HIDRADENITIS SUPPURATIVA (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 inflammation below the skin.

More than just what you see or feel

What can HS look like? It’s often seen as painful bumps, nodules, and abscesses on the surface of the skin. It usually develops in areas that grow hair, where skin rubs against skin like the armpit or groin. Nobody knows exactly what causes HS, but scientists understand it starts inside your body and your immune system may play a role. So, let’s start there.

How a healthy immune system works

• The immune system produces various cells and proteins that fight off disease-causing germs and bacteria throughout the body. It helps you recover from infections, wounds, broken bones, and more.

• When a healthy immune system detects a problem, it signals for a temporary increase in production of cells and proteins to deal with the problem and switching back to healthy once it is dealt with.

What can be going wrong with HS?

• With a systemic inflammatory condition like HS, your immune system is producing excess amounts of cells and proteins, even when there’s no problem to address.

• The ongoing overproduction of cells and proteins leads to chronic inflammation.

• This inflammation contributes to the symptoms that appear on the skin.

Looking beneath the surface

There’s a lot more to HS than what you can see on the skin. Here are the stages* that help show how HS can progress:

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<th>STAGE I (MILD)</th>
<th>STAGE II (MODERATE)</th>
<th>STAGE III (SEVERE)</th>
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<td>Abscess</td>
<td>Tunnels</td>
<td>Severe scarring</td>
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<td>Hair follicle</td>
<td>Scarring begins</td>
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Usually shows up as one or more abscesses with no scarring or tunneling under the skin. Flares may clear up but then come back during any stage.

Abscesses are widely spread and may become connected by tunnels. Tunnels (also known as tracts) 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.

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

With HS, inflammation starts inside the body and appears as symptoms you see on the skin.

*These descriptions are based on a well-accepted assessment of severity called the Hurley Staging System.
MORE HS QUESTIONS?

GET SOME ANSWERS

You’re not alone. People all over the world are living with HS. And chances are, others with HS have 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.

Did I do anything to cause HS?
You’re not to blame. HS is not caused by something you did or didn’t do.

• HS is not a sexually transmitted disease
• HS is not caused by poor hygiene
• HS is not contagious

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 hidden tracts, and/or press areas where trapped fluid may escape from a tunnel.

Is HS an infection?
HS is not caused by infection. 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 issues 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 signs of infection, HS can be misdiagnosed. But these smells are not your fault.

How is HS treated?
While there is currently no cure for HS, there are a number of options dermatologists recommend to help manage it. Their recommendation can depend on several factors, including severity—so having a candid conversation with your dermatologist about the symptoms you’re experiencing is key.

DERMATOLOGISTS CAN MAKE A DIFFERENCE

Dermatologists specialize in diagnosing and treating systemic inflammatory skin conditions like HS.

What have we learned about HS so far?
HS was first described by scientists nearly 200 years ago. But it wasn’t until recently that true strides in HS research have been made. In early 2019, the North American Clinical Management Guidelines for HS were issued to provide a framework for diagnosing and managing HS. Overall, research and interest in the medical community have been growing rapidly in recent years, with great strides being made in the understanding of HS and how to care for it.

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. The HS Foundation is a great place to start, offering a wide array of resources and support. You can also follow NoBSaboutHS on Facebook.

K E E P  I N  M I N D

HS can begin during adolescence. If you think your adolescent may be experiencing any signs or symptoms of HS, talk to a dermatologist experienced with HS as soon as possible.

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.

Sign up for more HS answers at NoBSaboutHS.com