



TAKE A DEEPER LOOK AT

HIDRADENITIS SUPPURATIVA (HS)

## UNCOVERING HS: YOUR GUIDE TO UNDERSTANDING THIS CONDITION

WHEN IT COMES TO HS,  
KNOWLEDGE IS EVERYTHING.

Elizabeth | Registered Nurse, Living with HS

### UNDERSTANDING HS

Hi-dra-den-i-tis sup-per-uh-tee-va (HS) is a chronic, systemic (throughout the body) inflammatory condition where an overactive immune system contributes to excess inflammation below the skin.

Whether you're adjusting to life with HS or have been dealing with it for decades, it's a condition that can be hard to understand. And, just as importantly, hard to predict.

HS can leave you unsure of what every day will bring. More flares? More wounds? More pain? While this uncertainty can impact you in many ways, the information you'll find here can help guide you in working productively with your dermatologist to manage your HS.



## THE ANSWERS BEHIND HS

Medical researchers have been learning about HS for quite some time. And although many strides have been made in understanding this condition, it still can be easy to mistake HS for other conditions. The abscesses and nodules associated with HS can often lead to misdiagnosis—and it can even go undiagnosed for years. So, let's set the record straight. Here's what HS is and isn't.

### What HS is:

**HS is a systemic inflammatory disease** that usually starts out as bumps resembling boils or pimples on the surface of the skin. These bumps are known as nodules or abscesses. They can develop into painful sores that could leak and produce an unpleasant odor, cause scarring, or even connect beneath the skin as tunnels or tracts.

**Why does this happen?** Doctors don't know exactly why yet, but they do know that inflammation and the immune system play a key role (for more on that, go to page 04).

### What HS isn't:

There are many myths and misunderstandings around HS. Let's clear up the facts:

#### HS is not:

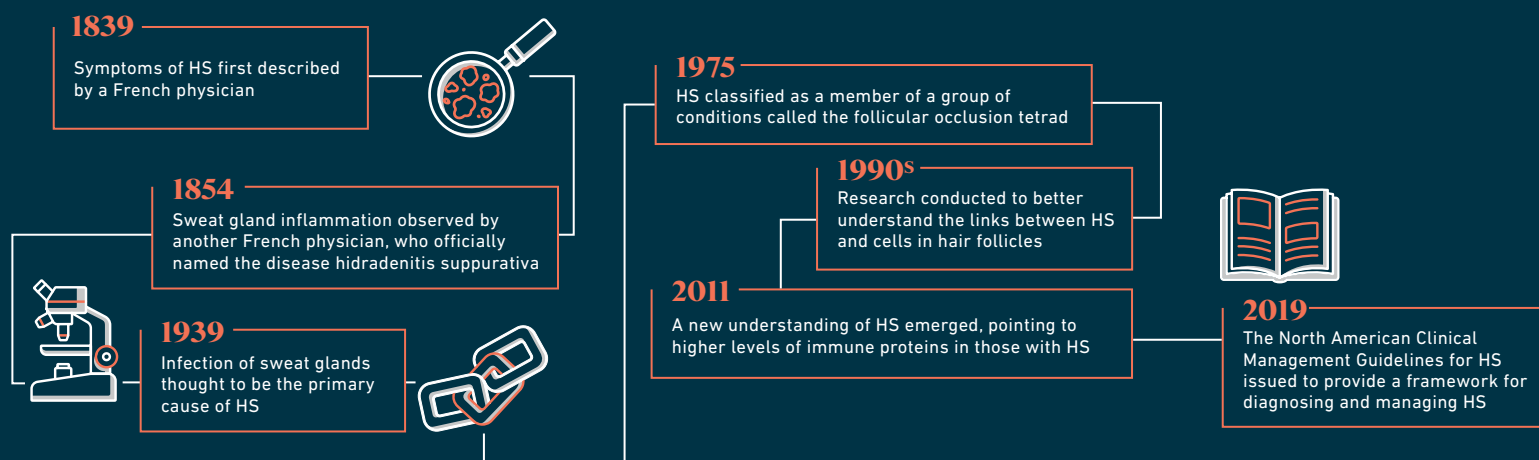
- an STD
- contagious
- due to poor hygiene
- due to smoking or obesity
- caused by infection
- your fault

## WHERE DOES HS APPEAR?

HS is different for everyone and can show up anywhere hair follicles are located on the body. It usually appears in places where skin touches skin. Common areas include: underarms, buttocks, underneath the breasts, groin area, inner thighs, ears, and back of the neck.

## How research has led us to where we are today

HS was first identified in the 1830s. Recent findings have shown that inflammation and the immune system may play a key role. Interest and research about HS in the medical community have been growing rapidly in recent years.



This research has led to many advances in the understanding of, and care for, HS. That's why it's important to connect with your dermatologist to ensure your management plan is best suited to your needs.



## WHO GETS HS?

While HS can affect different people in different ways, some groups are more likely to be affected than others.

### Age

HS commonly develops during adolescence or in young adults in their early 20s. People rarely develop HS after the age of 55. If you think your adolescent may be experiencing any signs or symptoms of HS, speak with a dermatologist as soon as possible.

### Gender

HS occurs more often in females. In fact, females are three times more likely to get HS than males.

### Family ties

There can be a genetic link to HS. More than 1/3 of people diagnosed with HS have a family member who also has the disease.



**KNOWING THAT MY FATHER HAD  
HS HELPED WITH THE DIAGNOSIS.**

Preshus | Living with HS



## WHAT CAUSES HS?

Although the exact cause of HS is unknown, it *is* known that the symptoms you see on the outside of your body come from inside your body. So, if you're ready to dive into the science behind HS, let's get started!

### It's related to your immune system

You're probably thinking "hang on a sec ... isn't my immune system supposed to help me?" And you'd be correct. In healthy bodies, the immune system operates like a network of factories. They produce highly specified proteins and cells to help you recover from problems like infections, wounds, and broken bones.

When a **healthy immune system** detects an issue, it signals for a **temporary increase** in production of cells and proteins to fight the problem. This increase in production can contribute to inflammation throughout the body. Once the problem is dealt with, another signal goes out to resume normal production.


### How are inflammation and HS connected?

For people with HS, their immune system **continues** producing increased amounts of cells and proteins that contribute to inflammation throughout the body—even though there is no injury to fix or harmful germ to fight. This is why HS is described as a **systemic** (occurring throughout the body) **inflammatory condition**.

This underlying inflammation starts deep in the body and contributes to the nodules, abscesses, and tunnels (also known as tracts) that can appear on the skin. Even when you're not seeing or feeling symptoms at the skin level, your immune system is still overactive, making it more likely you'll have flares in the future.

Learn more about  
inflammation and HS:

[NoBSaboutHS.com/MOD](https://NoBSaboutHS.com/MOD)



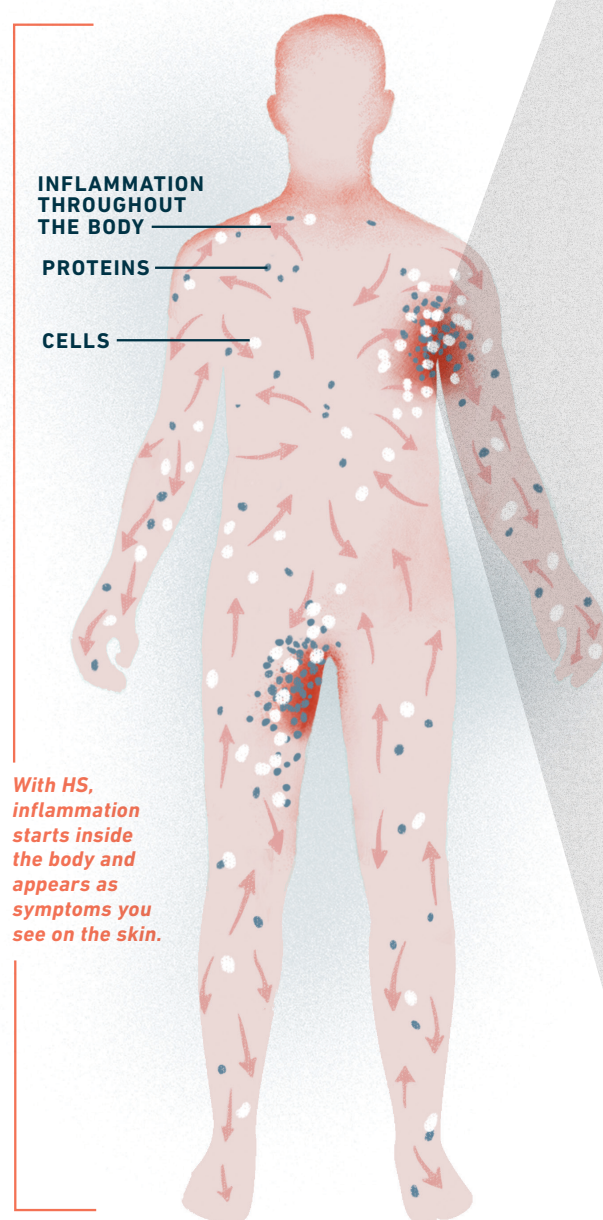
HS IS SOMETHING  
THAT YOUR BODY  
DOES — IT'S NOT YOU.

Will | Living with HS

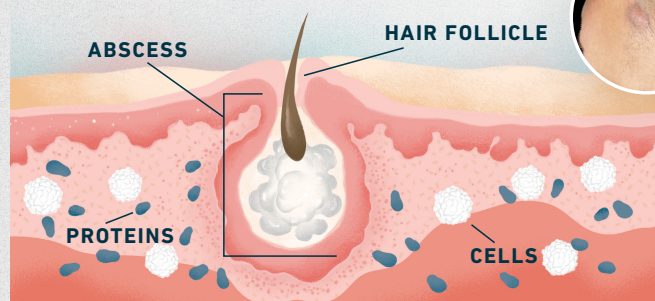


## HS ABOVE & BELOW THE SKIN

HS shows itself in the layers of the skin, causing nodules and abscesses. It can also form tunnels that grow between abscesses. Dermatologists often determine the severity of your HS by using the Hurley Staging System. Take a look at the images to the right to understand the impact inside and outside as the condition worsens.

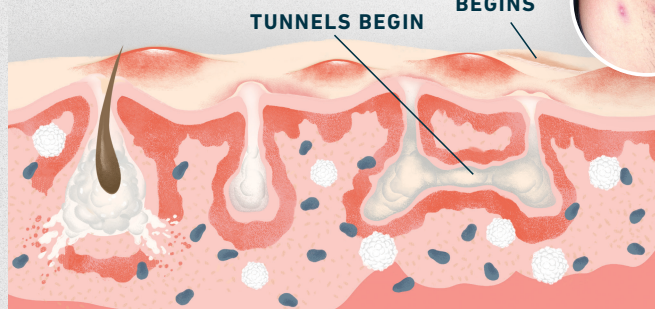


### STAGE I (MILD)



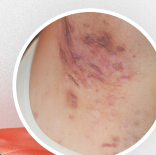
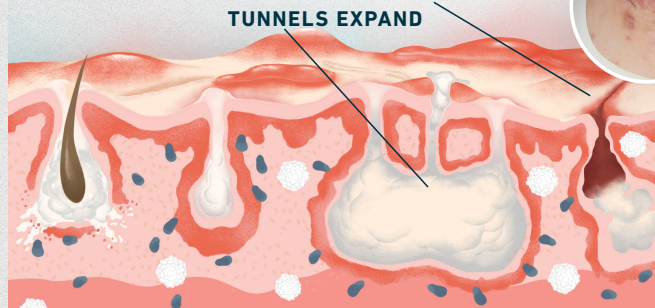
Usually seen as one or more abscesses with no scarring or tunneling under the skin. Flares may clear up but then come back during any stage.

### STAGE II (MODERATE)



Abscesses are widely spread and may become connected by tunnels. Tunnels can start forming deep in the skin, though they're not always visible on the surface. Scars begin to form on the surface and within the deeper tissue.

### STAGE III (SEVERE)



Large areas of the body are covered by abscesses and scarring with widespread tunneling beneath the skin, connecting multiple abscesses.



## HS & COMORBIDITIES

Comorbidities is a scientific term that simply refers to other conditions that are more likely to happen at the same time as your HS. Just because you have HS doesn't mean you will develop these comorbidities. It's important to monitor common symptoms related to these and **be sure to talk to a doctor if you are experiencing any of these symptoms.**

### Anxiety and depression

As with other chronic diseases that have a significant life impact, people with HS can also experience mental health issues such as anxiety and depression. Signs of depression may include fatigue, loss of pleasure in normal activities, a significant loss or increase in appetite, poor self-image, and withdrawal from personal contact.

### Metabolic syndrome

Metabolic syndrome is a group of conditions that increase the risk of heart disease and other health problems. These conditions include abdominal obesity, abnormal lipid levels, high blood pressure, and diabetes or prediabetes.

### Polycystic ovarian syndrome

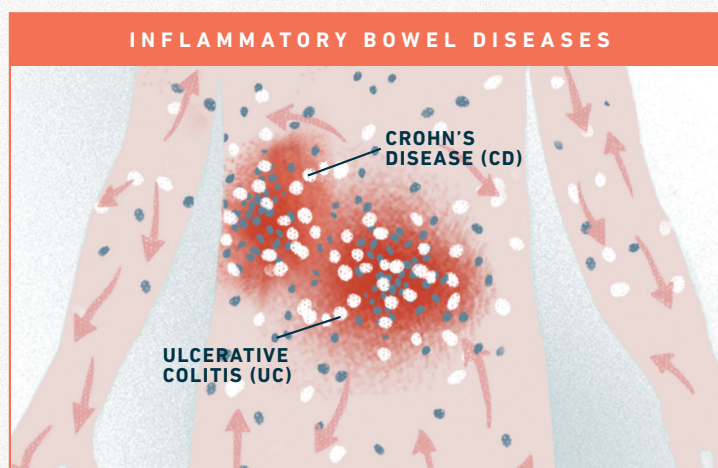
Polycystic ovarian syndrome (PCOS) is a disorder characterized by growths (cysts) on the ovaries and ovarian dysfunction. This can lead to irregular period cycles, infertility, acne, and facial hair.

### Acne conglobata

Acne conglobata is a severe type of acne that usually affects men more than women. Along with other chronic suppurative (pus-forming) skin diseases, it was one of the first conditions associated with HS. These conditions are long-lasting and can leave scars.

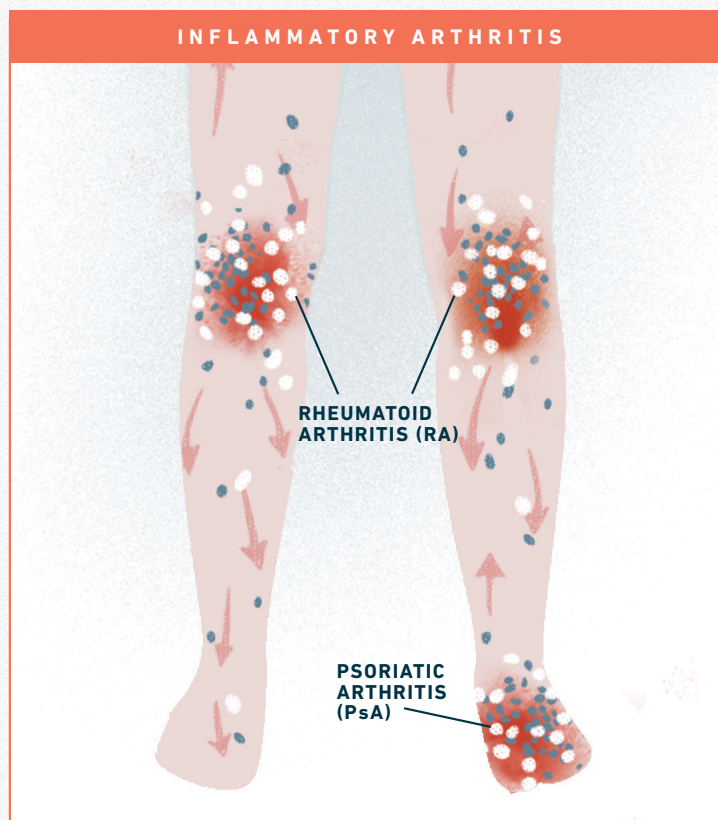
### Inflammatory bowel diseases

Inflammatory bowel diseases (IBDs) are a group of chronic inflammatory bowel conditions that affect the gastrointestinal system. These can include Crohn's disease (CD) and ulcerative colitis (UC). Early symptoms can include increased frequency in bowel movements, a hint of blood in stool, and abdominal discomfort/bloating.



### Inflammatory arthritis

Inflammatory arthritis is characterized by inflammation of the joints throughout the body, and can include disorders like psoriatic arthritis (PsA), ankylosing spondylitis (AS), or rheumatoid arthritis (RA), among others. Symptoms may include stiffness, pain in the back, heel, or fingers and toes, and/or swelling in the joints.





## PARTNERING WITH A DERMATOLOGIST

Dermatologists are doctors who specialize in diagnosing and treating inflammatory skin conditions like HS. That means they may have more experience treating patients with the disease.

Your appointment with your dermatologist should be a two-way conversation. It's important to come prepared so your doctor understands how HS impacts you and you get answers you need.

### How has HS recently impacted you?

Select all the ways HS impacts you, and be sure to print this page and bring it to your next appointment:

- ☐ Pain associated with my HS symptoms
- ☐ Limitations in mobility (e.g., lifting arms or legs, sitting, or walking)
- ☐ Experiencing fatigue
- ☐ Difficulty doing things around the house (e.g., cleaning, cooking, yardwork)
- ☐ Difficulty exercising or working out
- ☐ Missing work or school
- ☐ Missing or avoiding events with friends and family
- ☐ Feeling self-conscious about HS symptoms
- ☐ Feeling uncomfortable or limited in certain clothing
- ☐ Lack of desire or limited ability to be intimate
- ☐ Noticing or worrying about new or potential scarring from HS wounds
- ☐ Itching in affected areas

### Understanding HS and your treatment options

It's important to ask your dermatologist any questions you have about HS. They can help you understand the condition and will recommend a treatment option based on several factors, including the severity of your HS. To get the conversation started, here are questions to consider asking:

- 1** How does inflammation throughout my body contribute to HS symptoms on my skin?
- 2** Would you describe my HS as Stage I, Stage II, or Stage III?
- 3** Has it progressed since last time?
- 4** How can I ensure I'm getting symptom relief while also managing my HS over time?
- 5** What are my treatment options?
- 6** What other symptoms not relating to my HS should I tell you about?
- 7** What could happen if I don't treat my HS?

Don't have a dermatologist?  
Find one here:

**[NoBSaboutHS/derm-near-me](https://www.noBSaboutHS.com/derm-near-me)**



## GOT QUESTIONS? GET ANSWERS.

You're not alone. There are people with hidradenitis suppurativa (HS) all around the world. And chances are, others with HS have probably asked some of the same questions as you. See below for some helpful answers and guidance.

### Is HS an autoimmune disease?

While people sometimes use the term "autoimmune disease" to describe HS (as well as rheumatoid arthritis and Crohn's disease), research has shown a more accurate description—it's a systemic inflammatory condition that's related to the immune system.

### How do I know my HS has progressed?

Tunnels and scarring are a key sign that HS has progressed to Stage II—or even Stage III. But when tunnels begin to form, they aren't always immediately visible. So while your HS may look like Stage I on the surface, it may have already progressed.

That's why it's important to see a dermatologist experienced with HS and trained to recognize the symptoms you may not be able to see. They may use ultrasound technology or press the skin to feel for tunnels and/or areas where trapped fluid may escape.

### Is HS an infection?

HS is not caused by infection—it's a systemic inflammatory disease related to an overactive immune system. But sometimes abscesses and tunnels can provide an environment for disease-causing germs and bacteria to take hold and grow—leading to what's called a "secondary infection." This secondary infection is not the primary cause of HS, but an additional problem that can develop. It is one of a few factors that can lead to a misdiagnosis.

### Why do my abscesses smell?

Abscesses are pockets of fluid. Pus—like many other bodily fluids—often has an odor. Depending on the severity of your HS, you may have tunnels that can also be filled with pus and add to the smell. Because odor and pus are also signs of infection, HS can be misdiagnosed as an infection or blamed on poor hygiene. But these smells are not your fault.

### How is HS treated?

While there is currently no cure for HS, there are a number of treatment options available to help manage it. Dermatologists may recommend a combination of interventions that help with symptom flares or address ongoing disease progress. It's essential to have a candid conversation with your dermatologist about the symptoms you're experiencing and their impact on your life.

### What if my HS symptoms make it difficult to stay active?

Many people with HS have trouble staying active due to discomfort and pain. That's why it's important to work with a dermatologist who can help manage your symptoms so you're more comfortable when you're active.

### How can I connect with others who understand what I'm going through?

There are a number of online support communities for people living with HS across the web and social media. They provide a place to connect, share stories, and get tips on a range of topics, including wound care. **The HS Foundation** is a great place to start, offering a wide array of resources and support. You can also follow NoBSaboutHS on Facebook.

## CONTINUE THE CONVERSATION

**Now that you understand the role systemic inflammation plays in your HS, you can see why it's important to talk candidly with your dermatologist about your condition. Ongoing dialogue can help you work together to determine the best plan for managing your HS.**

# The answers behind HS **NoBSaboutHS.com**

Get more facts about HS:

**NoBSaboutHS.com/more-info**

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