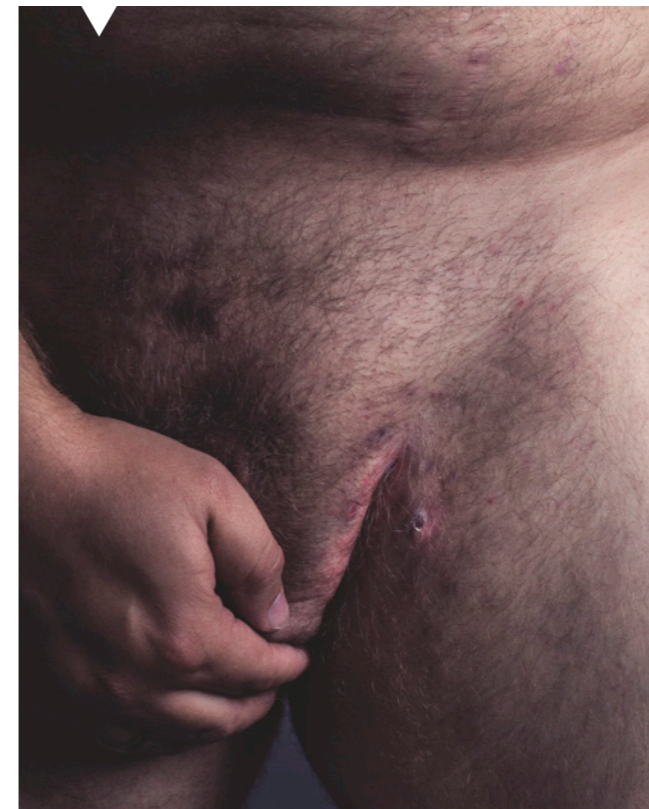
Symptoms of HS

- 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 poorly.
- After breakouts, the abscesses often turn to scars.
- The abscesses are often recurrent and can vary in size and severity.
- HS can coincide with other diseases such as rheumatism, psoriasis or the intestinal disease Morbus Crohn.

The patient's journey

The current journey from symptom to diagnosis and acceptance is often long and tough – and on average it takes up to eight years with negative consequences for patient's social life, education and career opportunities. The patient's journey should be shortened and improved.

"A big pimple under the arm developed into larger, recurring abscesses. Ignorant doctors and lacking information only added to the confusion and turned the course of disease into a long and tough struggle. Seven years had to pass with multiple visits to general practitioners and dermatologists, before a Google-search gave Mikkel the first real answer to the many years of torments, and he finally got a diagnosis in October 2014."



"Anne Louise got her first abscess at the age of 13. She had always had impure skin, and for the first couple of years she didn't consider it being a disease. That all changed as the disease worsened and occurred on multiple parts of her body. Anne Louise is most of all sick of people saying that abscesses are just pimples, and that it will pass, because that is so far from the truth. "They should try having an HS abscess on their own body"."



"The worst thing about HS is the great pain related to the abscesses, but besides that I have periods before the actual breakout, where I get fever. The fever usually lasts for five to seven days, where I get physically sick and totally drained of energy. It highly affects my social life and it can be really difficult to explain and get others to understand what's the matter with you, when you barely know yourself."

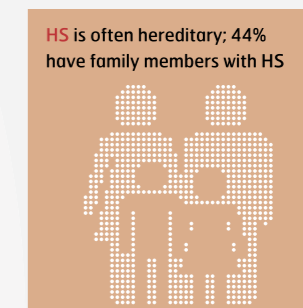
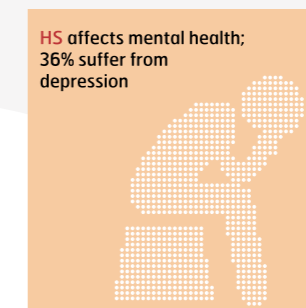
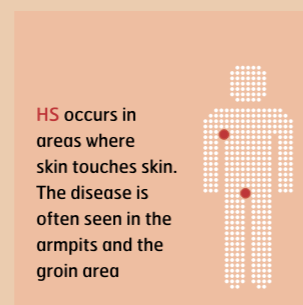
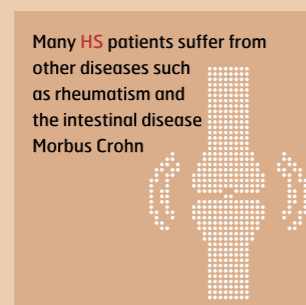
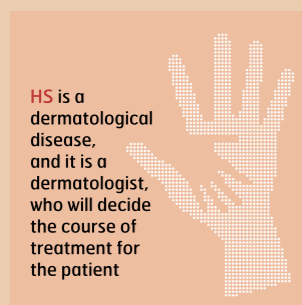
THREE QUESTIONS YOU SHOULD **ASK YOURSELF** IF YOU SUSPECT HAVING HS

1. History: Have you repeatedly had painful or fluid-filled abscesses more than twice within the last six months?
2. Position: Are the abscesses placed in the armpit, the groin, the area around the buttocks or under the breasts?
3. Hereditary disease: Has anyone in your family experienced similar recurring abscesses?

If you can tick off any of the above, you should contact your doctor immediately.

FOUR QUESTIONS YOU SHOULD **ASK YOUR DOCTOR** IF YOU SUSPECT HAVING HS

1. Have you heard about HS?
I suspect that my abscesses are caused by the chronic skin disease HS (if necessary, show your GP this material).
2. Can you refer me to a dermatologist?
It is important that I quickly figure out whether this is HS, so I can get the optimal treatment.
3. What is the course of treatment, if I have HS?
It is a chronic disease and it is important to know what is going to happen, who will be involved and what the consequences are.
4. Are there other diseases that may coincide with HS that I need to be aware of?



LEARN MORE AND TALK TO OTHERS, WHO LIVE WITH THE DISEASE

You can do something about HS. In addition to seeing your doctor 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.

The Patient Association HS Denmark

The Patient Association HS Denmark was established in 2013 and works to increase awareness on HS and thereby the quality of patients' everyday life. Together, we have a greater voice among decision-makers in Denmark. Join the Patient Association HS Denmark and learn more about the disease and get in contact with peers.

The patient association's advice to people, who show symptoms of HS

- Keep taking the initiative to get help and get a referral to one of Denmark's five dermatological departments, if you have any doubts about your diagnosis.
- • Accept the disease and get the best out of your life!
- Do not confine yourself – focus on what you can do!
- Engage in groups with other HS patients – it helps to be with people that understands you.
- In Denmark we have some of the leading specialists in the world, so there is a hope. It does, however, require that you get a referral to a dermatological expert and get a diagnosis. That way you can get the best treatment.

Get more information at www.hidrosadenitis.dk

Visit and follow us on Facebook

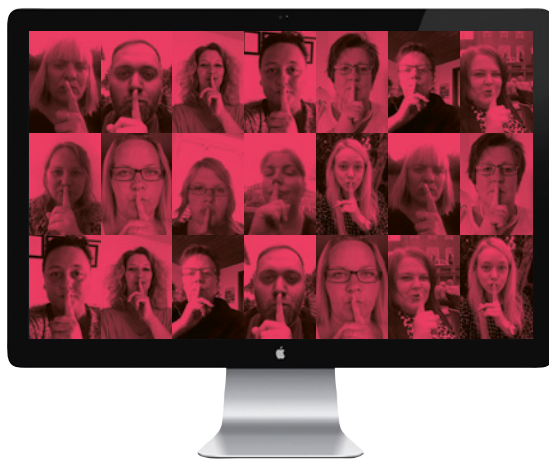


Patientforeningen HS
DANMARK

Information and support to people living with the skin disease **Hidradenitis Suppurativa**

SHH...

HELP US BREAK THE TABOO.



Help break the taboo surrounding HS!
Take Shh-selfie and share it on
Facebook or Instagram
#DonateAShh



JOIN OUR SHH CAMPAIGN

In October 2015 the Patient Association HS Denmark launches a campaign with an aim to increase awareness of HS among the public and medical practitioners. We want to break the taboo and facilitate understanding for the approximately 110,000 Danes that suffer from HS. Help us break the taboo!

Our disease is called HS, but no one talks about it. We carry it in silence, which is why we experience that the letters switch places to sh... as in "Shh".

Mikkel-Ernst Ertz-Madsen has taken the pictures in this material. He appears in the portraits and suffers from HS. The idea of this material is developed by Mikkel-Ernst Ertz-Madsen and the Patient Association HS Denmark.

