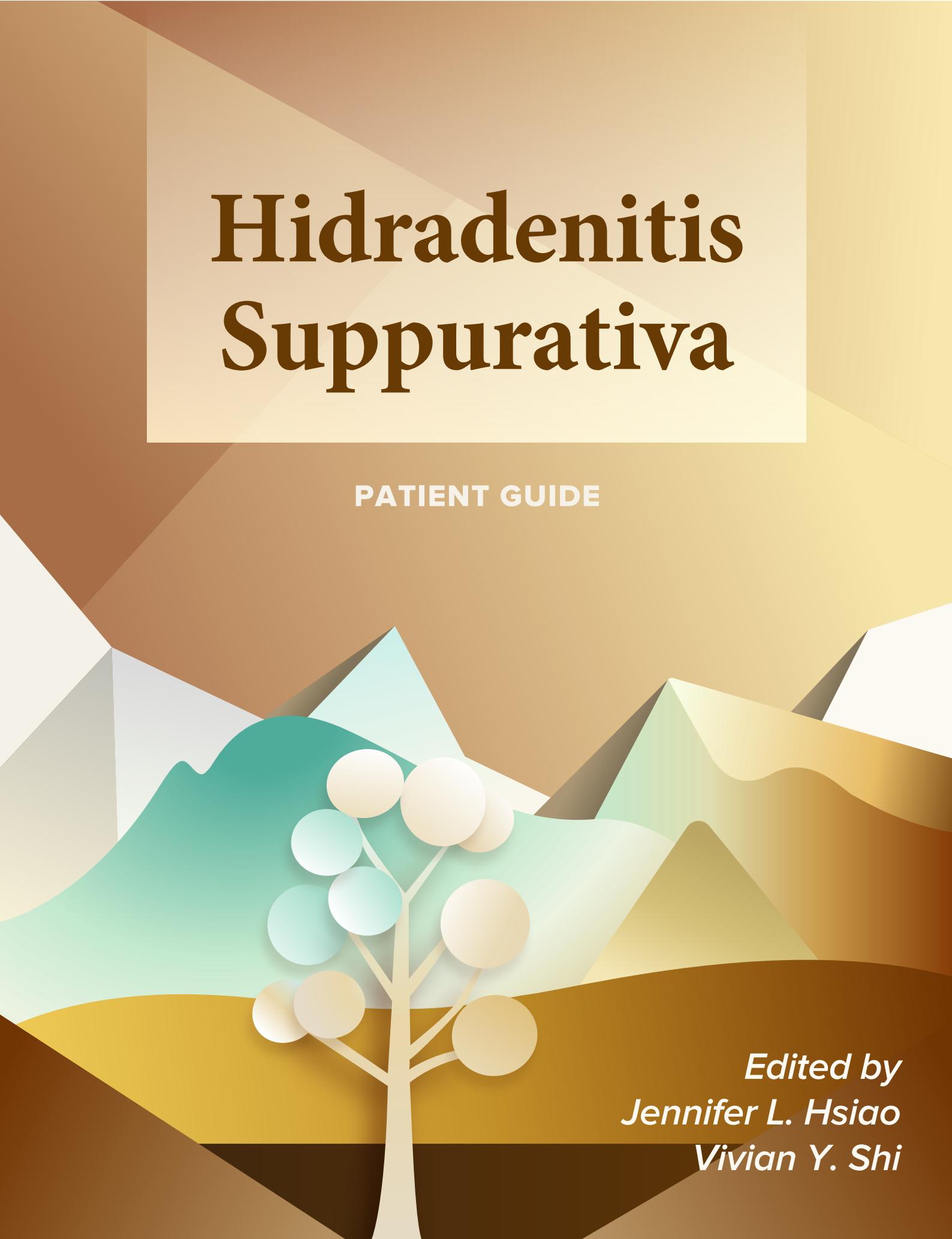


# Hidradenitis Suppurativa

PATIENT GUIDE



*Edited by*  
*Jennifer L. Hsiao*  
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# Hidradenitis Suppurativa Patient Guide

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# Foreword from the Editors

This handbook was created by experts in the field of hidradenitis suppurativa (HS), including scientists, researchers, HS healthcare providers, and people living with HS and their caregivers.

Broadly, the goals of this handbook are to share the current knowledge regarding HS, helpful tips regarding HS care, as well as persistent knowledge gaps. This is in order to offer a comprehensive guide for people living with HS, caregivers taking care of a loved one with HS, or anyone wanting to learn more about the condition. The chapters in this book cover relevant topics in HS backed by the most current research.

This handbook can serve as a resource for people who are first diagnosed with HS and would like a comprehensive overview of the disease, or for people who have lived with HS for a long time and would like to refer to this book as a reference.

We hope to inspire the global HS community, and all the current stakeholders, to recognize and find solutions to improve outcomes for people living with HS.

*This book is also available for viewing at [www.hspatientguide.com](http://www.hspatientguide.com)*

*The contents of this book are not meant to be a substitute for medical advice. Please consult with your qualified healthcare professional for any health and medically related concerns.*

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Authors: **Devea. R. De, Terri Shih, Vivian Y. Shi**

# Chapter 1

# Hidradenitis Suppurativa Overview

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- I. Introduction
- II. Epidemiology
- III. Clinical Presentation and Diagnostic Challenges
- IV. Causes of HS
- V. HS Burden, Comorbidities, Disease Complications
- VI. Special Populations
- VII. HS Management
- VIII. Experiences from People Living with HS and also HS Caregivers
- IX. Looking to the Future
- X. Questions and Answers

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## I. Introduction

Hidradenitis suppurativa (HS) is a chronic skin disease that causes recurrent painful boils. HS was originally considered a very rare disease, but over the past decade, research on HS has dramatically increased and we now know that HS is not rare. In this chapter, we will discuss how common HS is, who is more likely to get it, risk factors, and current challenges in the world of HS.

## II. Epidemiology

Epidemiology is the study of the distribution (how common is a disease, where in the world is it the most common) and determinants (causes and risk factors) of diseases in different populations. Below we will discuss the epidemiology of HS.

### • Prevalence and Incidence

Prevalence is the percentage of people who have a disease. Research on large populations have shown that, overall, about 0.1% to 4% of people have HS worldwide. These studies were done in different populations of the world, accounting for the wide range of percentages. The true prevalence is likely higher than the reported percentages, because of common instances of HS underdiagnosis or misdiagnosis.

The incidence of a disease is a percentage that tells us how many people are newly diagnosed with a disease every year. Recent studies have shown that HS has an incidence of 0.01% - 0.03%. The incidence of HS may rise as awareness of HS increases and more people are properly diagnosed.

### • Demographics

**Gender.** Research done in several countries has generally shown that in Western nations, twice as many women have HS compared to men. Interestingly, researchers in Asia (Korea and Japan) found the opposite was true, with almost twice as many men having HS. Overall, more women have been found to have HS, but this may vary depending on where you live in the world.

**Race.** HS affects people of all races. However, African Americans are disproportionately affected by HS. A study done in the United States found that African American patients were three times more likely to have HS compared to White patients. African Americans were also more likely to

consult healthcare providers at a more advanced stage of HS. There has been less HS research done in Africa, Asia, and South America. More studies are needed to determine how common HS is in different races.

**Age.** HS is most common in people in their 20s and 30s. Women tend to develop HS earlier than men, possibly due to their earlier onset of puberty. Some studies have shown that a certain subset of people develop HS before the age of 18, which is considered "early onset." People may also develop the disease later in their life, after the age of 40, which is considered "late onset."

### • Risk Factors

Risk factor is a term used to describe something that may increase your risk of developing a disease. There are risk factors that are non-modifiable, which means they are inherent traits you cannot change. There are also risk factors that are modifiable, which means they can be changed with lifestyle choices. Non-modifiable risk factors for HS include family history and genetics. Modifiable risk factors include smoking, obesity, skin friction, and diet. In *Chapter 14*, we will discuss why these risk factors increase HS disease, and how to improve your HS symptoms by making lifestyle changes to decrease your modifiable risk factors.

## III. Clinical Presentation and Diagnostic Challenges

The diagnosis of HS is based on how it presents clinically, meaning that a healthcare provider can diagnose you with HS by asking about your symptoms and examining your skin with a physical exam. There are three main things they consider:

1. How the lesions look.
2. Where the lesions are located  
(usually located in the skin fold areas, although it can be present in non-skin fold areas as well).
3. How often the lesions occur  
(at least two flares in a six month period).

Further information on clues that you might have HS can be found in *Chapter 2*. ►

## IV. Causes of HS

Although the exact cause of HS is not yet known, we know that HS is caused by a combination of several factors. These are discussed in detail in [Chapters 3 and 4](#).

## V. HS Burden, Comorbidities, Disease Complications

HS can put a huge physical and mental burden on people, affecting their overall quality of life. The impact of HS on mental health, daily activities, and sexual health is discussed in [Chapter 5](#).

HS comorbidities, or diseases that are associated with HS, can range from being very common to rare. Some of the common comorbidities include metabolic conditions such as obesity, high cholesterol, high blood pressure, diabetes, and polycystic ovarian syndrome (PCOS). [Chapter 6](#) discusses both common and uncommon diseases associated with HS.

Over time, HS may cause medical complications that occur on the skin and also throughout the body. Common medical complications of HS are discussed in [Chapter 7](#).

## VI. Special Populations

Women, especially of childbearing age, are disproportionately affected by HS. Because of this, women face unique challenges in dealing with and treating HS because of factors such as menses, pregnancy, breastfeeding, and menopause. Specific considerations for women living with HS are discussed in [Chapter 8](#).

Children, even those who have not yet reached puberty, can also develop HS. Often, children who develop the condition have a family member with HS, suggesting a genetic component. Treating children can be challenging because most of the current available medications were studied in adult populations. HS in children is further discussed in [Chapter 9](#).

## VII. HS Management

While there is currently no cure for HS, there are ways to control your disease.

The goal of HS treatment is to treat ongoing flares and pain, and to reduce the number of future flares through preventative treatment.

It is important to communicate with your healthcare provider when you feel something is working (or not working) for you. [Chapter 11, 12, and 26](#) discuss how to make the most of your HS visits (including how to track your HS journey) and how to set your treatment goals. The same treatment might not work for everyone—therefore, it is important to create an individualized plan. [Chapter 25](#) discusses how to create an effective treatment plan with your healthcare provider.

- **Types of treatment options available to treat HS include:**

**Topical medications:** medications and washes applied onto the skin. [Chapter 15](#) discusses skin and wound care and [Chapter 16](#) discusses topical medications and washes.

**Systemic medications:** medications taken by mouth or injected through the skin. [Chapter 17](#) discusses oral antibiotics, [Chapter 18](#) discusses other oral medications that are not antibiotics, and [Chapter 19](#) discusses systemic medications called biologics.

**Procedural treatments:** [Chapter 21](#) discusses how to know when surgery for HS is right for you. [Chapter 22](#) discusses surgical excisions done in the operating room while [Chapter 23](#) discusses procedures for HS that can be done in the office. [Chapter 24](#) discusses laser treatments for HS.

HS often requires a team of healthcare providers that specialize in different areas of medicine. Specialists commonly involved in the care of people living with HS include dermatologists, wound care specialists, pain management physicians, mental health professionals, surgeons, and nutritionists. [Chapter 13](#) goes into detail on specialists who may be on your care team and their roles. [Chapter 20](#) discusses pain control for HS.

Managing the different aspects of HS care can become expensive - [Chapter 10](#) has tips on how to manage HS on a budget. ►

## VIII. Experiences from People Living with HS and also HS Caregivers

Connecting with others who have HS can be very helpful for people with HS. *Chapters 27* and *28* are dedicated to describing experiences from people with HS, who themselves are leaders in HS advocacy.

## IX. Looking to the Future

Research on HS has grown rapidly in the past decade. However, there are still many challenges to overcome. Some of these challenges include not understanding the exact cause of HS, lack of awareness among the general public and medical community, missed and delayed diagnoses, and limited treatment options. As our understanding of causes of HS improves, it will help us develop new treatments to target those causes. We are hopeful that more effective treatments will become available in the upcoming years. *Chapter 29* discusses new medications for HS that are in development and being studied in clinical trials (also known as medications in the “pipeline”). *Chapter 30* discusses what the future of HS will look like.

## X. Questions and Answers

### ***Question 1***

**What important facts about HS should I be aware of?**

#### ***Answer***

You may hear myths about HS from other people and sometimes even from healthcare providers who are not aware of the disease. Here are some important facts about HS to keep in mind:

***HS IS NOT caused by poor hygiene.***

It is caused by a combination of factors including genetics, hormones, and inflammation.

***HS IS NOT caused by a sexually transmitted infection (STI).***

Unfortunately, people with HS may encounter this misdiagnosis if they have HS lesions on the groin.

***HS IS NOT contagious.***

You cannot “catch” HS or give it to another person.

***HS IS NOT caused by smoking or gaining weight.***

Things like smoking and excess weight are called risk factors which may worsen your HS symptoms. However, they are not the underlying cause. There are many people who do not smoke and who do not have excess weight but have HS, just as there are many people who smoke and who have excess weight who do not have HS.

### ***Question 2***

**Why is HS challenging for people with HS as well as for healthcare providers?**

#### ***Answer***

Many people with HS suffer with HS symptoms for years before getting properly diagnosed. During their healthcare journey, people with HS often get misdiagnosed. Then, when they finally get diagnosed, they may not receive appropriate treatment. This may lead people to feel rightfully misunderstood and frustrated. In addition, HS can also cause feelings of shame and loneliness because of the nature of the condition and the common myths about it.

From the perspective of healthcare providers, HS can be difficult to treat because there is not one right treatment plan that fits all patients. Finding the best treatment regimen for each patient can take multiple visits. As we learn more about HS and treatment options expand, we hope that management of HS will continue to improve.

Authors: **Muskaan Sachdeva, Afsaneh Alavi**

## Chapter 2

# Clues You May Have HS

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- I.** Introduction
- II.** Clinical Presentation
- III.** Subtypes of HS
- IV.** Physical Findings and Investigations
- V.** Physical and Emotional Symptoms
- VI.** Conditions that Resemble HS
- VII.** Questions & Answers

---

## I. Introduction

This chapter discusses the clinical features of HS and how to distinguish HS from other conditions that may look like it.

## II. Clinical Presentation

HS can be diagnosed based on your physical exam ([Table 2.1](#)) and your symptoms. No skin biopsy or lab test is needed for diagnosis.

**Three hallmark features of HS include typical lesions, typical distribution of lesions, and chronicity/recurrence ([Table 2.2](#)).**

HS usually presents after puberty; however, children can also have HS (see [Chapter 9](#) for more information on pediatric HS). The disease can start with occasional painful skin bumps and later involve abscesses, tunnels under the skin, and scars. The classic areas where HS lesions most commonly appear are in skin folds, such as the armpits and groin. Compared to women, men are more likely to also be affected by HS around the anus and buttock areas, as well as in non-classic areas such as the ears and legs. Women tend to be most affected on the frontal areas of the body, such as the breasts and groin.

**Table 2.1. Types of HS lesions**



**Abscess or boil.** A tender, swollen lesion that is usually filled with pus



**Comedone.** Blackhead



**Nodule.** A solid, spherical bump that is >1 cm and may be tender (inflamed) or non-tender (not inflamed)



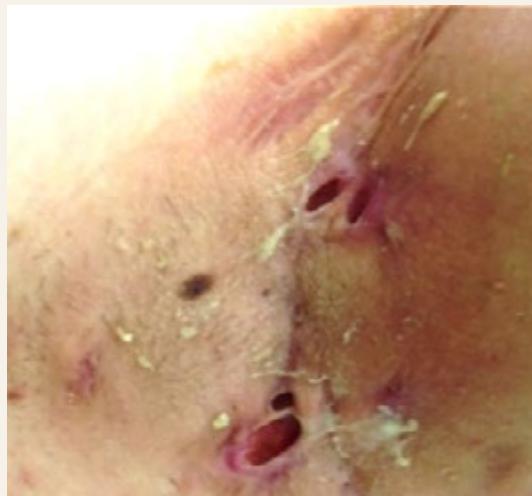
**Pustule.** A pus-filled bump

**Table 2.1. Types of HS lesions**

**Scar.** Irreversible tissue damage due to inflammatory HS lesions that can be flat, raised, or rope-like



**Sinus tract.** A linear tunnel that may open onto the skin surface



**Ulcer.** Open sore or break in the skin

**Table 2.2. Hallmark Features of HS**

<b>Characteristic of HS</b>	<b>Description</b>
Typical lesions	Blackheads, abscesses, nodules, tunnels, scars
Typical distribution of lesions	Skin folds, such as armpits, groin, buttocks, under the breast folds*
Chronic and recurrent disease	At least two flares within a six-month period

### III. Subtypes of HS

Different clinical subtypes of HS have been proposed. The characteristics of the “classic” HS subtype are: affected armpits and groin, female, and high BMI. Having “non-classic” disease or severe acne are features associated with severe HS.

The “follicular subtype” of HS is characterized by skin lesions such as the pilonidal sinus (a small tunnel at the top of the buttocks), comedones (blackheads), and severe acne. This subtype is more common in males, smokers, and those with a positive family history of HS. Other common characteristics of the “follicular subtype” of HS are increased disease severity and earlier disease onset.

Another subtype of HS, the “gluteal subtype,” is characterized by involvement of the buttocks and is commonly associated with less severe disease and lower BMIs. More research is being done to more accurately describe different subtypes of HS because this information may be helpful in guiding treatment decisions.

### IV. Physical Findings and Investigations

HS is a systemic disease associated with several comorbidities like metabolic syndrome and depression, so screening should be done based on HS screening guidelines and clinical clues.

Typical screening may involve blood pressure assessment, hemoglobin A1C (which measures average blood sugar level over the past three months), and cholesterol level measurements. In certain cases, a referral to a gastroenterologist may be needed to evaluate for inflammatory bowel disease. A referral to a psychiatrist or psychologist to address depression, anxiety, or other mental health conditions may be needed.

Hormonal assessments may also be performed if there is evidence of a hormone imbalance. For example, if a female patient has irregular periods. Patients with HS may suffer from arthritis and back pain; therefore, a referral to rheumatology may be required. Referrals for smoking cessation, nutrition counseling, and sexual health counseling may be needed in individualized cases. More information on HS associated conditions and screening may be found in [Chapter 6](#).

Importantly, skin biopsy, lab tests, and bacterial cultures are not needed to make the diagnosis of HS. If labs are checked, you may be found to have a low red blood cell count or high levels of inflammatory markers. You should discuss any lab abnormalities with your healthcare provider.

### V. Physical and Emotional Symptoms

You may experience many different symptoms with your HS. Physical symptoms may include pain, itch, odor, drainage, and swelling. Emotional symptoms may include anxiety, sadness, and anger. These symptoms can have a significant impact on your quality of life (for more information, please see [Chapter 5](#)).

### VI. Conditions that Resemble HS

Early HS lesions can mimic other disorders ([Table 2.3](#)). However, the chronicity and progression of HS, as well as the typical involvement of skin fold areas, can help distinguish HS from other conditions. If your healthcare provider is worried that your lesion is a furuncle (a skin infection), a bacterial culture can be performed to help with diagnosis, in addition to clinical information.

Another condition that can look like HS are the skin findings that can be seen in Crohn’s disease (CD). If you have perianal tunnels and are also experiencing gastrointestinal symptoms such as abdominal pain or diarrhea, you should talk to your healthcare provider to make sure you do not have CD. In addition, if you have ulcerative lesions and an anal fistula (an abnormal connection from the skin to the anus) that involves the anal sphincter, these are findings that tend to be suggestive of CD.

### VII. Questions & Answers

#### Question 1

**How is HS different from acne?**

#### Answer

Although HS and acne both affect hair follicles, they are typically found in different locations on the body. Acne typically affects the face, chest, and back, while HS typically affects the armpits and groin area. Several risk factors associated

with HS are not associated with acne, such as smoking and obesity.

### **Question 2**

**How is HS different from just having an abscess?**

#### **Answer**

HS is not caused by an infection. An isolated abscess that is not occurring in the context of HS is typically caused by a bacterial infection. Sometimes, for example, cultures can help distinguish HS from an infectious abscess caused by a Staph infection. Unlike an infected abscess, HS is the result of an uncontrolled immune response of the skin surrounding hair follicles. In addition, HS predominantly occurs in skin folds, whereas an isolated abscess can be found anywhere on the body.

### **Question 3**

**What are signs that my HS disease is quiet?**

#### **Answer**

HS is a disease that has periods of activity and inactivity. When lesions have minimal to no pain, itch, or drainage, and there are no new lesions forming, then the disease is in a “quiet” state. HS tunnels and cord-like scars can be removed with surgery when flares are under control.

Table 2.3. HS Mimickers

<b>HS Mimicker</b>	<b>How it differs from HS</b>	<b>Clinical Photo</b>
<b>Acne</b>	Acne is usually located on the face, upper chest, and back and does not present with tunnels.	
<b>Bartholin's cyst</b>	Presents with one-sided vulvar swelling and pain, tends to be solitary and to occur near the opening of the vagina.	
<b>Cutaneous Crohn's disease</b>	Cutaneous Crohn's can also present with peri-anal fistula, but will not have comedones. Pelvic imaging can be helpful.	
<b>Epidermal inclusion cyst</b>	Non-inflamed lesion, typically with a small dark-colored opening (a "punctum") in the center of the lesion.	
<b>Folliculitis</b>	Bacterial or fungal infection of hair follicles that presents as scattered or isolated pus-filled bumps. The bumps usually heal without scars.	
<b>Furuncle or Carbuncle</b>	A furuncle is a deep and tender nodule caused by staphylococcal infection. Both the follicle and surrounding tissue are involved. A carbuncle is a group of connected furuncles. The lesions are contagious, could be associated with fever, and are not as recurrent as HS lesions.	
<b>Pyoderma gangrenosum</b>	Ulcerative painful lesion with active purple border, often in sites of trauma.	

Authors: **Emily Kozera, Akshay Flora, John W Frew**

## Chapter 3

# HS Genetics and Inflammation

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- I. Introduction
- II. Genetics
- III. Epigenetics
- IV. Inflammation
- V. Questions and Answers

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## I. Introduction

The exact cause of HS is not yet known, but we do know a number of different factors that are more common in people with HS. This chapter discusses the role of genetics, epigenetics, and inflammation in HS.

## II. Genetics

Genes are instructions in every cell of the body that give it instructions on how to behave, how to grow and how and when to die. Everyone inherits genes from both their mother and their father.

People with HS are more likely to carry variations of certain genes that are not found in people without HS. Some of these genes control the machinery inside the cell, which carry signals on how to behave. A number of these genes affiliated with HS code for a group of proteins called the “Gamma Secretase Complex.” Not all people with HS carry these different genes, and they may be much more common in certain parts of the world than others. For example, HS patients from China are more likely to carry copies of these genes than HS patients from Europe. Scientists believe that up to 70% of the reason you get HS may be found in your genes. People with HS have certain genes that are also found in people with gut conditions such as Crohn’s disease as well as in people with other rare conditions that trigger periodic spontaneous fevers.

You cannot test for an “HS gene” currently, but scientists are sure that there are many other genes specific to people with HS that have yet to be discovered. Further research needs to be done to identify what genes signal HS, so that genetic screening tests can be developed in the future.

## III. Epigenetics

Some factors in the environment (such as food, infections, and stress) can sometimes alter the activity of genes. This change in activity is called “epigenetics.” Some epigenetic differences have been identified between people with HS and people without HS. However, they are also seen in many other diseases where there is a lot of inflammation. Scientists are currently trying to determine if these epigenetic changes are actually a part of

HS or whether they are just present in the background. There is currently no safe effective treatment for changing these epigenetic signals.

## IV. Inflammation

There are many different types of ways that inflammation can occur in the body. Some inflammation fights off viruses, some inflammation fights off cancer, and some inflammation fights off fungal infections. The immune system, which controls inflammation, is incredibly complex, and even the best scientists do not yet completely understand how it all works.

What we do know is that inflammation is everywhere in people with HS, not just in the skin. This inflammation is “dysregulated,” which means the inflammation is not working the way it should. When someone has HS, inflammation in the skin is triggered by something small, but the normal signals that tell the body to stop the inflammation are not working properly. The uncontrolled inflammation and follicular occlusion, or blocking of the hair follicles, cause HS. The result is painful swollen cysts, boils, and in some cases, permanent scar formation and odorous, pus-draining tunnels.

Testing the blood of people with HS shows inflammation throughout the body. The type of inflammation associated with HS is a mixture of different types. Numerous kinds of blood cells gather in the skin and produce chemicals that, in turn, produce the inflammation. This inflammation helps explain why people with HS tend to have other conditions such as arthritis, gut problems, and non-healing wounds.

Controlling excess inflammation helps stop the pain, swelling, lesions, and disease activity of HS.

This is how many medications for HS work: by reducing inflammation. There are specific inflammatory molecules that have been found to be elevated in people with HS. These include tumor necrosis factor (TNF)-alpha, interleukin (IL)-1, IL-17, IL-23, and IL-36. There are medications that specifically target these molecules to reduce inflammation and treat HS. Some people have HS that is well-controlled with these types of medication; however, people with severe HS have higher

levels of these inflammatory molecules so the disease can be more difficult to treat. The fact that people with HS have varying levels of inflammation - and therefore varying degrees of disease severity - helps explain why the same treatment does not work for everyone. For more information on factors that contribute to HS inflammation, see *Chapter 4*.

## V. Questions and Answers

### **Question 1**

#### **What causes HS?**

##### **Answer**

There is no single cause of HS. A combination of inherited genes and exposures in the environment contribute to the development of HS. Some other medical conditions like obesity, diabetes, gut problems like Crohn's disease, and other factors like smoking may heighten risk factors for HS. Overall, the cause of HS, and the reason it occurs in one person but not another is very complex, and still under investigation.

### **Question 2**

#### **Does HS run in families?**

##### **Answer**

HS can run in families, with up to one in three people with HS reporting that someone else in their family also has HS. Even after accounting for common environmental factors, there is still an inherited (genetic) component.

### **Question 3**

#### **Does having HS mean I have an autoimmune disease?**

##### **Answer**

No. Although HS is a complex inflammatory disease with some features similar to those seen in autoimmune diseases, it is better characterized as an "autoinflammatory" disease. The term "autoimmune" means the body is fighting itself, whereas HS is better described as a condition with dysregulated inflammation, or inflammation that is not working properly.

Authors: **Emily Kozera, Akshay Flora, John W Frew**

## Chapter 4

# Contributors to HS Inflammation

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- I.** Introduction
- II.** Hormones
- III.** Bacteria
- IV.** Diet, Weight, and Friction
- V.** Smoking
- VI.** Questions and Answers

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## I. Introduction

Many different factors can contribute to the dysregulated inflammation seen in people with HS. This chapter discusses some of those factors: sex hormones, bacteria living on the skin (the microbiome), body fat, friction, and smoking.

## II. Hormones

Sex hormones can play a big part in how severe and painful HS lesions become. Sex hormones, particularly testosterone, can trigger inflammation in both men and women. Many women report bad flares of HS before or during their period. Some women also report their HS improving or worsening during pregnancy, as well as more changes after giving birth. Additionally, some women report that their HS goes away after menopause while others report that the disease remains active.

This tells scientists that the inflammation that causes HS can go up and down when certain sex hormones (like estrogen, progesterone, testosterone) go up and down. However, the challenging part of understanding and studying the relationship between sex hormones and HS is that not everyone is the same. For example, not everyone has changes in their HS disease activity when their hormones change.

## III. Bacteria

HS lesions are red, swollen, painful, and leak pus. For many years, people mistakenly thought HS was due to an infection. We now know that the pus from HS lesions is largely sterile, meaning it contains no bacteria.

Yet bacteria still have an important part to play in why the disease occurs. The bacteria on the skin make up what is called the skin microbiome. Some scientists think that the immune system overreacts to normal bacteria (the normal microbiome) on the skin as part of the dysregulated inflammation of HS. Once the inflammation starts, bacteria can form biofilms (thick layers of bacteria that are highly resistant to antibiotics) in HS lesions. In order to properly treat HS, it is important to address biofilms if they are present in the skin; they can be addressed with the use of strong antibiotics or

surgery. Aside from their bacteria-killing properties, antibiotics also have anti-inflammatory properties that may be responsible for improving the condition of existing HS lesions and potentially preventing new lesions from forming.

## IV. Diet, Weight, and Friction

There is a lot of interest in the area of diet and HS. Some diets help people lose weight, which can help decrease the number of HS flares they have. Some diets contain anti-inflammatory foods, but so far, no specific food has been shown to work in everyone that has HS.

Because fat cells can produce some hormones that make HS worse, losing weight can be helpful by reducing the level of these hormones. Losing weight can also help prevent rubbing and friction that can worsen HS lesions found in skin folds. More information on diet and HS can be found in [Chapter 14](#).

For a long time, it was thought that HS lesions were found in skin folds because of the excessive sweating and rubbing seen in skin folds. Scientists believed that this helped explain why HS predominantly occurred in people who were overweight. We know now that HS can occur anywhere on the body, not just in skin folds, as well as in people of all body weights.

One possible explanation for why HS lesions tend to be found in skin folds is that while friction is not directly causing HS, friction creates an environment that allows HS to develop after certain bacteria and chemicals group together.

## V. Smoking

Cigarettes contain many chemicals that can cause inflammation in the body. Scientists think that smoking cigarettes and HS are linked. This is because smoking may trigger inflammation that causes HS and, once the inflammation begins, it is very difficult for it to stop on its own. Scientists are unsure whether vaping is as dangerous as smoking in terms of HS risk factors. Nicotine causes inflammation, but vaping does not contain many of cigarettes' tar-based chemicals that drive inflammation. Stopping smoking may make your current HS treatment work better.

More research needs to be done on how other forms of smoking, like vaping, influence inflammation in HS. Healthcare providers encourage everyone to stop smoking (even if it is unclear if that will help HS) in order to improve overall health.

## VI. Questions and Answers

### **Question 1:**

#### **Is HS an infection?**

##### **Answer**

HS is not due to infection. Swabs and tests on the skin often find normal bacteria on the skin, but this does not represent an infection. HS is due to dysregulated inflammation. There are many characteristics of HS lesions that can make them seem like an infection, but that is not the case.

### **Question 2**

#### **Why does HS get worse with my period?**

##### **Answer**

Levels of the female sex hormones estrogen and progesterone change before, during, and after a period, and these hormones can affect the amount of inflammation present in a woman's body. Therefore, in some women, HS disease may flare in a cyclic pattern that is strongly correlated with their periods. If you experience worsening of your disease with your period, you should talk to your healthcare provider about treatment options that can reduce these flares. For more information on hormones and HS, please see [Chapter 8](#).

### **Question 3**

#### **Can changing my diet cure my HS?**

##### **Answer**

Eating a healthy diet can help improve overall health, and some people with HS find that avoiding or limiting certain foods seems to reduce HS flares. However, changing diet alone is unlikely to completely control HS, especially severe HS. More information on diet and HS can be found in [Chapter 14](#).

### **Question 4**

#### **Will losing weight cure my HS?**

##### **Answer**

Body fat produces hormones and other chemicals in the body which can lead to inflammation. Thus, losing weight may improve HS disease by reducing the amount of body fat that contributes to a pro-inflammatory environment. Some people find losing weight reduces their HS disease, but others find that losing weight has no effect on their HS.

Research does suggest that weight loss may help make certain treatments more effective. Overall, losing weight when you have obesity is good for your overall health, and may also benefit your HS. However, in most people, other treatments are needed in addition to weight loss in order to adequately treat HS.

Authors: **Natalie M. Fragoso, Jennifer L. Hsiao**

## Chapter 5

# HS and Quality of Life

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- I.** Introduction
- II.** HS and Mental Health
- III.** HS and Daily Activities
- IV.** HS and Sexual Health
- V.** Questions and Answer

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## I. Introduction

Many people with HS report a decreased quality of life, or enjoyment of their life, due to their symptoms. HS can cause pain, odor, drainage, and itching; these symptoms can in turn affect mental health, daily activities, and sexual health. While there is no cure for HS, treatments can help reduce symptoms and improve quality of life.

You can keep track of how HS is impacting your quality of life by paying attention to how engaged you are in your daily activities and by tracking your mood. If you find that your HS symptoms are preventing you from enjoying activities as much as you could, that means that HS is having a negative impact on your quality of life.

## II. HS and Mental Health

HS can affect mental health in many ways. Up to 25% of people with HS may have a co-existing mental health condition. Compared to people without HS, people with HS are about twice as likely to experience depression and 70% more likely to have an anxiety disorder. Substance abuse is over two times more common in people with HS than people without HS as well. These risks are correlated to disease severity; they increase with more severe HS. HS is considered a condition that elevates the risk of suicide. However, proper treatment of both the physical and mental effects of HS can reduce that risk.

You can evaluate your own emotional well-being by keeping track of your mood and noting if you feel down or depressed. You should also try to assess if you feel a decreased interest in your usual activities or hobbies. Let your healthcare provider know right away if you have any negative mental health symptoms or any thoughts of harming yourself.

**It is just as important to address your mental health as it is to seek medical care for your HS skin condition.**

*Chapter 11* discusses how to make the most of your HS visit.

## III. HS and Daily Activities

Daily activities can be impacted by HS. In one

study, over 60% of people with HS reported missing work due to their symptoms. In another study, 20% of people with HS reported decreased productivity while at work. Some people with HS may face losing their jobs due to missed work days or the inability to perform work duties. In one study, almost 25% of people with HS reported that they were unable to advance in their jobs due to their HS. For younger people with HS, symptoms may get in the way of doing well at school.

It may be difficult to exercise with active HS disease. Tight clothing may also make HS worse, so loose-fitting clothing may be a better choice. Sleep may also be disrupted by HS. People with HS may experience difficulty falling asleep, less restful sleep, and daytime dysfunction as a result. Information on lifestyle changes that may be helpful for people with HS, including tips on exercising and clothing choices, can be found in *Chapter 14*.

Try to take note if there are any daily activities, school tasks, or job functions you do that seem to consistently worsen your symptoms. Your healthcare provider may be able to help you come up with helpful solutions or accommodations, such as requesting a standing desk at work (if buttock or groin bumps make sitting painful, for example).

## IV. HS and Sexual Health

HS symptoms such as odor, pain, and drainage can make it difficult to feel comfortable in social settings. These symptoms can also make intimate relationships difficult for both men and women with HS. This is especially true in cases of HS involving sensitive body areas such as the genitals or breasts. People with HS are around 40% more likely to find it difficult to participate in sexual activity compared to people without HS. In one study, 65% of women with HS reported that pain significantly affected their sexual relationships. The study also found that 56% of men with HS felt that drainage significantly affected their sexual relationships. Almost half of the survey respondents reported a fear of rejection or fear of how their sexual partner would react to their HS.

Sexual health concerns can and should be discussed with your healthcare provider. Just as it is useful to monitor changes to your physical and mental health, it can be helpful to take note of

changes to your sexual health and wellbeing. By integrating additional factors like this into your symptom tracking process, you may be able to better evaluate your treatment response.

**Identifying not only what triggers your HS but also all the ways that HS impacts you can be the first step to improving your quality of life.**



Information on effective tracking tools, including the free HS app that will be available soon, can be found in *Chapter 26*.

## V. Questions and Answers

### **Question 1**

#### **Why am I tired all the time?**

##### **Answer**

HS is a chronic condition that can require a lot of time and energy to manage, including changing bandages and trying to control pain and odor. It can be frustrating to deal with the impact on your daily activities, such as missing school or work. There are many factors that can contribute to fatigue. These include the inflammation from HS, sleep disturbance from HS, and also - for many people with HS - the associated anemia, a condition where a patient has a low number of red blood cells. Mood-related disorders, such as depression, can also make you feel tired or less interested in your daily activities. Treatment of your HS may reduce fatigue. Your healthcare provider can help you control your HS symptoms and also help treat any other associated medical conditions so you have more energy to do the things you enjoy.

### **Question 2**

#### **How do I discuss my HS condition with my partner?**

##### **Answer**

It is important to remember that HS is not contagious, and not sexually transmitted. Consider openly discussing your HS with your partner, and answering any questions they may have. Talking to other people living with HS, who have been in similar situations, may also be helpful.

### **Question 3**

#### **How can I prevent HS from interfering with my daily activities?**

##### **Answer**

Finding a healthcare provider who knows a lot about HS, and can start appropriate treatments, can help you gain control over the disease activity. This can hopefully allow you to resume daily life activities. Lifestyle changes that may be helpful are discussed in *Chapter 14*. Your healthcare provider can also help in other ways, such as combining different medications to optimize your care regimen. They can also recommend other non-prescription treatments.

Authors: **India Robinson, Chelsea Shope, Colleen Cotton**

# Chapter 6

# HS Associated Diseases

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- I.** Introduction
- II.** HS and Physical Conditions
- III.** HS and Psychological Conditions
- IV.** HS and Rare Inflammatory Syndromes
- V.** HS Associated Conditions and Impact on Treatment Decisions
- VI.** Questions & Answers

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## I. Introduction

It is not uncommon for people with HS to have other medical conditions. Conditions that are associated with HS are called HS comorbidities. We currently know of more than 25 conditions associated with HS (Table 6.1). Some of these associated diseases affect the skin while others affect other parts of the body.

**It is important for patients with HS to be screened for other conditions that may be occurring at the same time as their HS.**

Keep in mind that treating HS can become more complicated when additional diseases are involved. This is because treating both HS and another condition at the same time requires additional considerations (for example, recognizing potential drug interactions).

This chapter explores some of the more common diseases associated with HS as well as their impact on HS treatment decisions.

## II. HS and Physical Conditions

**Metabolic conditions.** Some of the most well-known conditions associated with HS are problems with metabolism, also called “metabolic diseases.” Patients with HS are more likely to have “metabolic syndrome,” which means having three or more of the following conditions: large waist size, high blood pressure, high blood sugar, high triglycerides in the blood, or low HDL (“good”) cholesterol in the blood. Obesity, high cholesterol, and high blood pressure are reported in over half of people with HS. Additionally, kids with HS have even higher rates of metabolic problems compared to adults.

Screening for diabetes, high blood pressure, high cholesterol, and other risk factors for heart disease is an important part of managing HS given that people with HS are at higher risk of having metabolic conditions. When you see your health-care provider, make sure you are getting checked for these diseases – regardless of your age, sex, or weight.

**Gut conditions.** People with HS are at higher risk of having issues with their digestive system, including inflammatory bowel disease (IBD). Two

Table 6.1. HS Associated Diseases

Type	Description
Eye	<ul style="list-style-type: none"> <li>• Uveitis</li> <li>• Keratitis</li> <li>• Conjunctivitis</li> </ul>
Gut	<ul style="list-style-type: none"> <li>• Inflammatory bowel disease (IBD) <ul style="list-style-type: none"> <li>◦ Crohn’s disease</li> <li>◦ Ulcerative colitis</li> </ul> </li> </ul>
Joint	<ul style="list-style-type: none"> <li>• Rheumatoid arthritis</li> <li>• Spondyloarthritis</li> </ul>
Lung	<ul style="list-style-type: none"> <li>• Asthma</li> </ul>
Malignancy	<ul style="list-style-type: none"> <li>• Squamous cell carcinoma (skin cancer)</li> <li>• Lymphoma</li> </ul>
Metabolic	<ul style="list-style-type: none"> <li>• Obesity</li> <li>• Type 1 Diabetes</li> <li>• Type 2 Diabetes</li> <li>• High cholesterol</li> <li>• High blood pressure</li> <li>• Hypothyroidism (low thyroid)</li> <li>• Adrenal hyperplasia (enlarged or overactive adrenal glands)</li> </ul>
Mood	<ul style="list-style-type: none"> <li>• Anxiety</li> <li>• Depression</li> <li>• Attention deficit disorder (ADD or ADHD)</li> </ul>
Reproductive	<ul style="list-style-type: none"> <li>• Polycystic ovarian syndrome (PCOS)</li> <li>• Precocious (early) puberty</li> <li>• Sexual dysfunction</li> </ul>
Skin	<ul style="list-style-type: none"> <li>• Acne (regular and very severe)</li> <li>• Pilonidal disease</li> <li>• Dissecting cellulitis of the scalp</li> <li>• Pyoderma gangrenosum</li> <li>• Psoriasis</li> <li>• Eczema</li> </ul>

major types of IBD exist: Crohn’s disease and ulcerative colitis. People with IBD often feel tired

and have abdominal pain, diarrhea, or blood in their stool. A patient may already have IBD at the time of HS diagnosis, or may go on to develop it later.



• **Figure 6.1.** Severe scarring and crusted nodules on the back from partially treated acne conglobata in a patient with HS.



• **Figure 6.2.** Psoriasis involving the elbow.



• **Figure 6.3.** Pyoderma gangrenosum on the leg.

**Skin conditions.** If you have HS, you are more likely to have other problems with your skin. The most common skin condition found in people with HS is acne. Acne can present as red bumps, blackheads, or whiteheads on your face, chest, back, or shoulders. HS is one of four conditions that make up the “follicular occlusion tetrad.” In addition to HS, this “tetrad” also includes acne conglobata, which is a severe form of acne with nodules that may drain and cause scars ([Figure 6.1](#)); pilonidal disease, or a cyst or tunnel at the top of the buttocks; and dissecting cellulitis, or abscesses on your scalp that may cause hair loss.

People with HS have a higher chance of having (or developing) any of the other three conditions that make up the “follicular occlusion tetrad.” Other skin conditions seen in patients with HS include psoriasis ([Figure 6.2](#)) and pyoderma gangrenosum, which presents as painful ulcers with a purple or ragged border ([Figure 6.3](#)). If you notice new or different skin problems that you suspect are not HS, be sure to tell your healthcare provider.

**Arthritis.** Almost half of people with HS have swelling of their joints called “arthritis.” This may occur years after the skin signs of HS appear, and is more likely in men. Two of the more common types of arthritis are spondyloarthritis and rheumatoid arthritis (RA). Spondyloarthritis causes chronic pain of the lower back, ribs, and hips. Common symptoms of RA are morning stiffness as well as pain and swelling of joints, including the fingers, wrists, and feet. About one in 10 people with HS have spondyloarthritis. People with HS are also twice as likely to have RA compared to people without HS. Furthermore, specifically among people with HS, there appears to be a correlation between the likelihood of RA and HS severity. Studies have seen a higher percentage of RA in patients with more severe HS than in those with milder HS.

**Polycystic ovarian syndrome (PCOS).** Women with HS are twice as likely to have polycystic ovarian syndrome (PCOS) compared to women without HS. PCOS is a disease where women have abnormal periods and may also have cysts on their ovaries. This can lead to difficulty getting pregnant, weight gain, acne, and hair growth on the face, neck, chest, and stomach. Hormone imbalances from PCOS can cause kids with HS to reach

puberty too soon, also known as “precocious puberty.” Signs of early puberty include acne, body odor, and hair on the genitals. If you or your child develop any of these signs, contact your healthcare provider.

**Sexual dysfunction.** HS can cause sexual dysfunction, or problems in a person’s sex life, for both women and men. Over half of people with HS report issues with sexual health, and this can happen for many reasons. HS commonly involves sensitive body areas such as the groin and genitals; in these cases, sex can cause pain and discomfort. If you feel comfortable, discussing your sexual health concerns with your healthcare provider may be helpful.

**Eye conditions.** Although it is less common, HS can be associated with inflammatory eye disease. This may range from very mild to very severe disease that can cause permanent damage to the eye. Although many forms of eye disease are not very dangerous, the most severe form seen with HS is called keratitis. Symptoms include eye redness, eye pain, and decreased vision. If you experience these symptoms, you should immediately alert your healthcare provider and make an urgent appointment with an eye doctor. If left untreated, keratitis can result in permanent vision loss.

### III. HS and Psychological Conditions

Mood disorders like anxiety and depression are at least twice as common among people with HS than among people without HS. These mood disorders are also associated with sexual dysfunction and can have a tremendous impact on quality of life. Just as it is important to discuss your physical symptoms from HS (such as pain and drainage) with your healthcare provider, it is important to also share any emotional symptoms from HS that you are experiencing. Let your healthcare provider know if you have thoughts about harming yourself. Addressing your mental health is a vital part of managing your HS.

### IV. HS and Rare Inflammatory Syndromes

Your HS may be just one part of a genetic syndrome causing an overactive portion of the im-

mune system. For example, “PASH” is when a person has pyoderma gangrenosum, acne, and HS. People with HS may also have “SAPHO” syndrome, which stands for Synovitis, Acne, Pustulosis, Hyperostosis, and Osteitis. Synovitis means inflammation of the joint space, and osteitis means inflammation of bone. Pustulosis refers to small bumps filled with pus, usually on the hands and feet. Hyperostosis is when ligaments, or the tissues that connect bones to each other, become hard and bone-like. These syndromes are very rare, but important to recognize.

### V. HS Associated Conditions and Impact on Treatment Decisions

HS associated conditions may change how your healthcare provider recommends treating your HS. Some HS associated diseases, like psoriasis, can be treated with medications that are also used to treat HS. This means that you may be able to use one medication to treat both conditions. Other times, your HS associated disease may prevent you from using certain types of HS medications. For example, people with inflammatory bowel disease (IBD) should be careful with interleukin-17 inhibitors. Even though these drugs can be useful in treating HS, they can worsen IBD. It is important that your healthcare provider is aware of all your other health conditions so that you can both engage in the decision-making process to choose the treatments that are right for you.

### VI. Questions & Answers

#### Question 1

**Is HS just a skin disease?**

#### Answer

Having HS puts you at a higher risk of having other conditions that affect other parts of your body, beyond just the skin. It is more common for people with HS to have other diseases like diabetes, high blood pressure, heart disease, digestive problems, depression, and anxiety compared to people without HS. ►

**Question 2****How do I know if I have an HS associated disease?****Answer**

Your healthcare provider should be aware of the diseases that have known associations with HS and should check you for signs of these conditions. However, you should make sure to let your healthcare provider know as soon as possible if you develop any new symptoms such as weight gain, tiredness, blurred or decreased vision, stomach pain, diarrhea, blood in stool, feeling sad, or feeling worried.

**Question 3****Did my HS give me anxiety and/or depression?****Answer**

While we do not know the exact cause and effect relationship between HS and mood disorders, we do know that people with HS are more likely to have anxiety and depression compared to people without HS. Make sure to let your healthcare provider know if you experience any changes in your mood, feelings of worry, or feelings of sadness.

Authors: **Jason Gomez, Leandra A. Barnes, Maria Aleshin**

# Chapter 7

# HS Disease

# Complications

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- I.** Introduction
- II.** Skin Complications
- III.** Systemic Complications
- IV.** Questions and Answers

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## I. Introduction

Over time, repeated episodes of HS disease flares can lead to complications. Not everyone with HS is going to experience complications. For those that do, the complications can be limited to affecting the skin only or can cause internal problems in the body. Complications that cause internal problems are called systemic complications.

To prevent complications, early diagnosis and treatment of HS is of great importance.

**It is easier to prevent complications than it is to treat existing complications.**

This chapter discusses skin and systemic complications that people with HS may encounter.

## II. Skin Complications

**Tunnels.** HS is a condition caused by an overactive immune system, as well as the abnormal plugging and rupture of hair follicles. These ruptured hair follicles are thought to be connected by tunnels formed under the skin. However, they can sometimes attach to the surface of the skin and drain foul-smelling fluid. In rare cases, tunnels will close and heal with medications that treat HS; however, most tunnels require surgical intervention. Your healthcare provider may assess the severity of your disease using a grading scale called “Hurley staging” which looks at the presence or absence of tunnels and scars, as well as the extent of disease involvement. Having tunnels signifies more advanced disease. Early diagnosis of HS and initiation of treatment may help prevent the formation of tunnels.

**Scarring and Contractures.** HS lesions can heal with discoloration and scarring. There are several types of scars that can form in people with HS, including:

- Depressed (indented) scars which can be darker or lighter than the surrounding skin.
- Thickened scars which are firm, raised, and can resemble a rope.
- Keloids, which are raised scars that extend past the area of the original wound or lesion.

These scars can make the affected skin look abnormal and can also cause sensitivity and pain. Scarring can also lead to limb contractures. Limb contractures are areas of tightening or shortening

of the skin that can limit movement, especially when occurring in the armpits or groin.

The best way to prevent scars is to diagnose and treat HS early. If scars do develop, your healthcare provider may suggest steroid injections or lasers to help with the appearance of your scars if they are bothersome. Scars can also be surgically removed, but there is risk of new scars developing in their place.

**Lymphedema.** Lymphedema, a type of swelling, occurs when scars form near lymph nodes. Lymph nodes are part of the immune system. They help the body fight off infections by filtering and trapping viruses, bacteria, and other causes of infection. When scars form near lymph nodes, they can make it harder for fluid to drain from the lymph nodes, which causes swelling. A common area for lymphedema in HS patients is the groin. However, swelling can occur in any part of the body.

Depending on the location, lymphedema may be managed with compression treatments. Swelling in the groin is more difficult to compress and may require surgery or laser therapy to help remove the affected tissue and lymph nodes.

**Fistulas.** Long-term inflammation of HS can cause abnormal connections (or passageways) to develop between two organs that do not normally connect. These are called fistulas. The most common kind of fistula seen in HS patients is a tunnel that forms between the skin and the anus. This is more common in men than in women.

Symptoms of an anal fistula include persistent pain, swelling, and drainage of blood or pus involving the perianal skin. If a fistula is suspected, imaging tests such as magnetic resonance imaging (MRI) or computed tomography (CT) scans may be ordered to better evaluate the area. Fistulas usually require surgical treatment. However, treating HS inflammation early may help prevent fistula formation.

**Skin Cancer: Squamous Cell Carcinoma.** Squamous cell carcinoma (SCC) is a type of skin cancer that - in rare cases - can develop in areas of HS scarring and inflammation that have been around for a long time. SCC is a rare but serious complication of HS. It more commonly occurs in men. SCC associated with HS is usually found on the buttocks but can also be found in other areas, including the thighs, groin, and genital area.

There can be a delay in the diagnosis of SCC. This may be because HS lesions can sometimes look like SCC. If you have longstanding HS lesions, it is important to regularly see a dermatologist so that they can evaluate your skin lesions to screen for skin cancer. To diagnose SCC, your dermatologist may take a biopsy. If the diagnosis of SCC is made, your dermatologist will work with a team of other doctors to treat the skin cancer, including a surgeon who will perform a surgery to remove it. SCCs may come back even after removal, so it is important to continue regular skin examinations with your dermatologist.

### III. Systemic Complications

**Serious Infections and Sepsis.** HS is not an infection. However, the areas affected by HS have the potential to become infected. This can result in serious infections of the skin, bone, and blood. Sepsis is an extremely rare but life-threatening complication that occurs when the body's infection-fighting response damages its own tissues. Symptoms of sepsis include fever, confusion, a drop in blood pressure, and difficulty breathing. In rare cases, an infected HS lesion can lead to sepsis, especially as some medications used to treat HS can suppress the immune system, making a person more likely to develop an infection. It is important to seek care with a healthcare professional if you suspect you may have an infection.

**Anemia.** People with HS are more likely to have low levels of red blood cells, a condition known as anemia. These red blood cells are needed to carry oxygen to your body's tissues. Having anemia can make you feel tired, weak, or short of breath. Anemia can develop when someone has a lot of chronic inflammation in their body, such as in people with HS. In these cases, treating the inflammation associated with HS may help improve the anemia.

Anemia can also be the result of having low levels of iron, which can occur from blood loss. People with HS may also have iron deficiency anemia. The cause of this is unknown, but may be related to blood loss from draining HS lesions, blood loss in women from periods, or bleeding from the gastrointestinal tract. A lab test can help determine the type of anemia that you have. If anemia is suspected, your primary care doctor can help with further work-up.

**Amyloidosis.** Many chronic inflammatory diseases, including HS, have the potential to cause amyloidosis. Amyloidosis is an extremely rare disease that occurs when a protein called amyloid builds up in your organs. This disrupts the normal function of your organs and, in severe cases, can cause organ failure. Although any organ can be affected, the kidneys are most often involved. Amyloidosis may improve with treatment of HS.

## IV. Questions and Answers

### Question 1

**What are the complications of HS?**

#### Answer

The table below lists both skin complications and systemic complications of HS.

Complications Limited to the Skin	Systemic Complications
<ul style="list-style-type: none"> <li>Tunnels under the skin</li> <li>Scarring and contractures</li> <li>Lymphedema</li> <li>Fistulas</li> <li>Skin cancer (most commonly squamous cell carcinoma)</li> </ul>	<ul style="list-style-type: none"> <li>Serious infections and/or sepsis</li> <li>Anemia</li> <li>Amyloidosis</li> </ul>

### Question 2

**What are the benefits of early diagnosis and treatment of HS?**

#### Answer

Early diagnosis and treatment of HS can help prevent many of the complications listed above. This can improve quality of life, as it is easier to focus on preventing complications than it is to treat existing complications. Early diagnosis and treatment can also bring quicker relief.

### Question 3

**Which doctors should I see to help diagnose or treat HS and its complications?**

**Answer**

Many different kinds of healthcare providers can help diagnose HS, including clinicians in primary care, obstetrics and gynecology, and emergency medicine. If you suspect that you have HS, please talk with any of your healthcare providers so you can be referred to a dermatologist for further management. A dermatologist can be your main HS care provider, help treat your HS, and coordinate referrals to other specialists as needed. Surgeons, psychiatrists, rheumatologists, and endocrinologists are just some of the other providers that can play an important role in your HS care. In addition, you should routinely follow-up with a primary care provider, who can help monitor for signs and symptoms of systemic HS complications. More information on specialists and the role they play in your care can be found in **Chapter 13**.

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## Chapter 8

# Women with HS: Periods, Pregnancy, and Menopause

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- I.** Introduction
- II.** HS and Periods
- III.** HS and Pregnancy
- IV.** Questions and Answers

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## I. Introduction

In the United States, HS is twice as prevalent in women than men. Women face unique challenges related to periods, pregnancy, breastfeeding, and menopause. For example, HS often flares around the time of periods. In addition, HS disease activity may change during pregnancy.

This chapter discusses women-specific challenges and suggests ways to improve HS disease with these factors in mind.

## II. HS and Periods

Sex hormones seem to play a role in HS disease. However, the exact way they impact HS is unclear. Women often find that HS is worse around the time of their period. In a survey of 279 women with HS, 77% reported worse HS disease with their periods, 22% reported no change, and 1% reported improvement. Estrogen and progesterone are often referred to as “female hormones”. During a menstrual cycle, estrogen and progesterone levels increase at ovulation and drop before menstruation. However, more research is needed to explore the specific roles progesterone and estrogen play in HS. Androgens (including testosterone) are hormones that are essential for male sexual development and are present at much higher levels in biological males compared to biological females, and these hormones are thought to worsen HS. For further information on causes of HS, please see [Chapter 3](#).

Certain recommendations are helpful for women whose HS worsens during their period. Some women have groin lesions and may find tampons more comfortable than pads. Pads may cause uncomfortable friction against HS groin lesions.

In addition, treatments that target hormones may be helpful. Women without immediate plans to get pregnant may consider oral contraceptive pills (commonly known as birth control pills) that contain a progesterone with low or anti-androgenic activity. Certain types of birth control methods, such as hormonal intrauterine devices (IUDs), may actually worsen HS. The medication spironolactone, which has anti-androgenic properties, may be helpful. For further information on using hormonal medications for HS, please see [Chapter 18](#).

## III. HS and Pregnancy

**HS During Pregnancy.** The way HS activity changes during pregnancy is mixed. Some women improve, some worsen, and some do not experience any changes. Overall, HS has been reported to improve in about 24% of pregnant women and worsen in 20%. It is important to remember that HS might worsen during pregnancy. Discuss your HS with your obstetrician-gynecologist (OB-GYN) and dermatologist, and continue proper treatment during pregnancy.

**HS Treatments During Pregnancy.** While you’re pregnant, there are medications considered safe to treat HS. Others are known to negatively affect the developing baby.

Topical antiseptic washes are generally considered safe. These include chlorhexidine (Hibiclens®) and benzoyl peroxide washes. Topical clindamycin is also considered safe to use during pregnancy. There are oral antibiotics that are also generally considered safe, such as clindamycin and cephalexin. However, use of other oral antibiotics that are commonly used to treat HS, such as rifampin, should be discussed with your doctor. There are some oral antibiotics, such as tetracyclines (doxycycline and minocycline), that should not be taken during pregnancy. In addition, there are also non-antibiotic oral medications, or supplements, including metformin and zinc, that are generally considered safe during pregnancy.

Use of biologics, or injectable medications that target the immune system in specific ways, during pregnancy should be discussed with your provider. Tumor necrosis factor (TNF)-alpha inhibitors (such as adalimumab and infliximab) have the most pregnancy data when compared to other biologics. Of note, biologics tend to have increased transfer across the placenta during the third trimester of pregnancy. However, certolizumab, a TNF-alpha inhibitor, has minimal to no placental transfer from mother to fetus. It is a biologic that your healthcare provider may discuss with you. More research is needed on how effective certolizumab is in treating HS. If you are on a TNF-alpha inhibitor or other biologic and are planning pregnancy or if you find out you are pregnant, talk to your provider. A plan can be made between you, your dermatologist, and your OB-GYN.

Other medications (besides tetracyclines mentioned above) that should not be used during pregnancy include retinoids (such as isotretinoin (Accutane®) and acitretin), finasteride, spironolactone, and methotrexate. Studies have shown these medications to negatively affect fetal health.

**Pregnancy Outcomes.** Some studies have looked at how HS might affect pregnancy course and outcomes. In an anonymous survey, people with HS who reported having disease in genital and/or anal areas shared their experiences with childbirth. Nearly a quarter reported that vaginal delivery caused an HS flare. Of those who received a C-section, 34% reported that HS interfered with healing, and 52% reported new HS lesions in their C-section scar. Therefore, it is important to continue HS care in the post-partum period.

Another study found that pregnant people with HS may have a higher-risk pregnancy compared to people without HS. However, it is not clear how factors such as HS disease severity or HS medications (or lack of medications) influence this risk. More studies on the pregnancy outcomes of people with HS are needed.

**Pregnancy-Related Conditions.** If a pregnant person with HS has other medical issues, such as anemia, obesity, diabetes, high blood pressure, or thyroid disease, these conditions should be followed carefully by their primary care provider or OB-GYN. People with HS have been found to be at higher risk of developing hypertension and diabetes during pregnancy, so blood pressure and glucose levels should be carefully monitored. Appropriate medications should be started based on your doctor's instructions.

**HS and Breastfeeding.** Women with HS may breastfeed if they choose to, and if they are able to. For women with HS lesions on the breast who plan to breastfeed, it may be helpful to treat active HS breast lesions in preparation.

Some HS treatments are safe during breastfeeding. Some are not, since they may be secreted into the milk and absorbed by the baby. Topical anti-septic washes, oral zinc, and metformin are generally considered safe. Many topical and oral antibiotics are generally considered safe as well, but you should check with your doctor about the specific medication you are taking.

TNF-alpha inhibitor biologics commonly used

for HS, such as adalimumab and infliximab, are generally considered safe to take, even while breastfeeding. However, as is the case with other medications, the use of biologics during breastfeeding should be discussed with your doctor.

**HS and Menopause.** Previously, menopause was thought to be associated with improvement in HS. However, one survey study found that many people with HS reported that their HS worsened (40%) or did not change (45%) after menopause. Therefore, even after experiencing menopause, it is helpful to continue seeing your dermatologist because your HS may need continued management.

## IV. Questions and Answers

### **Question 1**

**Does my period affect my HS?**

#### **Answer**

Many women with HS notice that their symptoms worsen around their period. This usually happens during the week before their period starts. The exact reason why this happens is not known. It does suggest that, for many women, hormones play a role in HS disease. For these women, it may be helpful to seek treatments such as spironolactone that target hormones.

### **Question 2**

**If I get pregnant, will that make my HS worse?**

#### **Answer**

Based on what we know so far, the way HS changes during pregnancy is mixed. Some women improve, some worsen, and others do not see any changes. A recent publication looked at reported HS activity during pregnancy across different studies. Overall, HS disease activity was found to improve during pregnancy in about 24% of women, worsen in 20%, and stay unchanged in the rest.

### **Question 3**

**If I have a C-section, will I develop HS lesions in my C-section scar?**

**Answer**

Some people with HS develop new HS lesions in their C-section scar. If this happens to you, you can discuss treatment options with your doctor.

**Question 4**

**Are medications for HS safe in pregnancy?**

**Answer**

If you are family planning or find out that you are pregnant, it is important to talk to your doctor. You and your doctor can come up with a plan for HS treatments during your pregnancy. While pregnant, it is a good idea to regularly follow up with your dermatologist and OB-GYN. They can closely monitor your HS condition and your pregnancy, and change medications as needed.

Authors: **Andrea L. Zaenglein, Laurie Krnjaic, Irene Lara-Corrales**

## Chapter 9

# Children with HS

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- I.** Introduction
- II.** Clinical Features of Children with HS
- III.** Associated Conditions
- IV.** Treatment of Children with HS
- V.** Tips to help your child with HS
- VI.** Questions and Answers

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## I. Introduction

HS is more common after puberty, but younger kids can have it as well. In the United States, girls are more likely to have HS than boys. In pediatric patients with HS, you often find that other close family members also have HS, suggesting there might be genetic factors that contribute to having the disorder.

## II. Clinical Features of Children with HS

**A good screening question to ask if you are trying to determine if your child has HS is: have they had outbreaks of boils or abscesses during the last six months?**

**Another good question to ask is: did they have at least two boils in one of the following locations: armpits, groin, genitals, under the breasts, buttocks, neck, or abdomen?**

A healthcare provider familiar with HS will be able to make the diagnosis of HS just by taking a medical history and examining the skin. No biopsies or lab tests are required.

## III. Associated Conditions

Pediatric patients with HS have a higher chance of being obese or overweight, having acne, and having other conditions such as inflammatory bowel disease, inflammatory joint disease, anxiety, and depression. Kids with Down syndrome are at increased risk of HS. Sometimes your healthcare provider will need to do further work-up to rule out other associated diseases.

## IV. Treatment of Children with HS

Treating HS is challenging. Unfortunately, treatments have largely not been studied in pediatric patients with HS, and treatment recommendations are taken from adult data. Early interventions might potentially modify disease progression. If inflammation is controlled early and disease severity does not progress, one could expect to prevent complications like scarring, but we need to study this further. Your healthcare provider might decide to start with topical treatments if the severity of the disease is mild; if moderate or severe, oral or injectable medications would be considered. Treatment options include antibiotics, retinoids, hormonal medications, biologics, laser, and surgery among others. As HS is made worse by heat, sweat, and friction, kids sometimes stop doing physical activities. It is important to control HS so they can continue to remain active and healthy.

## V. Tips to help your child with HS

It can be helpful to educate your child about HS.

**The more your child understands about what is happening to their body, the easier it will be for them to talk to their friends about it, ask for help, and make healthy decisions for themselves.**

Talking to your child to find out what bothers them most about their HS can also be helpful. As adults, our perceptions and values are different than that of our kids. You may focus on the long-term effects of the disease, whereas your child may just be trying to figure out how they can change their clothes for gym class without anyone noticing, or how to apply their skin care while staying overnight at a friend's house.

Finally, it is important to observe your child for signs of pain or depression and also assess their overall well-being. Pain related to an infection or worsening inflammation may be perceived by your child as "the usual chronic pain" they endure, and they may miss the opportunity to prevent a larger flare. Kids with HS have higher rates of depression. The emotional stress associated with HS can lead to feelings of sadness and hopelessness, causing kids to withdraw from normal activities and relationships. Growing up is challenging, but growing up with a chronic health problem can be overwhelming for some children. It is important to be aware of all the support services available to you and your child, and to encourage your child to talk to someone about their HS and how it affects them. This can happen through a counselor, support group, or even by joining a recommended online support group.

## VI. Questions and Answers

### Question 1

#### Will my child grow out of HS?

##### Answer

Not likely. HS is a chronic inflammatory skin condition, meaning it does not go away on its own, but it can be treated. The severity of HS may vary over time. It may go through periods of time when it is not very active, but it can get worse and more severe with time. That is why early diagnosis and treatment are so important. The earlier HS is treated, the less severe it may become.

### Question 2

#### Is HS different in kids than adults?

##### Answer

No. It is the same disease process, but children and teens with HS may be more likely to have hormonal imbalances. Kids should always be screened for hormone-related diseases, such as causes for early puberty, obesity, and metabolic syndrome (including high cholesterol, diabetes, and high blood pressure).

### Question 3

#### Are sports and exercise bad for my child's HS?

##### Answer

Keeping active is important. The goal is to allow kids to participate in activities they enjoy. Sports are a way for kids to socialize with their peers, and exercise can help kids maintain a healthy weight. However, the sweating and skin friction experienced with some sports may irritate existing HS lesions or create new ones, worsening pain. Ideally, the chosen exercise increases heart rate but minimizes sweat and friction.

### Question 4

#### Can my child participate in age-appropriate activities such as swimming or sleepovers?

##### Answer

Yes! The exercise from swimming is very

beneficial. There may also be benefits when swimming in a chlorinated pool. However, a child who is experiencing a flare with open wounds may want to wait until the wounds have healed before swimming. As for sleepovers, absolutely. The more friends and laughter, the better. You may need to explain HS to other parents or your child's friends, so they understand that your child does not have a contagious disease. Let your child lead as normal a life as possible.

### Question 5

#### Will laser hair removal help my child's HS?

##### Answer

Some data suggests that laser hair removal in HS patients is helpful. It appears to be most effective in early stages of HS. However, it may not be covered by insurance and can take several treatments, which can be expensive. More information regarding laser treatments for HS can be found in Chapter 24.

### Question 6

#### My relative has severe HS—will my child's HS be as severe?

##### Answer

While HS can run in families, the severity of disease can vary between family members. Not all people with HS develop severe disease, and for many patients, HS can improve over time if diagnosed and treated early.

### Question 7

#### Is my child contagious?

##### Answer

HS is not an infection. It is not sexually transmitted or caused by poor hygiene. It is an inflammatory skin condition believed to be caused by an overactive immune response. However, HS lesions can become infected with bacteria. It is important to keep those infected areas covered when they are draining, as the bacterial infection (not the HS) could be contagious.

Authors: **Adam Garibay, Jan Smogorzewski**

# Chapter 10

# Work, School, and Budget Considerations

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- I. Introduction
- II. Work and School Considerations
- III. Disability Assistance
- IV. Transportation
- V. Nutrition and Exercise
- VI. Support Groups
- VII. Clothing Considerations
- VIII. Wound Supplies and Medications
- IX. Questions and Answers

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## I. Introduction

HS can be a debilitating disease and studies have shown that patients suffering from HS are more likely to be of low socioeconomic status, potentially making it challenging over time to cover medical co-payments, pay for medications and wound care supplies, and/or maintain a healthy diet.

This chapter provides recommendations on how to manage HS on a budget as well as suggestions on how to manage work/school, disability claims, transportation, and other considerations.

## II. Work and School Considerations

Due to the recurrent pain and chronic nature of HS, people with HS lose an average of 34 work-days per year compared to the general population, which loses only 7.5 days per year. The most commonly reported triggers for flares include stress, sweat, and hot weather. In the ideal scenario, you manage to find successful treatments for managing your HS, so that your HS does not limit the type of job you can choose to pursue. However, if your HS makes it difficult for you to work outdoors because sweating triggers your symptoms, considering an indoor job or one that provides adequate shade may be helpful.

People with HS may experience pain and have limited mobility requiring a different job or changes in the workplace. You can request reasonable accommodations at work (such as padded chairs, standing desks, or looser-fitting uniforms to minimize friction on the skin) which can help make you feel more comfortable and therefore increase work productivity. If your disease is not well-controlled and you are unable to complete a full day of work, some options could include asking employers about the possibility of flexible work hours or applying for disability benefits (see below).

Those still in school may need to provide doctor's notes for absences because of HS flares, ask for extensions on assignments, or even request adjustments to assignments that may be difficult to complete because of HS.

If you feel comfortable doing so, it may be worthwhile to consider sharing information with teachers and/or employers about HS, and the impact it may have on attendance or productivity.

This could potentially lead to better understanding and help address any needed accommodations during disease flares.

## III. Disability Assistance

People with HS may miss work due to physical disability from their condition. In the case of being unable to work during severe flares, or after surgical procedures in the doctor's office, one could apply for short or long-term disability benefits. The Social Security Administration lists several skin conditions that may qualify for disability assistance; HS is a condition that qualifies. There are also state-specific and private insurance options for obtaining disability payments when HS makes it difficult to work. Healthcare providers themselves do not determine whether patients are eligible for disability. Rather, they provide objective data regarding the condition and treatments, and a third party reviews the information and determines eligibility.

## IV. Transportation

People with HS may struggle to make it to outpatient appointments for various reasons, including lack of transportation. Some healthcare plans may help with the travel costs associated with medical appointments, and it is worthwhile to ask insurance providers whether transportation to the doctor's office is included in the coverage plan. Free or low-cost transportation may also be available directly through hospital and local county healthcare systems.

If one is eligible for disability, the Social Security Administration can also help with travel costs, and the Veteran's Administration provides transportation to appointments for veterans or active-duty service members. If applicable, you may contact Medicaid to determine your eligibility for reimbursement of appointment travel costs. Maintaining accurate records of your travel and appointments may be important when trying to get reimbursement. Charitable foundations can also help with covering transportation costs, but this may be limited in availability, so researching them on the internet from time to time can be helpful. ►

## V. Nutrition and Exercise

With HS patients, obesity is known to play a role in the severity of disease. Accessing nutritious food at a low cost may be challenging, particularly in neighborhoods that have fewer grocery stores with fresh produce and more fast-food options. However, there are several online resources available that may be helpful for people looking to improve their nutrition. The National Institute of Health (NIH) lists several tips for healthy eating on a budget, including buying bulk, using coupons when available, and comparing the unit price of items. The US Department of Agriculture (USDA) has advice regarding free and low-cost nutrition classes, resources on food composition and diet, as well as interactive tools for planning meals and exercise. Also, the USDA's Supplemental Nutrition Assistance Program (SNAP) serves as a free resource with low-cost nutritional recipes for families. Outside of online resources, fresh fruits and vegetables may be found in community gardens, as well as local food banks and drives that are sometimes sponsored through hospitals and community centers.

Additionally, exercise can be challenging with time and financial limitations. However, there are many low-cost exercise options that do not require expensive equipment or significant time commitments. Some of these can be found at the U.S. Department of Health and Human Services health.gov website (<https://health.gov/our-work/nutrition-physical-activity/physical-activity-guidelines>) with specific examples described. You can also consider bringing family members to your follow-up visits, which can help to make the home environment more encouraging for exercise and weight loss.

## VI. Support Groups

Patients with chronic conditions who participate in support groups tend to have higher self-esteem and confidence in managing their condition. HS support groups can help you feel supported by people who may best understand the way you feel. Groups such as Hope for HS, HS Warriors, HS Connect, and the International Association of HS Network are national organizations with free resources available to people with HS. HS support

group meetings can also be virtual, which removes the burden and cost of traveling to in-person meetings.

## VII. Clothing Considerations

When purchasing clothing, it helps to avoid tight clothing, elastic bands, and bras with underwire. Choose looser fitting clothes. Drainage of lesions may require more frequent replacement of clothing, leading to increased cost. 100% cotton clothing is easy to find and reasonably priced, but you may also consider alternative materials like rayon and bamboo fabric that are also soft but more absorbent. Bulk shopping and searching for coupons and discounts online or at large retailers (such as Walmart, Amazon, Target), are small ways to help control costs.

## VIII. Wound Supplies and Medications

Specialty wound care products may not be covered by insurance companies, and many people with HS may not have insurance to cover any wound care supplies. Even if supplies are covered, choosing which dressings to use can also be confusing given the many different brands and dressings. Patients and providers must recognize the difficulties in getting wound care supply coverage, and to keep trying to get insurance reimbursement through repeated applications. Please see *Chapter 15* for more information on wound care.

The most affordable absorbable dressings in HS wound care are over-the-counter (OTC), and can often be bought in bulk – menstrual pads, adult diapers, and gauze. Abdominal pads are more expensive than other OTC dressings, but may be obtained in bulk from online pharmacies or surgical supply companies. Medicare, Medicaid, and other commercial insurance companies offer some coverage of more specialized wound care dressings as well. Information about your condition may need to be updated monthly to have insurance companies continue covering wound care supplies. Costs of tape and bandages can be lowered by using reusable wraps and biker shorts to help hold dressings in place.

Medication costs pose another financial stress for people with HS. Discounts for generic medications are available directly from various pharmacies. For instance, GoodRx offers coupons for

generic medications to significantly lower their prices. Commonly prescribed medications for HS (i.e. antibiotics and oral contraceptives) can be found at Target and Walmart in 30-day supply and 90-day supply for \$4 and \$9, respectively (based on a search in 2022). Utilization of 90-day supply offers may also reduce monthly co-payments due to less frequent refilling of medications at pharmacies.

For more expensive medications like biologics, applications for patient assistance directly from the pharmaceutical company can sometimes result in partial or full coverage of the cost. Patients who feel comfortable can also explore clinical trials listed on government-run websites like [www.clinicaltrials.gov](http://www.clinicaltrials.gov) that offer access to new and established HS therapies.

## IX. Questions and Answers

### **Question 1**

**Smoking is associated with HS.**

**How can I quit smoking at low cost?**

#### **Answer**

There are many free smoking cessation resources and classes available. The easiest way to be connected to free resources is to call 1-800-QUIT-NOW. Government run websites include <https://smokefree.gov>. In addition to the health benefits, quitting smoking results in an annual savings of \$2000-\$4000 for many former smokers.

### **Question 2**

**How can I apply for and obtain disability assistance if I cannot work?**

#### **Answer**

There are several sources for disability assistance. The Social Security Administration offers disability assistance at a federal level. State-specific and private insurance options also exist. Most of these forms and applications can be found online. Prepare for filling out these forms by collecting relevant documents including proof of residency, medical documents such as doctor's notes, medications, and dates of hospitalizations. If

access to the internet and/or printing is difficult, local libraries often offer free internet access and printing.

If the applications above require forms for your doctor to fill out, try to set a separate appointment with your doctor specifically for assessing your eligibility for disability. Bring all the paperwork that needs to be filled out by the provider; do not assume that the provider has the forms or that the provider has ever filled out these documents before. When possible, try to find healthcare providers who are familiar with HS, and have filled out disability paperwork before.

### **Question 3**

**Can anyone help me with navigating insurance, disability, transportation, and medication issues and costs?**

#### **Answer**

Social workers can be valuable members of your care team both inside and outside of the hospital. They can be especially important during any hospitalization to help with insurance, transportation, and the high costs of hospital stays. They have been shown to assist patients with saving costs and with improved health outcomes. Consider asking your providers if they can connect you to any social workers, including at outpatient visits and during any hospitalization.

Authors: **Ramie Fathy, Robert G. Micheletti**

## Chapter 11

# Making the Most of Your HS Doctor Visit

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- I.** Introduction
- II.** Telling Your Story
- III.** The Physical Exam
- IV.** Communication and Expectations
- V.** Questions and Answers

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## I. Introduction

Whether it is your first doctor's visit for HS or your tenth, it can be challenging to cover all the topics and questions you hope to discuss. With a condition as complicated as HS, it is important to use your time with your healthcare provider as efficiently and effectively as possible to explain your concerns and receive the advice that fits you best. This chapter shares strategies and resources you can use to get the most out of your visits with your healthcare provider.

## II. Telling Your Story

To make the most of your clinic visit, it is helpful to be familiar with the sorts of questions your healthcare provider might ask, and the way your healthcare provider may be thinking about your HS and evaluating your response to treatment.

- **How active has your HS been over the last few months (or since the last visit)?**

People with HS and their healthcare providers understand that the condition has its better days and its worse days. In other words, your HS might be acting up at the time of a visit, or it might happen to be doing better that day. Healthcare providers understand this. They care about how things are doing the day you see them, but they are most interested in what the overall trend has been.

When your healthcare provider can understand how your HS is trending - if things are going overall better or overall worse (and how much better or worse) - they can more effectively determine if a change in treatment is needed.

- **What are your symptoms, and how is HS affecting you?**

Symptoms like pain, itch, swelling and drainage help convey how "active" your HS is. Describing how severe the symptoms are also provides a sense of how much the condition is affecting you. Be sure to mention all your physical symptoms associated with HS, if present.

It is also helpful to know how HS may be impacting your work, your personal life, or your mental health. If you are having trouble sitting or performing certain tasks, or if you find yourself skipping important work or life events because of

your HS, your healthcare provider should know about that. HS can impact many aspects of your life, including friendships and intimate relationships. It can also contribute to feelings of depression and anxiety. Sharing the way HS burdens your life will help your healthcare provider understand your condition better.

- **What are you doing to treat your HS?**

To prepare for your first visit with your healthcare provider, make a list of the medications and other treatments you have used in the past, including topical, oral, and injectable medicines, and any surgical procedures. Try to be specific about the name and dose of each medication, as well as the length of time you were using it. Other helpful information includes how consistently you took the medications, whether there were any side effects, and whether you found them helpful. Your healthcare provider will use this information to help create your treatment plan going forward.

For follow-up visits, be prepared to describe how your HS has changed since the last visit, if at all.

Keep track of how your symptoms change over time, and if you have noticed any potential triggers or anything that seems to alleviate your symptoms.

If you began a new medication since your last appointment, tell your healthcare provider if it helped, and about how long you were taking the medication before you saw an improvement. If you have developed any new symptoms, share these with your healthcare provider as well, in case they would like to consider alternative or additional treatments for your HS.

You should also include information about any complementary and alternative therapies you may have tried, such as special diets, vitamins or supplements, or cannabidiol (CBD), and whether or not you found them helpful. Providers are generally supportive of patients using complementary and alternative therapies to supplement traditional HS treatments, so you should feel comfortable sharing this information. It is important for your healthcare provider to know about these alternative therapies to determine whether they are safe or effective, or if they might potentially interact with your other medications.

### III. The Physical Exam

Your healthcare provider will need to see and evaluate your HS lesions in order to help determine your most appropriate treatment options. This is a very important part of your visit. Think of the physical exam as your chance to show your healthcare provider what you are dealing with. Whether your HS is mild, moderate, or severe, there are treatment options for you. Your healthcare provider will use the information you provide, along with the physical exam, to help you choose the right treatments.

Be prepared to show your healthcare provider the areas where you have HS. Your healthcare provider may also ask to examine other areas of your body, even if they are not problem areas for you. These areas include places where HS tends to occur, such as the underarms, groin, buttocks, and under the breasts to look for early signs of disease, as well as places where skin conditions associated with HS appear, such as your face or back for acne. Please see **Chapter 6** for more information on skin diseases associated with HS.

The areas often affected by HS can be sensitive or private. While it is normal to feel a bit embarrassed, remember that your healthcare provider is a professional who has seen this before, and is on your side. This condition is not your fault, and there is no reason to feel ashamed.

Wear clothing that will be comfortable during your visit, and easy to take off and put back on. Plan to change into a patient gown to help make it easier to examine your skin. You can ask for an extra gown or sheet to help you cover up. It is also okay to ask to have a chaperone (usually a clinic staff member) or loved one in the room with you during the exam.

### IV. Communication and Expectations

**Healthcare is a partnership between patient and healthcare provider.**

We must communicate with one another effectively to be successful. Clinic visits can be stressful. It can be hard to remember everything you want to discuss, and harder still to take in everything the healthcare provider says. It may be helpful to make a list of questions to bring with you to the

visit (please see the Q&A section at end of this chapter for some ideas). It may also help to ask a loved one to accompany you or listen in by phone. Ask your healthcare provider for a printed summary of instructions to take home with you.

**Be prepared to commit to a plan and course of treatment for at least three months.**

HS is a chronic condition that needs long-term treatment. The goal is to find something that works well and that you can continue over time to prevent new lesions. You may have to try a few different therapies to find the treatment(s) that work best for you. Usually, a healthcare provider will want you to stay on a treatment regimen for at least three months before determining if things are on the right track and making any adjustments. Stopping early or switching before the three month period ends can be counterproductive. This is because if you stop before a medication has had an adequate chance to take effect, you may never know if it would have worked. Please see **Chapter 12** for further discussion regarding HS treatment goals.

That said, you are never locked into a treatment if it simply is not right for you. If you think you might be experiencing a side effect of a medication, or if you do not see much improvement in your condition by the 3-month mark, let your healthcare provider know so adjustments can be made. If you think you may want to stop a treatment, please let your healthcare provider know right away so you can discuss it.

We hope these recommendations help you plan and make the most of your time with your healthcare provider. HS is a challenging disease and successful treatment can take time, but there is hope for better days ahead when we work together.

### V. Questions and Answers

#### **Question 1**

**How should I keep track of my HS to discuss how it is doing with my healthcare provider?**

#### **Answer**

You can visit the HS Foundation website to help you evaluate how severe your HS

is and help you describe symptoms you experience to your healthcare provider. While tracking your condition, you can also make a list of factors you think may be triggering or worsening your HS, such as specific foods, certain types of clothing, your menstrual cycle, stress, and so on.



Symptom trackers can help keep things straight and tell your story over time. Please see **Chapter 26** for more information regarding how to track your HS.

### **Question 2**

**Are photos helpful to show my healthcare provider during my visit?**

#### **Answer**

It can be useful to take good-quality photos when your HS is acting up. Sharing these with your healthcare provider can provide a sense of what you have been dealing with over time, even if things happen to be okay on the day of your visit. You can find some advice on taking good photographs of your HS on the VisualDx ([visualdx.com](http://visualdx.com)) website.

### **Question 3**

**What are some good questions for me to consider asking during my first visit with my healthcare provider?**

#### **Answer**

Some questions which may be useful to ask your healthcare provider include:

- What is hidradenitis suppurativa (HS), and what triggers the disease?
- In what ways can HS impact my personal or work life?
- What can I do at home to help treat or prevent HS flares?
- What are my treatment options? What are the risks and benefits of different therapies?
- What is the usual disease trajectory for people with HS? What should I expect over time?
- How often should I come in for a follow-up visit?

Authors: **Diana Seoak Kim, Martina Porter**

## Chapter 12

# HS Treatment Goals

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- I. Introduction
- II. Speed of Onset of Treatment Benefit
- III. HS Severity
- IV. Managing Treatment Expectations
- V. Individualized Treatment Plan
- VI. Questions and Answers

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## I. Introduction

While there is no cure for HS, there are ways to reduce the number of flares you suffer and decrease the pain, drainage, and extent of your disease. This can be done by taking medications, undergoing procedures, and making changes to your lifestyle as recommended by your healthcare provider.

The goal of HS treatment is not only to treat what is painful now, but also to prevent flares from occurring in the future. This means that, even if your condition improves soon after you begin treatment, you should continue to follow the plan set by your healthcare provider to prevent new lesions from appearing in the future.

**When deciding on a treatment plan with your healthcare provider, things to consider include: how quickly a treatment will start to work, whether a treatment provides short-term or long-term benefits, how severe your HS disease is, and how different treatments can be used in combination for you.**

It is also helpful to have a discussion with your healthcare provider regarding treatment expectations.

## II. Speed of Onset of Treatment Benefit

There are many different treatments for HS. Some may work very quickly, while others may take longer - sometimes many months - for you to notice an improvement. For example, if you receive an "intralesional kenalog injection," or a steroid shot, in a painful lesion during your visit, you can expect pain and redness in the area to decrease within a few days. These shots are useful for treating what is painful now, but are not useful for preventing future flares. In contrast, if you start taking a type of injectable medication called a "biologic" (such as adalimumab, or "Humira"®), it might be a few months before you notice an improvement.

While these medications do not always provide immediate pain relief, they are a long-term management option for HS.

## III. HS Severity

**Regardless of the severity of your HS, the goal of HS treatment will be to reduce pain, drainage, scarring, and the intensity and frequency of flares.**

However, the best treatment to achieve these goals may vary based on the severity of your disease.

Disease severity is often categorized as mild, moderate, or severe. It is important to know that patients with mild disease may suffer the same impact on their quality of life as those with more severe disease. Healthcare providers will recommend a treatment for you based on the severity of your disease, the expected benefits and side effects of potential treatments, your medical history, and your personal preferences for treatment. Thus, a healthcare provider may recommend that, if your disease is mild, you start with one or two topical or oral medications, such as topical benzoyl peroxide and oral antibiotics. If your disease is severe or does not respond well to treatments, the most effective treatment may be a combination of biologics, oral medications, topical medications, and steroid injections. It is important to discuss with your healthcare provider how severe your disease is, and to understand why certain treatments were suggested to you.

## IV. Managing Treatment Expectations

Given there is currently no cure for HS, understanding the expected benefits that your treatments may have can be helpful to avoid disappointment. Goals of treatment should always include reducing any physical symptoms (such as pain and drainage). In addition, it is helpful to evaluate whether you think a treatment is helping in terms of the intensity, frequency, and duration of your flares. This means that you may still get lesions, but they may be smaller and less painful. Instead of getting flares every month, for example, they may occur less frequently - such as every other month - and last for shorter periods.

If you have many large lesions or lesions with drainage in multiple areas of your body, or if you have extensive scarring from past lesions, an additional treatment goal may be to remove diseased tissue. Even if medical treatment is effective and flares occur less frequently, medical treatments will not make a tunnel disappear or remove exist-

ing scars; it is likely that you will still have some scarring, unless you have a treatment aimed specifically at reducing your scars—such as a surgical procedure.

## V. Individualized Treatment Plan

Treatment responses can vary from person to person, meaning that a treatment that helps someone else may not help you to the same degree. Once you begin a treatment, following up regularly with your healthcare provider can help you determine whether a treatment is working well for you. Depending on how your body responds, your healthcare provider may change your medication or add new ones. It is common for patients to use a combination of treatments. HS is a chronic condition that requires long-term care. Visiting your healthcare provider regularly to track your condition and determine what treatments work for you can keep painful flares at bay and prevent permanent damage to your skin.

## VI. Questions and Answers

### Question 1

**How will I know if a treatment is working?**

#### Answer

If a treatment is working, you can expect the number of painful lesions to decrease. You can also expect flares to occur less frequently, and with less severity. It can become easier to perform daily activities if they were previously difficult, such as walking or raising your arms. You may also notice that scars from past lesions become softer or return to your original skin color, although this process takes months to years.

### Question 2

**How do healthcare providers know if a treatment is working?**

#### Answer

Healthcare providers often use grading scales to determine if your condition is getting better or worse. The scales may use factors such as: the number and type

of painful lesions, the number of different body areas affected by HS, and the level of pain you feel based on a scale of 0-10 to track changes to your condition. Healthcare providers may also use a grading scale to determine how HS is affecting your daily life, mood, and relationships.

### Question 3

**How long will it take for a treatment to start working?**

#### Answer

This depends on the treatment. If you get an injection of “steroids” into a painful lesion, you can expect pain relief within a few hours to days. If you take a type of injectable medication called a “biologic,” it may take longer, sometimes months, before you notice significant changes to your disease. Often, healthcare providers will suggest giving a biologic at least a three-month trial to see if you have any benefit before deciding to change treatment course. Some patients may have only mild improvement after three months, but can continue to improve. Therefore, it may be recommended that they continue on this medication for a longer period of time before changing therapies. Hormonal treatments (such as spironolactone or some forms of birth control pills) that are used to help reduce menstrual flares of HS may take even longer, sometimes four to six months, before all the benefit is seen.

### Question 3

**What will my skin look like after successful treatment?**

#### Answer

After successful treatment, your HS lesions should first feel less painful and swollen. Patients with HS then notice that their flares do not last as long as before, even if they are having the same number of flares. Or, they will notice their active lesions becoming smaller. Finally, HS

patients will note fewer lesions that are both smaller and less bothersome, and - with the best outcomes - they may have almost no lesions, or almost no flares. In addition, new scar formation should have stopped or dramatically slowed. Over the long term, scars may become softer in texture and darker, or discolored skin may slowly change back to your normal skin color as you continue your treatment. This will take many months and can continue to change for up to two years. Sometimes, the skin texture is permanently changed in areas where you had active HS lesions, and you may be left with skin that looks slightly discolored and is thinner or thicker than areas of unaffected skin.

**Question 5**

**Will my flares stop once I start treatment?**

**Answer**

If your treatment is effective, flares should occur less often. Whether or not flares stop completely will depend on how effective the treatment is for your HS. For most people with HS, continued treatment can improve the intensity and duration of flares significantly, but it is not uncommon to still get one or two flares throughout the year, especially in times of hot weather, stress, or other triggers.

**Question 6**

**Can I stop treatment when my condition gets better?**

**Answer**

It is best to continue treatment until your healthcare provider tells you otherwise. In addition to following your treatment plan, it is important to have a wound care plan and to avoid triggers.

**Question 7**

**Is there a cure for HS?**

**Answer**

Unfortunately, there is still no cure for HS. While you cannot get rid of it, you can help prevent painful lesions from occurring by following treatment plans that you and your healthcare provider have discussed and agreed upon. Healthcare providers are still doing a lot of research on HS, and we hope to have better treatments in the future.

# HOW TO KNOW IF A TREATMENT IS WORKING

## WHAT PATIENTS AND HEALTHCARE PROVIDERS LOOK FOR

	Number of painful lesions decrease
	Number of abscesses, nodules, and tunnels decrease
Flares are less frequent and involve less lesions	Number of affected body areas decrease
Scars become softer and return to your original skin color- this process can take a long time!	Overall pain level decreases
It becomes easier to perform daily activities, such as walking	Quality of life increases

## HS Patient Handbook

# Key Points: Treatment Goals

Continue treatment even if your condition improves.

Some treatments work quickly, while others take longer.

An effective treatment will reduce the number and severity of flares.

See your healthcare provider regularly to keep HS under control.

**HS TREATMENT CAN BE EFFECTIVE WITH THE  
RIGHT MEDICATIONS AND LIFESTYLE CHANGES**

Authors: **Tiffany T. Mayo, Yonesha Cole, Ginette A. Okoye**

## Chapter 13

# Multidisciplinary Care

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- I.** Introduction
- II.** HS Care Team Specialists
- III.** Questions & Answers

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## I. Introduction

Multidisciplinary care is when different types of health care professionals work together as a team to provide coordinated and comprehensive care for a patient. The health care providers who may treat people with HS include dermatologists, wound care specialists, pain management specialists, mental health professionals, surgeons, and nutritionists (Table 13.1). Not every person with HS will need to see different types of health care professionals. This need depends on your disease severity and other medical conditions. Where you live may also determine which types of health care professionals are available in your area.

Table 13.1. *Specialists and Their Roles in HS care*

Specialist	Role in HS care
Dermatologist	Main provider in charge of treating HS
Primary Care Provider	Work together with your dermatologist to treat HS, and keep an eye on your other medical conditions
Surgeon	Treat HS by removing the affected skin if surgery is a good option for your HS
Wound Care	Help take care of HS wounds to improve healing and decrease odor and drainage
Rheumatologist	Help take care of joint pain
Nutritionist	Give advice about food to decrease flares and help with weight loss
Mental Health Professional	Help take care of anxiety, depression, or negative feelings caused by HS

## II. HS Care Team Specialists

**The dermatologist** is the main provider in charge of treating HS. Dermatologists see all conditions

concerning the hair, skin, and nails. There are different types of dermatologists.

General dermatologists may see all conditions, including HS. Their office may be in a teaching hospital or a private doctor's office. Some dermatologists only see patients for surgery or cosmetic treatment, so you should check the dermatologist's website or call their office to find out if the dermatologist is a general dermatologist.

Dermatologists treat HS in different ways based on how severe your HS is and the part(s) of the body affected by HS. They may prescribe medications and tell you ways to have fewer HS flares. They may also inject painful boils with a steroid medication, or perform laser treatments and surgeries to areas that are not getting better with other medications. If needed, dermatologists will also help plan care with other healthcare professionals, such as plastic surgeons, nutritionists, and pain management health care providers.

**A primary care provider (PCP)** is a healthcare professional who treats common medical conditions. Every person should have a PCP. Your PCP may be a family medicine doctor, internal medicine doctor, nurse practitioner, or physician assistant. PCPs may be the first providers to diagnose a person with HS and work together with dermatologists to treat the disease. Your PCP can help check for other medical conditions that are associated with HS, such as diabetes and high blood pressure, and manage these conditions if they are present. Additionally, your PCP may also play an important role in setting up care with other providers.

**Dermatologic surgeons, plastic surgeons, and general surgeons** are different types of surgeons that may treat HS by removing skin affected by HS. Finding a surgeon who feels comfortable treating HS is important. If surgery is potentially a good option for your HS, you can meet with a surgeon to have your HS examined and to formulate a surgical plan. After the discussion with your surgeon, you can decide if you would like to move forward and schedule a surgery. If you opt to have surgery, a follow-up visit (called a postoperative or post-op visit) will also be scheduled to make sure the surgical site is healing well. After seeing the surgeon, you should continue following up with your dermatologist.

**Wound care teams** involve doctors and nurses who take care of hard-to-heal wounds. They may recommend special bandages to improve healing that help decrease odor, drainage, and pain. When wound care centers are far away or are not covered by insurance, your dermatologist may help with wound care. Please see Chapter 15 for further information on wound care.

**Rheumatologists**, doctors that take care of joints, can also be part of the care team for a patient with HS who experiences joint pain in addition to skin lesions. Let your health care professional know if you have joint pain, and they can help make an appointment with a rheumatologist to ensure your joints are examined and treated.

**Mental health professionals** can help people deal with the stress of living with HS. Feelings of worry, anxiety, or depression are mental health conditions suffered by many people with HS. These feelings can affect health and quality of life, and can be treated with the help of mental health professionals, such as psychiatrists, psychologists, therapists, and counselors.

**A nutritionist** teaches patients about different types of foods, and how they can improve overall health through diet. Some people with HS notice that some foods worsen their HS. A nutritionist may help you find foods that do not worsen your HS. If you know which foods improve your HS, a nutritionist can provide advice and recommend similar foods. Nutritionists may also help with weight loss if needed, and this can be helpful for some people with HS.

**Pain management providers** help to manage chronic pain, which is pain due to long-term conditions. Primary care providers, dermatologists, and other healthcare providers may help to manage pain during short flares, but ongoing pain may require a pain management specialist to help safely combine different medications and pain relief methods.

### III. Questions & Answers

#### Question 1

**Which healthcare providers should help care for my HS?**

#### Answer

Dermatologists, primary care providers,

and surgeons often work together to treat HS. Other specialists that may take care of people with HS are rheumatologists, mental health professionals, wound care specialists, nutritionists, and pain management providers.

#### Question 2

**Who should be my main HS care provider?**

#### Answer

A board-certified dermatologist should be your main HS care provider. They can help get other types of health care professionals on your treatment team, if needed.

#### Question 3

**Will insurance cover my HS medications and treatments?**

#### Answer

Most insurances cover treatment for HS but every insurance plan is different. Your provider's office will usually take care of finding out if medications and procedures are covered, but you can also find out. You can call the Member Services number listed on your insurance card. The representative should be able to answer your questions about insurance coverage, including which providers, procedures, and medications are covered under your plan. All medical conditions have a special code to identify it for insurances; this is called the ICD-10 code. Procedures also have an identifying code called a CPT code. Below is a list of codes you may be asked for when speaking to someone about insurance coverage.

The ICD-10 diagnosis code for Hidradenitis Suppurativa is L73.2

Common Procedure codes:

- Intralesional injection (steroid injection to inflamed boils): 11900 or 11901
- Incision and drainage (cutting open and draining of boils): 10060 or 10061
- Laser hair removal: 17999
- HS surgery for the underarms: 11450

- HS surgery for the groin: 11462
- HS surgery for the buttocks: 11470
- Nutrition services: 97802 and 97803

Example questions that you may ask:

- Are intralesional injections (code 11900 or 11901) covered for hidradenitis suppurativa (code L73.2)?
- Is \_\_\_\_\_ (name of the medication that you and your provider are interested in trying) \_\_\_\_\_ covered for hidradenitis suppurativa (code L73.2)?

#### **Question 4**

**Are there resources to find healthcare providers who specialize in HS?**

#### **Answer**

To find a provider that specializes in HS, you may contact a local dermatology office to see if they treat patients with HS. If they do not, ask if they can provide a recommendation for someone who does. You may also check the internet for more information. The Hidradenitis Suppurativa Foundation website has a list of HS specialists in the United States (<https://www.hs-foundation.org/hs-specialty-clinics>). There are also online HS support groups that can provide information such as personal experiences that other people with HS have had with dermatologists.

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## Chapter 14

# Lifestyle Changes and Complementary and Alternative Medicines

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- I.** Introduction
- II.** Lifestyle Changes
- III.** Complementary and Alternative Medicine
- IV.** Questions and Answers

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## I. Introduction

Making lifestyle changes and adding complementary and alternative medicines (CAM) to your treatment plan can improve your HS by working together with your HS medicines. This chapter reviews common lifestyle changes that can help your HS, such as exercise, weight loss, clothing choices, stress reduction, quitting smoking, and CAM.

Table 14.1. *Foods That Might Help Improve HS*

Whole grains	Brown or wild rice, barley, buckwheat, bulgur, millet, oatmeal, quinoa; 100% whole wheat-based carbohydrates such as bread, crackers, pasta, tortillas
Vegetables	Arugula, beets, broccoli, brussels sprouts, cabbage, carrots, celery, chicory, collard greens, cucumbers, fennel, kale, leeks, lettuce, onions, peas, pumpkin, radishes, scallions, shallots, spinach, sweet potatoes, zucchini
Fruits	Apricots, apples, avocado, cherries, clementines, dates, figs, grapefruit, grapes, lemons, melons, nectarines, olives, oranges, peaches, pears, pomegranates, strawberries, tangerines
Protein	<p><b>Meats</b> White meat chicken and turkey, fish (such as salmon), eggs</p> <p><b>Legumes</b> Beans: black, fava, chickpeas, red or white kidney Lentils: brown, green, red</p>
Fats	Olive oil, canola oil, almonds, hazelnuts, pine nuts, pistachios, walnuts, chia seeds, flax seeds

## II. Lifestyle Changes

**Nutrition and Diet.** Changing what you eat can help with weight management and your HS symptoms. Nutrition can affect your HS symptoms because foods can increase or decrease inflammatory cytokines in your body. Cytokines are small proteins in our body that help cells in our immune system communicate. Current research suggests that the best diet for patients with HS is the Mediterranean diet. Examples of foods included in this diet are shown in [Table 14.1](#). Several research studies have shown that patients with HS following the Mediterranean diet experienced a decrease in the severity of their HS symptoms. In one study, they compared two groups of people eating the same number of calories. One group ate mostly unprocessed foods included in the Mediterranean diet, and the other group ate more processed foods. Although both groups were consuming the same amount of calories, the group eating more unprocessed foods had significant improvements in HS symptoms.

Similarly, foods containing dairy, Brewer's yeast, and simple carbohydrates can worsen HS by increasing inflammatory cytokines in the body. Studies have found that patients experienced significant improvement in their symptoms with the elimination of these foods. Examples of these foods are outlined in [Table 14.2](#).

Table 14.2. *Foods That Might Worsen HS*

Dairy	Milk, yogurt, cheese, cottage cheese, creamer
Brewer's yeast	Baked products, vinegar, soy sauce, beer, wine, fermented cheeses, mushrooms
Simple carbohydrates	White rice, white pasta, white bread products, juice, soda, candy

Highly-processed carbohydrates – or simple carbohydrates – are easy for the body to digest. As a result, they spike your blood sugar very quickly, which is pro-inflammatory. Complex carbohydrates are mainly unprocessed carbohydrates that contain more fiber and take

Table 14.3. Healthy Food Swaps

Instead of...	Choose this instead...
White rice, white bread, white pasta	Brown rice, 100% whole wheat bread and pasta products
Canned vegetables (with added salt and sugar)	Fresh, frozen, or canned vegetables with no added salt and sugar
Potato chips	Rice cakes
Sweet desserts	Fresh fruit
Soda or juice	Sparkling water
Sugar	Stevia

longer to digest, which help to stabilize your blood sugar levels. Simple carbohydrates are more often found in highly-processed foods because they taste good. Limiting processed foods is a key component of the recommended Mediterranean diet. Processed foods usually come in a package, and the ingredients will have many taste-enhancing ingredients and preservatives. Although it is hard to completely cut out some of these foods, limiting them can also help. [Table 14.3](#) below lists some healthy food swap ideas to help with lifestyle changes.

While incorporating healthier foods into your diet, to make foods taste better you can season with different spices and herbs which add great flavor and taste without adding extra fat or calories. Small swaps to ingredients in regular dishes can help make your food that much healthier. For example, if you are used to eating a lot of white rice or white bread, you can swap for whole wheat rice and bread, instead of eliminating those foods completely.

The fields of nutrigenetics and nutrigenomics study how our bodies respond to nutrients and how nutrients affect our bodies based on our unique genetics. This means that the diet that works for one person might have different effects on another. To find your ideal diet, you may have to work with your healthcare providers or nutritionist and try different foods.

**The best way to make long term nutritional modifications is through small changes that will help you sustain your lifestyle long term.**

These changes may seem very hard at first, but over time, as you develop new recipes and routines for healthy eating, it will become easier.

**Exercise.** Exercise is very helpful for HS because it can help you lose weight if needed, boost your mood, and improve your overall health. However, exercising can be hard for patients with HS because the friction of common exercise methods can worsen HS symptoms. Try activities that are low intensity and low impact to decrease over-sweating and overheating. Exercising in a cool environment can help with keeping you cool. Swimming, yoga, and Pilates are some of the best exercise methods for HS. After your exercise session, take a short lukewarm shower to wash off any sweat.

**Weight Management.** Many studies have found that excess weight can contribute to increased HS symptoms. Extra fatty tissue can cause your body to produce increased hormones or cytokines that worsen inflammation and HS symptoms. Losing weight decreases the amount of fat cells, also known as adipocytes, which leads to fewer hormones, cytokines, and overall less inflammation in the body. Weight loss can also help decrease the amount of skin that rubs together in skin fold areas where HS is common, like the armpits, under the breast, and groin.

One common myth about HS is that weight loss will “cure” HS. However, this is not true. Weight management can be used with other lifestyle modifications and medications to help control symptoms and flares. Several studies following people with HS who have lost a significant amount of weight showed improvement in their HS symptoms. Diet and exercise are the recommended ways to lose weight. The ideal way to lose weight is through small healthy changes that can help you maintain your weight loss long term. This can take many months to several years. Your doctor may be able to recommend nutritional and weight loss programs often covered by insurance.

If you have previously tried diet and exercise to lose weight for a long time and it has not worked for you, you may be eligible for weight loss surgery.

Currently, medical guidelines recommend considering weight loss surgery for people who have a body mass index (BMI) over 40, those who have a BMI over 35 with other health concerns, or those who have previously tried diet and exercise without results. There are many different types of weight loss surgeries. Some examples are gastric banding, sleeve gastrectomy, and gastric bypass surgery. Ask your main healthcare provider if this is an option for you, and they can refer you to a weight loss surgeon who specializes in these surgeries.

### Clothing Choices.

**HS can be triggered by friction between skin folds or between skin and clothing.**

Therefore, it is important to pick your clothing - particularly undergarments - very carefully and take into consideration clothing material and clothing fit. **Table 14.4** provides a summary of recommended undergarment styles and fabrics for clothing.

**Table 14.4. Recommended Clothing Choices for People with HS**

<b>Underwear</b>	<p><b>Women:</b></p> <ul style="list-style-type: none"> <li>• Seamless or laser-cut underwear</li> <li>• Boy shorts, briefs, high-cut briefs, and cheeky underwear styles</li> <li>• Abdominal liners for underbelly</li> </ul> <p><b>Men:</b></p> <ul style="list-style-type: none"> <li>• Loose boxers or trunks</li> <li>• Avoid tight-fitting briefs</li> </ul>
<b>Bras</b>	<ul style="list-style-type: none"> <li>• Sports bras</li> <li>• Camisole tanks with built-in wireless bras</li> <li>• Bra liners and breast pads</li> </ul>
<b>Clothing fabric</b>	<ul style="list-style-type: none"> <li>• Rayon cellulose-based (Lyocell such as Tencel)</li> <li>• 100% cotton</li> <li>• Bamboo-based</li> </ul>

Wearing light and breathable clothing can help control your body heat and sweating. This can be important since sweat is commonly reported

as a trigger for HS flares. Clothing made with nonabsorbable fabrics can worsen HS because of increased heat and sweating. Fabrics like nylon and wool might irritate your skin so should be avoided. On the other hand, clothing made with cotton are typically soft and comfortable. Some other fabrics that may be comfortable for people with HS include moisture-wicking fabrics, such as Lyocell or bamboo-fiber. Though often more costly compared to cotton, these moisture-wicking fabrics provide the added benefit of even greater temperature control and absorbency.

Especially during flares, it can help to wear loose, comfortable clothing that will not rub against your skin. When selecting undergarments, keep in mind that the groin and buttock areas are especially prone to developing lesions and wounds in many people with HS. It can help to choose undergarments without underwires and without tight elastic bands, and to avoid wearing very tight clothes over areas where HS flares occur. Cotton bra or tummy liners can help wick away sweat and prevent clothes from rubbing and further irritating HS lesions in those areas. They can also help absorb drainage.

For women with HS, it can be helpful to avoid bras that contain underwire and bras with tight, thin linings. If this is difficult, consider using padding (for example, in the form of bra liners discussed above) to help minimize the pressure and stress on your skin. When possible, consider wearing sports bras or camisole tanks that can provide support without being too tight or chafing your skin. For underwear, women can consider wearing styles like boy shorts, briefs, high-cut briefs, and “cheeky” underwear.

Men with HS should consider avoiding tight briefs and instead wear loose boxers or trunks.

**Smoking.** Smoking cigarettes/cigars, vaping, or using other tobacco products may worsen HS. When inhaled, the ingredients in tobacco products can increase inflammatory cytokines in your body that worsen HS and can also plug the hair follicles. Several studies have shown that smoking rates are higher among people with HS. Patients with HS that smoke cigarettes are encouraged to quit smoking. It can be helpful to speak to your healthcare provider to discuss medications that can help you quit smoking, and for referral to a

smoking cessation program for support.

**Decreasing Stress.** Many patients with HS experience stress and mental health conditions like depression and anxiety. This can be due to many things, such as the physical and social impact that HS lesions have on people. There is also evidence that shows inflammatory cytokines involved in HS can have a direct impact on the brain, causing depression. Studies have shown that patients with HS are more likely to have mental health conditions compared to the general population. Fortunately, there are resources to support patients with HS to reduce stress.

**If you feel that your HS is affecting your mental health, you should ask your doctor about going to see a mental health counselor or psychiatrist.**

There are also support groups specifically for HS that can help you connect with other HS patients, or those offering helpful HS resources.

### III. Complementary and Alternative Medicine

**Supplements.** Supplements can be used in addition to the medication that your healthcare provider prescribes for your HS. Speak to your healthcare provider before starting any supplements to make sure it is okay with your current medical regimen. Supplements that have been found to be helpful for patients with HS include vitamin D, niacinamide/nicotinamide (vitamin B3), vitamin B12, zinc, and magnesium.

Studies have shown patients with HS who had a vitamin D deficiency experienced a decrease in their HS symptoms when they treated the vitamin D deficiency. For the average person, 1,500 to 2,000 International Units of daily vitamin D is recommended through diet and supplements to maintain healthy levels. If you are found to have a deficiency, you may temporarily require a higher dose which has to be prescribed by your healthcare provider.

When Vitamin B12 is low in the body, inflammatory markers that contribute to HS symptoms can increase. Therefore, it is important for patients with HS to maintain normal levels of vitamin B12. In a study where patients with HS were given high doses of vitamin B12, patients reported

a decrease in HS flares. The dosage of vitamin B12 used in this study was 1,000 micrograms.

Zinc and niacinamide/nicotinamide (vitamin B3) have been shown to help patients with HS by decreasing inflammatory cytokines. In a study where patients with HS received zinc gluconate and niacinamide supplementation, patients had a significant decrease in HS flares. The study supplemented patients with 30 milligrams (mg) of niacinamide. The recommended dose of zinc is 100 mg daily. When taking zinc supplements, it is important that you also take copper supplements at the same time. This is because zinc in high amounts can block your body from absorbing copper, which is necessary for your body to function. When taking 100 mg of zinc, you should also take 10 mg of copper.

Magnesium has been shown to help patients with HS by decreasing inflammatory cytokines, decreasing pain, and improving metabolic profile which is the way your body responds to sugars and fats that you eat. There is currently no recommended dose of magnesium for treatment of HS, but you should take no more than 350 mg daily.

*Please consult with your healthcare provider before starting any supplements to discuss recommended dosing and any potential safety issues.*

#### Bathing Regimens

##### Bath Instructions

Diluted Bleach bath	Add $\frac{1}{4}$ - $\frac{1}{2}$ cup of 5% household bleach to a standard-sized bathtub filled with lukewarm water. Soak in the tub for about 10 minutes. Limit diluted bleach baths to no more than twice a week. Do not submerge your head under the water, and be very careful to avoid getting diluted bleach into the eyes. Rinse off with fresh water and apply moisturizer after drying.
Magnesium sulfate bath	Use 2 cups of Epsom salt for a standard-size bathtub filled with warm water. Pour the salt into running water to help it dissolve faster into the bath. Soak in the tub for about 10 minutes. Rinse off with fresh water and apply moisturizer after drying.

Bleach and magnesium sulfate baths can be used to relieve pain and itching caused by HS lesions. They are thought to work by decreasing inflammatory cytokines and blocking the pain pathway from the skin to the brain. Baths are helpful because they can cover your whole body if you have widespread lesions. The table below describes how to prepare both types of baths.

**Acupuncture/Acupressure.** Acupuncture is a traditional Chinese therapy in which very thin needles are placed onto your skin at different points of your body to reduce pain. Battlefield acupuncture focuses on points on the ear, and is a technique that was developed to help war veterans with chronic pain. Acupressure uses pressure instead of needles to achieve the same effect. There are ongoing studies to look at the benefits of acupuncture for patients with HS. Acupuncture/acupressure can be used along with your other medicines to decrease pain.

## IV. Questions and Answers

### Question 1

**I have been trying lifestyle modifications and none of them seem to help me, what should I do?**

#### Answer

Lifestyle modifications and CAM often take longer to work, compared to prescription medications. Although the results from your changes are more gradual, you should continue to work on these changes because they will help you in the long run and work together with your medications to improve your HS symptoms over time. Lifestyle changes and CAM should not replace your medications prescribed by your doctor but should be used in conjunction to achieve the best results.

### Question 2

**Should my doctor check my blood levels before and during treatment with a supplement to prove deficiency and avoid overdose?**

#### Answer

This depends on what blood level your physician is checking and what current medical guidelines recommend. For many of the vitamins that we mentioned, although blood tests will show that you have normal levels, the actual functional status can be low. This means that the lab result can show up as normal, but the amount in your body is not enough to produce the beneficial results to help your HS symptoms. For this reason, regardless of lab test results, you can discuss taking supplements with your healthcare provider for their anti-inflammatory effects.

### Question 3

**I lost weight and my HS got worse, why?**

#### Answer

One possible reason for this could be that, during the first stages of weight loss, excess skin creates more friction between skin folds, which in turn can increase HS symptoms. As time passes and your skin naturally tightens, HS symptoms should improve. If you have been struggling with this for a long time, your healthcare provider may be able to discuss surgical options to help with loose skin.

### Question 4

**What resources are there to help me lose weight?**

#### Answer

Nutritionists/dieticians and personal exercise trainers can help you with your diet and exercise goals for weight loss. Most of the time, nutritionist visits can be covered by your insurance. Your healthcare provider may have recommendations for nutritionists that have helped previous patients with HS with weight loss. If you have been struggling with losing weight for a long time, you can ask your healthcare provider if you are a candidate for weight loss surgery. ►

**Question 5**

**Eating healthy is too expensive, what can I do?**

**Answer**

Eating healthy can seem like it's more expensive. However, there are ways to reduce costs of nutritious foods to fit healthy eating into your budget. For fruits and vegetables, frozen options are often cheaper and have the same nutritional value. Frozen options can also last in your freezer for a long time to help reduce food waste. Buying food in bulk/wholesale portions, although more expensive upfront, can reduce the cost of each portion overall. Finding local farmers markets or bulk food grocery stores can help you buy fresh produce and proteins at a more affordable cost.

**Question 6**

**My stomach gets upset with zinc and copper, what can I do?**

**Answer**

Upset stomach is a common side effect of taking zinc and copper. One way to reduce this is to take your zinc and copper supplements at the same time as a meal. If you take other medications including antibiotics or other prescriptions that can potentially upset your stomach, plan to take your zinc and copper supplements at a different time from those other medications.

Figure 14.1. *Lifestyle Modifications*

# LIFESTYLE MODIFICATIONS



## NUTRITION

The Mediterranean diet is the best diet for HS. Try to limit foods with simple carbohydrates, dairy, and brewer's yeast.



## EXERCISE

Exercise can help you lose weight. The best exercises for HS patients are swimming, yoga, and Pilates for minimal friction between skin folds.



## WEIGHT LOSS

Losing weight, if indicated, can improve your HS symptoms. The best way is through diet and exercise with the help of nutritionists and personal trainers if available.



## CLOTHING

Choose undergarments without wires or tight elastic bands. Fabrics should contain rayon cellulose-based fabrics, cotton, and bamboo-based fabrics.



## QUITTING SMOKING

Smoking cigarettes is associated with HS and is not good for your overall health. Speak to your healthcare provider for support in quitting smoking.



## RELAXATION

HS can impact mental health. Speak to your healthcare provider for options on counseling and support groups.

Authors: **Divya Chopra, Neil Seth, Hadar Lev-Tov**

## Chapter 15

# Skin and Wound Care

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- I.** Introduction
- II.** Hygiene and Antiperspirant
- III.** Shaving and Hair Removal
- IV.** Clothing
- V.** Dressings
- VI.** Questions & Answers

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## I. Introduction

HS is a chronic skin disease that causes painful boils and tunnels that can drain a lot of fluid from the body called exudate. The boils and tunnels can also sometimes break down and appear as open wounds in the skin that take a long time to heal. Due to these wounds, many people with HS have trouble with everyday activities, such as sitting down or walking.

While treating this condition and the associated wounds can often be difficult, people with HS should stay informed about their condition and work alongside their healthcare provider to develop a proper treatment plan. This chapter provides information about the basics of caring for HS-related drainage and wounds.

## II. Hygiene and Antiperspirant

**HS is not a result of poor hygiene. However, once HS is already active, maintaining basic hygiene of problem areas is important in order to help reduce infections and flares.**

Having some bacteria on the body is normal, but too much bacteria (or maybe too many of certain types of bacteria) may lead to increased pain and odor and may also cause inflammation that slows down the healing process. Gentle application of saline or clean water onto the wound is a great first step that can help to slow down bacterial growth.

Antibacterial washes are often used by healthcare providers to help prevent the wound from getting infected or irritated. Diluted bleach baths and over the counter washes containing antiseptic ingredients, like benzoyl peroxide or chlorhexidine, are other common options. Lastly, prescription creams containing antibiotics like clindamycin can be used alongside the washes to help maintain proper wound care. Please see [Chapter 16](#) for more information on topical medications and washes.

Since the underarms are commonly affected by HS, choosing a proper deodorant is of particular importance for people with HS. There is no specific deodorant that is best for HS. When choosing products, it is useful to check if they contain harsh chemicals like aluminum or fragrance because

these ingredients can aggravate the skin and make it more difficult to manage wounds. However, there is no specific recommendation regarding the type of deodorant delivery method. Stick, spray, wipe, or gel — use the product that is most comfortable for you. Though keep in mind that it is important to avoid applying these products directly to open wounds.

## III. Shaving and Hair Removal

The blockage of hair follicles plays a role in the development of HS. Proper choice of hair removal methods is important because certain methods can aggravate your HS while other techniques can help. Waxing and shaving are common and inexpensive methods of hair removal. However, these practices are discouraged for people with HS because they may aggravate the condition. Remember to use caution if shaving or waxing, and try to avoid shaving during a flare-up.

On the other hand, laser hair removal can remove hair for good and often improves HS symptoms. Laser hair removal uses high intensity light to selectively destroy hair follicles, and therefore addresses a root cause of the disease. This option is more expensive upfront, and may irritate the skin in advanced disease stages. Benefits of laser hair removal include: providing the longest lasting effects, improving quality of life, and preventing future development of HS boils and tunnels, and therefore wounds. You can also ask your healthcare provider to submit a prior authorization request to your insurance for laser hair removal for HS to see if insurance coverage may be possible.

## IV. Clothing

Information on clothing recommendations can be found in [Chapter 14](#).

## V. Dressings

Choosing wound dressings is best done together with your healthcare provider. If wounds are severe, it is best to consult a wound care expert. There is no single dressing that is perfect for all HS lesions, and your lesion and wound care needs may change over time. However, some helpful

suggestions and considerations are discussed here.

HS boils, tunnels, and wounds are often painful, have a lot of drainage, and are associated with a foul odor. Choice of dressings should be made with these factors in mind:

1. Colonization: All HS lesions have some bacteria present and it is important to keep those bacteria in balance.
2. Odor: Is there odor?
3. Pain: Is the lesion painful?
4. Exudate: How much exudate (drainage) is expressed?

The authors of this chapter like the acronym COPE (colonization, odor, pain, exudate) to help remind us of these four important considerations for wound care choices. You can discuss the following with your healthcare provider. For colonization, antimicrobial dressings that contain materials like silver, honey, copper, or dialkylcarbamoyl chloride (DACC) are sometimes used to decrease bacteria on the wound. By using materials that help prevent the buildup of bacteria, there is usually less pain, odor, and drainage from the wound. For wounds with odor, dressings containing silver and salt may help decrease the smell. For pain, dressings made

of hydrated gels can soothe and cool the skin, and non-adherent dressings can protect the wound from trauma. Lastly, foam dressings, abdominal pads, and dressings made of absorbent materials like calcium alginate or gelling fibers can be used to manage wounds with exudate.

While many dressings are expensive and difficult to obtain, there are still affordable and accessible options. Most insurances will cover some wound care products and it is important to discuss with your wound care expert what can be ordered for you. Fortunately, many household items and products at convenience stores can also function as dressings for HS wounds. Gauze, menstrual pads, and abdominal pads are commonly sold at most local pharmacies. These products can be adjusted to appropriately fit the contours of the body. Additionally, using cloth tape that is easy on the skin is helpful.

For more advanced wounds, higher quality dressings are strongly recommended. Remember to take note of which dressings work and which do not work for your wounds so you know the best ones to order.

Here is a list of common dressings used for HS:

Dressing	Pros	Cons
Gauze, Menstrual Pads, Diapers	Easy to find, cheap, absorbent	Less comfortable, can be bulky
Nonadherent dressings (Abdominal pads, Telfa)	Absorbent, gentle on wounds	Bulky, more expensive
Hydrofiber dressings	Very absorbent, easier to use	Harder to get, more expensive
Calcium alginate dressings	Very absorbent, easier to use, can help with bleeding	Breaks down easily into small pieces that can stick to the wound and/or tunnels - may cause painful dressing changes
Foam dressings	Soft, generally non-adhesive, easier to fit in folds of skin, comfortable, very absorbent	Harder to get, more expensive

## VI. Questions & Answers

### **Question 1**

#### **What dressing is best for my wounds?**

##### **Answer**

Your choice of dressing should be individualized to your kind of wounds. When choosing a dressing together with your healthcare provider, consider the COPE principles discussed above.

### **Question 2**

#### **How can I find affordable wound care supplies?**

##### **Answer**

You can use items you can find at a drug store or around the house like menstrual pads, adult or infant diapers, and more. These items are available in bulk for a discounted price in many stores, and are effective. For more advanced dressings, work with your insurance to see if they will cover some of the expenses. Your

insurance may cover some wound care products, so ask your healthcare provider. These dressings can also be found through online stores in bulk at a cheaper price. For further information on managing HS on a budget, please see Chapter 10.

### **Question 3**

#### **What skin care routine is good for HS?**

##### **Answer**

When choosing a skin care routine, begin by eliminating harsh chemicals and fragrances from your products. Consider using lightweight moisturizers and other products that will not block the hair follicle. Use of an antiseptic cleanser on a regular basis is important to help keep your wounds clean and decrease the likelihood of developing new lesions. Remember to avoid shaving or waxing, especially during flares of your HS.

Authors: **Steven Daveluy**

# Chapter 16

# Topical Medications and Washes

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- I. Introduction
- II. Topical Antibiotics
- III. Topical Antiseptics
- IV. Topical Keratolytics
- V. Bathing Regimens
- VI. Complementary and Alternative Topical Treatments
- VII. Questions and Answers

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## I. Introduction

Topical medications, or topicals, are medicines applied to the skin. They come in creams, washes, ointments, gels, foams, sprays, and others. Topicals are often used to treat skin diseases since they are easy to use and relatively safe, though all topical medications have the potential to cause skin irritation or allergic reactions in some people.

**Topicals are often prescribed for patients with mild HS. For patients with moderate to severe HS, topicals are typically recommended in combination with other treatments, such as oral or injectable medications.**

There are five kinds of topical medications used to treat HS symptoms: antibiotics, antiseptics, keratolytics, bathing regimens, and complementary and alternative treatments.

## II. Topical Antibiotics

There are bacteria, or germs, living on our skin and in our hair follicles all the time. Some bacteria do not cause any problems for us, while others can cause disease. Even though HS is not an infection, bacteria can play a role in the disease. Antibiotics are medications that kill bacteria by preventing the bacteria from doing specific activities. For example, antibiotics can damage the protective casing of bacteria, prevent the formation of the protective casing, or prevent bacteria from dividing and spreading. Each antibiotic works on certain types of bacteria. Antibiotics can also help in other ways, such as by reducing inflammation. Bacteria can find ways to survive antibiotics, called antibiotic resistance, if the antibiotic is used alone for a long time. To avoid this problem, antibiotics can be used for less than twelve weeks, or they can be combined with antiseptics, like benzoyl peroxide wash. Topical antibiotics alone are only helpful for very mild cases of HS. Most people need additional treatments.

**Topical Clindamycin.** Topical clindamycin has been proven to treat HS in more than one study. For patients with mild HS, topical clindamycin can work similarly to the oral antibiotic tetracycline. It works well to treat HS bumps near the surface of the skin, but does not work as well for tunnels, ab-

scusses, or nodules that are deeper in the skin and seen in patients with more severe disease. Topical clindamycin comes as a lotion or liquid solution. It is usually applied twice a day to the areas of the skin affected by HS and allowed time to soak in.

**Topical Fusidic Acid.** Topical fusidic acid comes as an ointment or cream. The 2% strength ointment helped heal HS lesions in one study when it was used three times a day for four weeks. More studies would help us better understand how useful it can be for patients with HS.

**Topical Dapsone.** Topical dapsone can sometimes help patients with HS, but it has not been well studied. Topical dapsone comes in a 5% and 7.5% gel.

**Topical Gentamicin.** Topical gentamicin has been studied in post-surgery HS patients. It helped the wounds heal and prevented infections, but it did not help prevent HS from coming back in the surgery areas. Topical gentamicin comes as a cream or ointment.

## III. Topical Antiseptics

Like antibiotics, antiseptics also kill bacteria. For example, antiseptics can break the outer coating or protective casing of bacteria, causing the bacteria to die. Bacteria cannot find ways to survive antiseptics, so there is very little risk of bacterial resistance with the use of topical antiseptics. This is why using antiseptics in addition to antibiotics can be helpful. The antiseptics can kill any bacteria that are finding ways to survive the antibiotics.

Antiseptic washes are recommended to nearly all patients treating their HS. They are used to wash the areas affected by HS when bathing. Antiseptic washes work best if they are left on the skin for a few minutes before rinsed off. They do not need to be used on areas of the body not affected by HS. Many antiseptic washes can cause skin dryness, so some people with HS find it helpful to also use a moisturizer.

**Chlorhexidine Wash.** Though there have not been any published studies to prove that chlorhexidine wash helps with HS symptoms, health-care providers and patients with HS have found it beneficial. Chlorhexidine is available over-the-counter. It can cause skin irritation or an allergic rash, but that is rare.

**Topical Benzoyl Peroxide and Wash.** Benzoyl peroxide is available over-the-counter as a wash,

gel, lotion, or cream in strengths from 2.5% to 10%. For patients with HS, the wash is typically the option used. Though it is primarily an antiseptic, benzoyl peroxide also has a keratolytic effect (please see “topical keratolytics” section below).

**Topical Zinc Pyrithione and Wash.** Zinc pyrithione is available over-the-counter as a spray, shampoo, or soap. It can kill yeast that grows on the skin. There are currently no published studies to prove that it can work to treat HS, but some healthcare providers report that it works as well as chlorhexidine.

**Topical Ammonium Bituminosulfate (Ichthammol).** Topical ichthammol is recommended by some experts, especially in Europe. There are no published studies to prove that it works. Ichthammol is available over-the-counter and the strength of topical ichthammol used by some people with HS is the 10% ointment. It can cause skin irritation, stain fabrics, and has a foul odor.

#### IV. Topical Keratolytics

Studies have shown that HS can block the openings where hairs grow out of the skin, called the hair follicles. This traps bacteria and oil in the hair follicle, which leads to the skin changes seen in people with HS. Keratolytics are medications that help the dead skin cells on top of the skin peel off, which helps prevent the blockage of hair follicles.

**Topical Resorcinol.** Resorcinol is only available from specialty compounding pharmacies in the United States. Studies have shown that resorcinol can help decrease pain from HS and make HS lesions heal more quickly, with 80% of abscesses healing within a month. It does not help the scars and tunnels caused by HS though. The strength of topical resorcinol prescribed for people with HS is usually around 15% but can range from 10-30%. It is applied once or twice daily. Potential side effects include skin irritation, peeling, and darkening. It should not be used on open wounds or used by pregnant women.

**Topical Azelaic Acid.** Some healthcare providers find azelaic acid helpful for people with HS, especially children, but there are no published studies on its use. It is available as a gel, cream, or foam that is applied once or twice daily. Topical azelaic acid can cause skin dryness, irritation, allergic rash, and sun sensitivity.

#### V. Bathing Regimens

Bathing regimens can help by reducing inflammation, pain, and itching. While formal studies have not been conducted on bathing regimens, patients with HS have reported benefits from bleach baths and Epsom salt baths. Bleach (sodium hypochlorite) is well-known to kill bacteria on surfaces when used at a high concentration. Studies have shown that bleach baths work not by killing bacteria but instead by reducing skin inflammation, itching, and pain. Epsom salt, also known as magnesium sulfate, can help relieve skin and muscle problems. We think the magnesium and sulfate are absorbed into the skin to relieve pain nerves and relax muscles. Please see [Chapter 14](#) for more details on bathing regimens.

#### VI. Complementary and Alternative Topical Treatments

Complementary and alternative treatments are not standard medicines used to treat disease, and they usually do not have as many, or any, studies to support their benefit. They are often used with traditional medicines, especially for difficult diseases like HS, where traditional medicines often are not enough to bring relief. Examples of complementary and alternative topicals that patients have reported using include topical cannabidiol (CBD) oil and topical turmeric. Keep in mind that these complementary and alternative topical treatments should not be applied directly to open wounds unless directed.

**Topical Cannabidiol.** CBD is a chemical that is found in marijuana and hemp plants. It does not cause people to feel “high,” a different chemical called tetrahydrocannabinol (THC) is responsible for that feeling. CBD oil or cream may help with wound healing and reducing pain when used as a topical. There are no published studies on topical CBD use for patients with HS, but a survey of people with HS found that it is a commonly used complementary treatment and many feel it can be helpful. There is no regulation over the purity or dosage of over-the-counter CBD products as none of them have been FDA-approved.

**Topical Turmeric.** Turmeric is used as a spice in cooking (the active ingredient is called curcumin). It has been used as a medicine in many parts of the

world for hundreds of years. There are no studies to show that turmeric can help treat HS when applied to the skin, but some patients have found it helpful.

## VII. Questions and Answers

### Question 1

#### Are topicals ever helpful for HS?

##### Answer

Yes, topical treatments have been proven to help patients with HS, specifically clindamycin, benzoyl peroxide, and resorcinol. For people with mild HS, topical washes and topical antibiotics may be enough to control their HS. For people with more severe HS, topical washes and topical antibiotics are often included in the treatment plan along with other systemic treatments.

### Question 2

#### Can I use only topicals to treat my HS?

##### Answer

Possibly – it depends on the severity of your HS. If you have mild HS that is well-controlled by topicals, they may be the only treatment you need. However, if you have more severe HS, you most likely need to use topicals in combination with other treatments.

### Question 3

#### Should everyone with HS use topical treatments?

##### Answer

Healthcare providers recommend topical treatments for all HS patients since they can be helpful regardless of disease severity. The most common recommendation is a topical antibiotic (usually clindamycin) with an antiseptic wash (benzoyl peroxide or chlorhexidine). Even if topical medicines only help a little bit for a patient, they can be combined with other treatments for added benefit. Patients using a topical antibiotic should combine it with an antiseptic wash, so the bacteria

cannot find ways to survive the antibiotic (antibiotic resistance).

### Question 4

#### I have so much drainage, it is hard to keep topical medications on my skin. What should I do?

##### Answer

Applying topical medications can be challenging if you have drainage. Keep in mind that some of the medication may be absorbed into the skin and start working before the drainage washes it away. If it is not too painful, you can gently wipe any drainage away and try to dry the skin before applying topical medications so they may have time to work before any drainage starts again. You may also find that washes and baths are good options, since drainage usually does not interfere with them.

### Question 5

#### When my lesions are flaring, it is very painful to apply topical medications. What should I do?

##### Answer

It is okay to take a break from your topicals if applying them causes pain. If certain areas are less painful, you can apply the topicals to those areas and avoid the painful ones. You can also apply topicals lightly to the skin instead of rubbing them in. You may be able to apply thin topicals like liquids and solutions above painful areas and allow them to run onto the painful areas by way of gravity to avoid putting any pressure on the areas.

You can also use this strategy for washes, letting them gently run onto the painful areas. If you have a topical that helps relieve pain, apply that topical first to see if it reduces the pain and makes the application of other topicals more tolerable. Baths may be helpful during painful flares, since they do not require any touch or pressure, just soaking.

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## Chapter 17

# Antibiotics

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- I.** Introduction
- II.** Antibiotics: Role in Treatment of HS
- III.** Choosing an Antibiotic
- IV.** Questions & Answers

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## I. Introduction

As previously described, HS is a chronic skin condition that flares and recedes over time. Although HS is frequently treated with systemic antibiotics, it is important to remember that the main cause of HS is not infection. HS is a long-term condition in which inflammation in the skin has become overactive, but antibiotics have been used with some benefit for decades. Antibiotics can be taken by mouth, injection, or intravenously through an IV.

Occasionally, an infection can develop in HS-affected skin, but antibiotics probably work for other reasons. This may prompt you to ask, if the condition is not thought to be caused by infection, why are antibiotics effective?

**While antibiotics are often used to treat infection because they kill dangerous bacteria, they have other effects that are important in the treatment of HS.**

## II. Antibiotics: Role in Treatment of HS

We all have normal bacteria on our skin, but the mix of bacteria present can be different in people with HS. It is likely that the immune system in people with HS can be triggered by bacteria that are usually considered “normal.” One theory is that antibiotics alter the number and type of skin bacteria in a way that reduces how inflammation is triggered. Another well-observed effect of some antibiotics is that they can be anti-inflammatory. This means that antibiotics can calm down areas of the body that are irritated or inflamed. Since inflammation is increased with HS, the anti-inflammatory effects of antibiotics is likely beneficial. Several commonly used antibiotics for HS treatment and their most notable side effects are listed in [Table 17.1](#), though many other types of antibiotics may be used based on patient and provider preference.

Antibiotics help improve the bothersome symptoms of HS that include drainage, pus, and odor. Pus is an inflammatory substance that the body creates as a reaction to different types of infection, including infections from bacteria (like a “staph” infection, for example). In the case of HS, the body creates pus possibly as a reaction to normal skin bacteria or possibly for other reasons that

are not yet completely clear to researchers at this time. The pus and bacteria that live in the pus may produce odors. Since antibiotics alter the number and type of skin bacteria, the body does not produce as much pus and drainage when antibiotics are taken, which can provide relief for HS patients. Some antibiotics are also thought to directly block inflammation, though the role of antibiotics in reducing inflammation specifically for patients with HS is still unclear.

## III. Choosing an Antibiotic

As outlined in [Table 17.1](#), if a person has mild to moderate HS, a healthcare provider may choose to prescribe one antibiotic or a combination of antibiotics.

**In many cases, the initial antibiotics chosen for a patient may not be effective or may cause side effects, so alternatives might be chosen. As the disease becomes more severe, it is typical to combine two or three oral antibiotics at a time.**

Increasing the number of antibiotics that you take can increase the risk of side effects; however, the benefits may outweigh the risks. Antibiotics may be taken intermittently for flares, or - in some cases - they may be taken for months or years for longer-term control when they work well.

In the most severe cases, IV antibiotics, such as ertapenem, may be given for weeks at a time. Since symptoms tend to recur quickly after the course of treatment ends, it is important to have a long-term treatment plan in place.

Antibiotic side effects should be taken into consideration when a treatment plan is made. If you have a history of any allergic or unpleasant reactions to an antibiotic, be sure to inform your healthcare provider. As with all medications, the benefits of taking antibiotics must be weighed against their side effects. It is hard to predict how individual people will react to different antibiotics. Most antibiotics can cause stomach upset for some people. Other side effects are less common; however, if you have a bad reaction to a medication, it is important to stop taking the medication and let your healthcare provider know.►

Table 17.1. Systemic Antibiotics for HS

Name	HS Severity	Usage	Notable Side Effects
Tetracyclines (e.g., doxycycline, minocycline)	Mild, Moderate	Acute flares, long-term management	Abdominal pain, increased sun sensitivity, not safe in pregnant women
Clindamycin	Mild, Moderate, Severe	May be used on its own or combined with other antibiotics	Diarrhea, nausea, vomiting
Rifampin	Mild, Moderate, Severe	Combination therapy with other antibiotics	Hepatitis, can reduce birth control effectiveness, can turn urine and other bodily fluids orange in color
IV Ertapenem	Severe	12 week course, requires a special IV called a PICC line for home IV infusion	Nausea, vomiting, skin rash, requires regular lab tests
Metronidazole (Flagyl®)	Mild, Moderate, Severe	Combination therapy with rifampin and moxifloxacin	Nausea, vomiting, severe reaction with alcohol use
Cephalosporins (e.g., cephalexin/ Keflex®, cefdinir)	Mild, Moderate	Acute flares, long-term management	Nausea, vomiting, rashes, dizziness
Fluoroquinolones	Moderate, Severe	Combination therapy with rifampin or metronidazole	Tendon inflammation (more common in elderly patients), heart arrhythmias, nausea, vomiting, not safe in children and pregnant women
Trimethoprim-Sulfamethoxazole (i.e., Bactrim®)	Mild, Moderate	Acute flares, long-term management	Nausea, vomiting, severe rash, not safe in pregnant women

It is possible that, in milder cases, your health-care provider might start treatment with a single antibiotic such as doxycycline, then change the type of antibiotic or add others as the condition worsens or as certain antibiotics are shown not to improve the condition. For people with more severe disease, a regimen of two or three antibiotics, or even IV antibiotics, might be started immediately. As the severity is reduced with treatment, some antibiotics with more risks might be stopped or avoided. Sometimes, if one antibiotic stops working, it helps to rotate to different antibiotics over time.

Doxycycline and minocycline are commonly used to treat other skin conditions like acne, and are frequently prescribed to treat people with

mild-to-moderate HS symptoms. Clindamycin and rifampin used in combination are frequently used as well, though some studies show rifampin may reduce how well clindamycin works over time. Common combinations for disease flares that are used for shorter periods of time include antibiotics such as a quinolone (levofloxacin, ciprofloxacin, or moxifloxacin) in addition to metronidazole and rifampin. In very severe cases, an IV antibiotic like ertapenem may be used for 6-12 weeks with home IV infusions. Both short and long-term side effects limit how often some of these antibiotics should be used. Some antibiotics may interact with other medications to make them either less effective or more likely to have side effects; an example is rifampin, which can make oral

contraceptive pills (birth control pills) work less well and lead to pregnancy. Discuss possible medication interactions with your healthcare provider.

There is no specific antibiotic that works best for every person with HS, but in many cases the right antibiotic can play a positive role. Flares generally require shorter courses of antibiotic treatment, whereas more chronic disease may require long-term antibiotic treatment. It may take time to figure out which antibiotics help you the most and do not cause side effects, and sometimes non-antibiotic options end up being a better choice. The benefits and risks of current HS symptoms can be weighed against antibiotic side effects and overall effectiveness when determining the treatment plan. While antibiotics are not curative, they may be an important part of treatment to control your HS.

## IV. Questions and Answers

### Question 1

**Can taking antibiotics create “superbugs”?**

#### Answer

Sometimes. “Superbugs” is a general term used to describe bacteria that have become highly resistant to our available antibiotics in people that have been exposed to many antibiotics. This is more common in patients staying in hospitals. Using one or two antibiotics does not create resistance to all antibiotics, so you are unlikely to develop an infection that could not be treated with a different antibiotic. Make sure to use antibiotics as directed by a physician to help reduce issues of resistance.

### Question 2

**Will HS antibiotic treatment mess up my microbiome?**

#### Answer

Not usually. Microbiome is the collection of all microbes. The bacteria microbiome includes bacteria that naturally live on our bodies and inside us, commonly known as “healthy bacteria.” With HS, the goal of antibiotic treatment is to alter

bacteria on the skin and reduce inflammation. However, antibiotics can also inadvertently target healthy gut bacteria. Most of the time, the change in normal bacteria does not cause problems, and the bacteria normalize once the antibiotic is stopped. Usually, the benefits of treating HS outweigh the potential risks. Furthermore, dermatologists experienced in treating HS can help people with HS by identifying combination therapies that reduce the risk of long-term side effects of antibiotic regimens.

### Question 3

**How long should I take antibiotics for?**

#### Answer

It depends. Short courses of antibiotics may be used on an as-needed basis to treat occasional flares for 1-2 weeks at a time. Often, treatment lasts longer, but there is typically an effort to limit treatment with a specific antibiotic to an 8-12 week period. In some instances, people who achieve very good disease control only while on certain antibiotics may consider taking them for months or years if the benefits seem to outweigh the risks in their particular case. Speak with your healthcare provider to determine the proper treatment length for you.

### Question 4

**Should I take probiotics?**

#### Answer

Some research studies have pointed to certain aspects of the microbiome that are altered in people with HS. These alterations could potentially play a role in contributing to the development of HS. As with other chronic inflammatory skin diseases, probiotics could be a helpful part of the treatment plan for HS; however, more conclusive evidence is needed to understand if they truly help, and - if so - which probiotic strains would be the most optimal.

### Question 5

**Can I get vaginal yeast infections if I take antibiotics?**

#### Answer

Yes. Vaginal yeast infections are possible in women who take antibiotics that target a broad range of bacteria, including healthy bacteria normally found in the vagina. Antibiotics reduce healthy bacteria, which can allow yeast to grow more, causing a yeast infection. Symptoms of a yeast infection include burning (especially with urination), itching, odor, rash, and non-menstrual vaginal discharge (may appear milky white or watery). Oftentimes, vaginal yeast infections occur within 1-2 weeks of starting antibiotics, although they can occur later in an antibiotic treatment course. Talk with your healthcare provider before starting antibiotics if you have a history of vaginal yeast infections. They can often provide medication to reduce this risk or treat the yeast infection if this occurs.

### Question 6

**Some antibiotics upset my stomach. How can I prevent that?**

#### Answer

Taking antibiotics with meals can usually decrease the risk of stomach upset, though certain foods can decrease effectiveness of certain antibiotics. Check the label on your prescription or ask your provider to determine whether your prescribed antibiotic should be taken on an empty stomach or with meals. To reduce the chance of nausea, especially if you are prescribed multiple antibiotics, your provider may have you start one antibiotic, take it for a few days, and then have you start the next antibiotic if you are not experiencing nausea. Sometimes spacing out antibiotics throughout the day (for example, taking them once in the morning and once at night) can also reduce the chance of nausea. Lastly, nausea medicines may be helpful, but if this problem

persists, it is probably time to switch to another antibiotic or different kind of treatment. If diarrhea, nausea, or vomiting persists for more than one week after stopping antibiotics, make sure to discuss this with your doctor.

### Question 7

**Can inflammatory bowel disease impact antibiotic effectiveness?**

#### Answer

Yes. HS is associated with a number of comorbidities (having more than one medical condition in the same person), including inflammatory bowel disease (IBD). Fundamentally, IBD can affect absorption of food, nutrients, and medications as they pass through the gastrointestinal track. This means that, compared to a normal healthy person, a person with IBD may not absorb the same amount of medication. This means that there is potential for antibiotic treatment to be less effective in patients with HS and IBD compared to patients with HS without IBD, though definitive research in this area is lacking.

### Question 8

**Will my HS come back after I finish my antibiotics?**

#### Answer

Very often, HS symptoms improve while on antibiotic treatment and can worsen once the treatment stops. Unfortunately, HS is a long-term condition that improves and worsens periodically over time. While taking antibiotics for a flare may calm things down to an extent, recurrence is common. Long-term treatment with antibiotics is sometimes used to help manage the disease over the long-term, but it is important to remember that antibiotics are not curative.

In most cases, your doctor will not use antibiotics as your only treatment. For many, antibiotics are a short-term solution to a more long-term condition

that requires additional treatments. Most patients with HS take antibiotics in addition to other treatments, which may include taking medications that alter hormones or making diet and lifestyle changes. However, if a patient with HS finds that taking an antibiotic alone is beneficial and they are not experiencing any side effects, the benefits of taking antibiotics alone outweigh the risks (such as antibiotic resistance) that are associated with long-term use.

**Question 9**

**What antibiotics should I avoid if I am pregnant?**

**Answer**

Tetracyclines, fluoroquinolones, and trimethoprim-sulfamethoxazole/Bactrim® are generally avoided during pregnancy. However, clindamycin and cephalosporins are usually considered safe to use for pregnant patients with HS. Please see Table 17.1 for full descriptions of antibiotics and their side effects.

**Question 10**

**What method of antibiotic administration should I avoid if I am pregnant?**

**Answer**

PICC: peripherally inserted central catheter. A PICC line is often placed in a blood vessel on the inner part of your upper arm. The line remains in your arm for the duration of treatment, but is kept covered with sterile bandaging when not in use. A PICC line during pregnancy is associated with risk of infection and blood clots. Thus, it should be avoided unless deemed absolutely necessary and discussed with obstetrician.

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## Chapter 18

# Non-Antibiotic Oral Medications

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- I.** Introduction
- II.** Hormonal Regulators
- III.** Retinoids
- IV.** Non-biologic Immunosuppressants
- V.** Questions and Answers

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## I. Introduction

There is no “one size fits all” treatment for HS so there are a number of medications that dermatologists recommend. This chapter explains non-antibiotic medical approaches to empower you to make informed decisions about your care alongside your healthcare provider. It is possible that one of these treatments, or a combination of treatments, may be helpful for you.

## II. Hormonal Regulators

Hormones are molecules that act as messengers in the body. Androgens are a hormone type that affect growth and reproduction. Androgens can cause skin cells to overgrow and block the hair pore. This can spark early HS stages. Androgens can further trigger hyperactive immune response, worsening HS symptoms.

**Oral Contraceptive Pills.** Oral contraceptive pills (OCPs) contain two sex hormones: estrogen and progesterone. They stop pregnancy by blocking egg maturity. OCPs can help with HS symptoms by decreasing active androgens, lessening hair pore blockage and hyperactive immune response. OCPs may also treat HS by stabilizing hormones. Hormonal changes during menstrual cycles (“periods”) and pregnancy may also affect HS patients. Please see [Chapter 8](#) for more information.

The research on the effect of OCPs on patients with HS is mixed. If you are a patient whose HS symptoms fluctuate with hormonal changes (examples: menstrual cycles, pregnancy), you and your healthcare provider can discuss OCPs as a treatment option.

Recommended dosage of estrogen content for OCPs is less than 50 micrograms per day. It may be combined with other treatment methods, including antibiotics and non-biologic immunosuppressants. Side effects include vaginal bleeding/discharge, nausea, headaches, abdominal cramping, and breast tenderness. Do not take OCPs if you are pregnant, smoke, or if you suffer from high blood pressure, valvular heart disease, or migraines.

**Spironolactone.** Spironolactone has been typically used a diuretic. Diuretics treat heart failure and high blood pressure. However, spironolactone

also has the added benefit of decreasing androgen production as well as androgen effects. It is taken by mouth and recommended dosage starts at 25-50 milligrams (mg) per day (can increase up to 50-200 mg/day) based on response. Spironolactone may be combined with other therapeutics like OCPs.

Female HS patients may benefit from spironolactone therapy. Male patients cannot take spironolactone due to the breast enlargement side effect in men. Other side effects include liver toxicity and electrolyte abnormalities. Do not take spironolactone if you are pregnant, already take certain diuretic medications for high blood pressure or heart failure, have irregular periods, or suffer from Addison’s disease.

**Finasteride.** Finasteride is a 5-alpha reductase inhibitor. 5-alpha reductase converts weak androgens into stronger androgens. This medication type is typically used for patients suffering from benign prostate hyperplasia and male pattern baldness. Strong androgens interact with the skin to produce HS symptoms (hair pore blockage). Finasteride blocks 5-alpha reductase, decreasing the amount of strong androgens in the skin.

Both men and women can take finasteride. It is notably good for those with other hormonal conditions like polycystic ovary syndrome (PCOS), metabolic syndrome, and precocious puberty. Patients with PCOS experience irregular periods, excess facial and body hair, severe acne, and cystic ovaries. Metabolic syndrome is a cluster of conditions that occur together (high blood pressure, high blood sugar, high cholesterol, and excess body fat around the waist). Precocious puberty is when a child’s body goes through puberty too early (before age eight in girls and before age nine in boys).

Finasteride is taken by mouth and the recommended dosage ranges from 2.5-10 mg per day. Side effects include erectile dysfunction and low blood pressure while standing. You should not take finasteride if you are pregnant, breast-feeding, or planning to become pregnant.

## III. Retinoids

Retinoids are vitamin A derivatives that are known to treat acne. Retinoids decrease skin inflammation and hair pore blockage. They also prevent

hyperactive immune responses, which normally incite HS symptoms. They include a variety of medications such as isotretinoin and acitretin.

Besides antibiotics, pain medication, and topical steroids, retinoids are the most prescribed medication for HS. Some studies suggest that isotretinoin is better for milder HS, or for patients with both acne and milder HS. Severe, difficult-to-treat HS may respond well to acitretin. It is taken by mouth and the daily recommended dosage is 0.5-0.6 mg per kilogram (kg) of body weight. Studies suggest therapeutic benefit in combining isotretinoin with other HS treatments, such as antibiotics and surgery. However, more studies are needed.

Common side effects of retinoid medication include skin dryness and eye dryness. Blood work needs to be checked closely, as it can affect liver function as well as increase fat levels in the blood. Retinoids are harmful to fetuses, and should not be taken if you are pregnant or breast-feeding. Women of child-bearing potential are required to either commit to abstaining from sexual intercourse or use two forms of contraception such as condoms and birth control pills.

#### IV. Non-biologic Immunosuppressants

Hyperactive immune response can lead to HS symptoms. Two different medication classes are used to fight this hyperactive immune response: immunomodulators and immunosuppressants. Biologic immunomodulators target specific parts of our immune systems. Immunosuppressants decrease the body's overall immune response. In rare cases, biologic immunomodulators may trigger immediate side effects (examples: allergies, infusion reaction, serum sickness). "Biologic" medications are derived from natural sources.

The rest of this chapter focuses on different non-biologic immunosuppressants. Each immunosuppressant has risks and benefits. Overall, immunosuppressants do decrease immune function, which includes the ability to fight infection. Appropriate use and routine monitoring by your doctor is the key.

**Colchicine.** Colchicine is an immunosuppressant which disrupts the movement and development of immune system cells called neutrophils.

Without colchicine, these cells are part of the hyperactive immune response that assists in HS lesion development. Colchicine may be best for mild-moderate HS.

Colchicine is taken by mouth at a recommended dose of 0.5 milligrams twice per day. Combining colchicine with tetracycline antibiotics (examples: tetracycline, doxycycline, minocycline) may boost HS symptom relief. Potential side effects include nausea and diarrhea. You should not take colchicine if you are pregnant, or suffer from liver or kidney disease.

**Methotrexate.** Methotrexate is an immunosuppressant which inhibits immune cell activity. It is taken on a weekly basis by mouth or injection. Patients may experience stomach upset when taken by mouth. Methotrexate depletes the body's folic acid storages, so patients taking methotrexate must also take folic acid supplements.

Methotrexate is combined with other immunosuppressants to increase effectiveness and prevent treatment tolerance, which is when the medication at your current dose has stopped working as effectively as it once did. Potential side effects include liver toxicity, nausea, and decreased bone marrow activity. You should not take methotrexate if you are pregnant. Methotrexate may slightly increase the risk of developing lymphoma.

**Dapsone.** Dapsone is both an antibiotic and anti-inflammatory agent. It blocks immune cell movement (neutrophil migration). Dapsone may be beneficial for patients with mild-moderate HS. It is taken by mouth at an initial daily dose of 25 mg twice per day (can increase up to 100 mg twice per day). Dapsone has been combined with other HS therapies in small studies, but more research is needed. A major side effect of dapsone therapy is decreased white and red blood cell counts, as well as shortness of breath. For this reason, frequent lab tests and symptom monitoring are required.

**Prednisone.** Prednisone is a steroid medicine used in many health conditions to decrease immune hyperreactivity. It is taken orally at varying doses. Side effects include mood/sleep disturbance and high blood sugar.

It should be noted that long-term treatment with prednisone alone is not recommended, given the side effects of long-term steroid use (osteoporosis, weight gain, skin thinning). However, it may

be helpful as a short-term treatment for HS flares, and can be combined with other treatments.

**Cyclosporine.** Cyclosporine is an immunosuppressant that blocks immune cell development and inflammatory response pathways. While there are a few reports of successful treatment with cyclosporine, more studies are needed. Patients with severe HS may find cyclosporine helpful. It is taken by mouth and the daily recommended dosage range from 1-6 mg/kg. Side effects include enlargement of gums, high blood pressure, and kidney damage. Lab monitoring is required for this reason. Cyclosporine may also increase the risk of developing cancer, especially lymphoma.

## V. Questions and Answers

### **Question 1**

**Why am I asked to take more than one immunosuppressant?**

#### **Answer**

Immunosuppressants work through a variety of mechanisms. Treating HS may require more than one immunosuppressant, so that the hyperactive immune response can be stopped through multiple pathways. Immunosuppressants can sometimes be combined with biologic medications such as adalimumab to maximize one another's effect. Additionally, more than one immunosuppressant can sometimes help the body optimally respond to treatment.

### **Question 2**

**Will other forms of birth control medications work for HS, like injectable progesterone and intrauterine devices (IUDs)?**

#### **Answer**

IUDs and injectable progesterone will not treat HS. Please see Chapter 8 for a more detailed discussion.

### **Question 3**

**Given COVID, how do immunosuppressants affect my vaccination needs?**

#### **Answer**

As recommended by the CDC (Center for Disease Control), individuals taking immunosuppressant medications should get vaccinated for COVID-19. Ask your healthcare provider for exact information on timing of medication and vaccinations.

Table 18.1. Non-Antibiotic Oral Medications

Treatment	Usage	Selective List of Side Effects
Oral Contraceptive Pills (OCPs)	Female patients with HS typically with flares around menses	Nausea Headaches Abdominal cramping Breast tenderness Vaginal discharge
Spironolactone	Female patients with HS	Liver damage Electrolyte changes When taking during pregnancy, a male baby can have female sexual characteristics (should not be taken when pregnant)
Finasteride	Female and male patients with HS. Used as supporting therapy in those with precocious puberty, metabolic syndrome, and/or PCOS	Impotence Blood pressure regulation issues
Retinoid -Isotretinoin	Patients with mild-moderate HS	Birth defects Skin dryness Liver damage
Retinoid -Acitretin	Patients with mild-moderate HS	Blood work abnormalities
Colchicine	Patients with mild-moderate HS	Nausea Diarrhea
Methotrexate	Typically used in patients who are on a biologic	Liver damage Bone marrow suppression Nausea
Dapsone	Patients with mild-moderate HS	Decreased red and white blood cells
Prednisone	Short term for flares or can be used as a bridge-therapy to more long-term treatment	Sleep/mood disturbance Elevated blood sugar
Cyclosporine	Patients with moderate-severe HS who have failed or are unable to take standard therapy	Enlargement of gums Elevated blood pressure Kidney damage

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# Chapter 19

# Biologics and Small Molecule Immunomodulators

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- I.** Introduction
- II.** Tumor Necrosis Factor (TNF) Inhibitors
- III.** Other Biologics
- IV.** Comorbidity Considerations
- V.** Side Effects of Biologics
- VI.** Questions & Answers

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## I. Introduction

Currently, there is growing research on the role of biologic therapies in HS. Biologics are injectable medications that target small molecules in the immune system that cause inflammation. These include tumor-necrosis factor (TNF), interleukin-1 (IL-1), IL-12, IL-23, and IL-17. Biologics bind to these molecules, and prevent them from causing inflammation in the body. This lowers inflammation from HS.

## II. Tumor Necrosis Factor (TNF) Inhibitors

**Anti-tumor necrosis factor (TNF)-alpha inhibitors** bind to TNF-alpha. TNF-alpha plays a role in causing inflammation. This medication blocks its function and decreases inflammation.

Adalimumab is a TNF-alpha inhibitor. It is known by the brand name Humira®. Adalimumab is the only drug federally approved by U.S. Food and Drug Administration (FDA) to treat moderate to severe HS. It can be used in adults and adolescents 12 years or older who weigh more than 30 kg (66 lbs). Adalimumab is self-injected using a syringe or pen injector. Typically, adalimumab dosing is 160 mg at week 0, 80 mg at week 2 and then 40 mg weekly or 80 mg every two weeks starting at week 4. Some people may benefit from a higher dose. Large clinical trials, with a total of more than 800 people with HS, have shown adalimumab to be safe and effective. A recent trial also demonstrated that adalimumab is safe to continue while undergoing surgical excisions for HS: after surgery, there was no increased risk of complications with continued therapy.

Infliximab is a TNF-alpha inhibitor known by the brand name Remicade®. You cannot receive infliximab at home. It is given as an IV (intravenous) infusion in a clinic or hospital. The prescribed dosage is based on weight. This allows physicians to change dosing to get better results. The standard dosage is 5-10 mg/kg at week 0, 2, and 6, then every 4-8 weeks after that. Infliximab is not FDA-approved for HS. However, several small clinical trials and studies suggest infliximab is effective in HS.

Sometimes, the body can make antibodies against biologics. These will bind to the medica-

tion, making it less effective. An immunosuppressant medication, such as methotrexate, may also be taken to try to prevent this antibody formation from happening.

Infliximab can cause infusion reactions, which may happen immediately. Symptoms may include itching, shortness of breath, flushing, and/or headache. Less commonly, more severe reactions can occur. These symptoms may include fever, skin rash, breathing issues, and blood pressure changes.

Mild IV infusion reactions can sometimes be treated by slowing how fast the medication is given through the IV. With severe reactions, the treatment may need to be stopped. Sometimes, medications can be given prior to the infusion to help lower the chance and severity of these reactions. Examples include antihistamines, fever-reducing medications, or steroids. However, more research is needed on how effective these agents are in preventing IV infusion reactions.

Other TNF-alpha inhibitors include etanercept (Enbrel®), golimumab (Simponi®), and certolizumab (Cimzia®). Etanercept is currently not recommended for HS. It did not improve HS symptoms in patients in small trials. Both golimumab and certolizumab were found to improve HS in small studies. Golimumab can be given as an infusion or injection. Certolizumab is given as an injection. Certolizumab does not cross the placenta so it may not affect a developing baby during pregnancy. If you are pregnant or planning for pregnancy, your healthcare provider may bring up this medication as a possible treatment option.

## III. Other Biologics

**Interleukin (IL)-1 Inhibitors.** IL-1 inhibitors bind to and block the function of IL-1, a molecule that promotes inflammation. Canakinumab (Ilaris®) and anakinra (Kineret®) are both IL-1 inhibitors that are given as injections. Canakinumab is dosed at 150 mg every 4-8 weeks. Anakinra is dosed at 100 mg every day. Since anakinra requires daily injections, this may be a barrier for some people. Both medications have been found to be helpful in small, limited studies of people with HS, including some who also have pyoderma gangrenosum (PG). PG is a condition that causes large, painful ulcers on the skin, most often on the

lower legs. More information about other diseases associated with HS can be found in Chapter 6. Your healthcare provider may be more likely to discuss one of these medications with you if you have both HS and PG.

**IL-12/23 Inhibitors.** Guselkumab (Tremfya®), risankizumab (Skyrizi®), and tildrakizumab (Ilumya®) bind to IL-23. Ustekinumab (Stelara®) binds IL-12 and IL-23. These medications block the pro-inflammatory actions of IL-12 and IL-23. They are given as injections every eight (guselkumab) or twelve (risankizumab, tildrakizumab, ustekinumab) weeks for people with psoriasis. Doses for patients with HS may need to be more frequent. Small studies on the use of guselkumab for patients with HS had been promising. However, a recent clinical trial on guselkumab did not meet its treatment efficacy goals. More research is needed on the efficacy of IL-12 and IL-23 biologics for patients with HS.

**IL-17 Inhibitors.** Secukinumab (Cosentyx®), ixekizumab (Taltz®), brodalumab (Siliq®), and bimekizumab (Bimzelx®) bind to IL-17 and block its function in the immune system. These IL-17 inhibitors are typically given as injections every two (brodalumab) or four (secukinumab and ixekizumab) weeks for people with psoriasis, and for people with HS the dosing may need to be more frequent. Studies on the use of IL-17 inhibitors for patients with HS have been promising. In fall 2022, it was shared that two large HS trials for secukinumab showed greater response rates for secukinumab compared to placebo. In winter 2022, we learned that two large HS trials for bimekizumab showed superior response rates for bimekizumab compared to the placebo. Each of these trials had over 500 people with HS enrolled.

**Small Molecule Inhibitors.** Tofacitinib (Xeljanz®) is an immunosuppressant that binds and inhibits Janus kinase (JAK) proteins. Blocking JAK interferes with one of the immune signaling pathways in the body. There are different JAK proteins. Tofacitinib inhibits JAK1, 2, and 3. It has been reported as helpful for a few people with HS who had previously not responded to multiple biologics. Povorcitinib, a JAK1-selective inhibitor, had promising results in an early phase trial that enrolled over 200 people with HS. Two larger trials are planned to further explore how effective and

safe povoricitinib is as a treatment for HS.

Sirolimus is a different medication that blocks mTOR, which is also involved in signaling pathways in the body. Like tofacitinib, sirolimus suppresses the immune system. At this time, sirolimus has only been studied in a few people with HS who were on biologics that were not fully effective at controlling their HS disease. Sirolimus was prescribed to these individuals as an additional treatment, with reported benefits.

More studies are needed to see if these small molecule inhibitor medications are good treatment options for HS and to determine how best to use them.

#### IV. Comorbidity Considerations

Biologics are a treatment option for many different conditions. These include psoriasis, rheumatoid arthritis, and inflammatory bowel disease. Therefore, one biologic treatment may adequately treat multiple conditions in people with HS. Your healthcare provider can help choose the best treatment for you based on your medical history. It is helpful to share your preferences regarding type of treatment, dosing regimen, and lab monitoring schedule with your healthcare provider so you can make treatments decisions together.

#### V. Side Effects of Biologics

**Injection Pain and Reactions.** Injections can be uncomfortable. Insertion of the needle may cause pain. There can also be pain while the medication is being injected. Steps can be taken to reduce injection-related pain (see Q&A section).

Sometimes, a skin reaction may occur at the injection site. This can look like red patches that appear minutes to hours after the treatment. Medications like topical steroid creams, antihistamines, non-steroidal anti-inflammatory drugs (such as Ibuprofen®), or acetaminophen can treat this. Cold packs may help as well. In rare cases, severe pain or swelling may occur at the injection site. If you have an injection site reaction, you should let your healthcare provider know.

**Infection Risk.** Because biologics modulate the immune system, you may have a higher risk of getting infections while you are on a biologic. Sometimes, a biologic therapy can reactivate infections

that are present but not active in your body. These infections include Hepatitis B and tuberculosis. It is important to screen for both of these before starting a biologic therapy. While taking certain biologics, it is also recommended to screen for tuberculosis every year. Different biologics have different needs for lab monitoring. If you are starting a biologic, you should discuss with your healthcare provider what your lab monitoring schedule will look like.

## VI. Questions and Answers

### Question 1

**If I am on a biologic for HS, do I have to be on it forever?**

#### Answer

Not necessarily. Biologics are long-term treatments that are different from short-term treatments such as antibiotics. However, your therapy plan may change over time. Different people respond to medications differently. For example, if a biologic is only minimally effective for your HS, it can be switched to another medication. If a biologic stops working as well, your healthcare provider can work with you to optimize your treatment plan. New medications are also being studied, and may be available in the near future.

### Question 2

**When can I expect a biologic to start working?**

#### Answer

The effects of a biologic may not be seen right away. Different people can respond to the same treatment differently. Your healthcare provider may encourage you to stay on a biologic for at least three months to give it a chance to work. Continue monitoring your HS during this time period and keep your healthcare provider updated on how you are doing. If there is no change after three months, make sure to talk to your healthcare provider. It may be time to switch to a different biologic, add a new medication, or

re-evaluate your treatment regimen as a whole. And if you experience a side effect from the biologic, make sure to let your healthcare provider know right away.

### Question 3

**If I am on a biologic, can I get vaccines?**

#### Answer

Most vaccinations can still be taken after starting biologic therapy. This includes the COVID-19 vaccine. There are some vaccines that contain live viruses. Examples include the chickenpox, measles-mumps-rubella, and rotavirus vaccines. It is recommended to get any live vaccines that you may need before starting a biologic therapy.

### Question 4

**How can I minimize injection pain?**

#### Answer

There are different ways to try to minimize injection pain. Certain formulations of medications are meant to decrease injection pain, so you can ask your healthcare provider if any of those options are available for you. For example, citrate-free adalimumab (Humira<sup>®</sup>) is associated with less pain following injection. In addition, allowing your medication to reach room temperature prior to injecting can also minimize injection pain. A topical anesthetic or cooling spray can be applied to the skin before injecting as well. Finally, you can also take over-the-counter medications such as acetaminophen/paracetamol (Tylenol<sup>®</sup>) one hour before treatment to help with injection pain.

### Question 5

**Does using biologics long-term lead to cancer?**

#### Answer

Currently, there is no data to suggest that people with HS who use biologics are at greater risk of developing cancer

than people with other conditions, such as psoriasis or rheumatoid arthritis, who are taking biologics. And for people with psoriasis or rheumatoid arthritis, many have been taking biologic medications for several years without any issues. If you have any concerns, you should discuss them with your healthcare provider.

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## Chapter 20

# Pain Control

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- I.** Introduction
- II.** Types of HS Pain
- III.** Communicating About Your Pain
- IV.** Managing HS Pain
- V.** Developing a Pain Plan
- VI.** Questions & Answers

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## I. Introduction

In HS, pain has a major impact on quality of life. Pain is a significant cause of suffering for individuals living with HS. HS pain can be caused by acute flares, or by damage from long-standing disease.

Surveys have shown that pain from HS is more severe than pain from other inflammatory skin diseases like eczema or psoriasis. And pain itself has a greater impact on overall wellbeing than disease severity, as measured using standard clinical staging scales, including Hurley stage. Many people living with HS, however, feel that their overall wellbeing and pain are not addressed adequately by healthcare providers.

The goal of this chapter is to provide you, the patient, with knowledge and tools that may improve your overall understanding of HS pain, common pain management strategies, and to help you better communicate with your healthcare teams.

## II. Types of HS Pain

There are different kinds of pain in HS which may require different treatments. Understanding the different kinds of pain from HS and learning how to describe your pain may help you receive more effective treatment.

There are two major types of pain from HS: no-ciceptive and neuropathic pain. Nociceptive pain may be caused by flares of painful skin lesions. Common words used to describe this type of pain are “throbbing,” “aching,” or “gnawing.” Neuro-pathic pain is caused by nerve damage or changes in parts of the brain responsible for sensing pain. Neuropathic pain is often described as “burning,” “electric,” or “shooting.” There is ongoing research to study which types of pain are more common in people with HS.

Figure 20.1 includes common words people with HS have used to describe their pain. In this figure, the most commonly used terms appear largest in



Figure 20.1 Words Used to Describe HS Pain by People With HS Created using data presented in Nielsen 2020 et al.

size. Finding the right words to describe your pain is important because different treatments may be recommended for different kinds of pain.

### III. Communicating About Your Pain

Though finding the right medications may take time, it is important to work with your dermatologist to come up with an effective treatment plan. Finding an effective treatment plan may involve trying different medications to see which one works best for you. During this time, it is important to stick with the treatment plan for long enough to judge if it is really working. It is also important to tell your provider whether or not you are satisfied with the results. Many medications used to treat HS take three to four months of regular use before you will see the greatest improvement.

HS may also worsen over time. Your dermatologist will want to see you regularly to understand how you are doing, and to adjust your HS medications if needed. Though changing medications and taking time from work to attend visits can be difficult, it is important to remember that better treatment of your HS can also reduce your pain.

Your dermatologist may work with a team of other healthcare professionals to manage your HS pain. This may include your primary care provider, mental health professionals, pain management specialists, palliative care providers, or a clinical pharmacist. [Table 20.1](#) highlights the role these providers may play in treating your HS. Working with these providers to develop a pain management plan is important, and may decrease the need for urgent care or emergency room visits. You, however, are the most important member of the care team. Communicating your symptoms and describing your pain are critical to ensuring they are addressed and properly treated. Please also see [Chapter 13](#) for more information regarding multidisciplinary care.

Many people with HS have difficulty communicating details about their pain. [Table 20.2](#) includes details that may help you communicate with your healthcare providers. If your HS pain is a concern, you should bring it up to healthcare providers during your visits.

**Table 20.1. Healthcare Professionals Involved in Managing HS Pain**

Provider	Role
Dermatologist	The dermatologist is the provider who manages your HS. They monitor your HS symptoms and may prescribe medications, perform procedures, and refer you to other specialists, as needed.
Primary Care Provider (PCP)	A PCP helps to manage your overall health. This includes treatment of any other medical conditions. A PCP may also help to coordinate care and prescribe pain or psychiatric medications, as needed.
Clinical Pharmacist	A pharmacist may help with medication safety monitoring and insurance approvals.
Mental Health Professional	Psychiatrists, psychologists, and counselors can play a key role in managing HS pain. They may also help to manage feelings of distress, anxiety, or depression. Pain is worsened by feelings of sadness and worry, and feelings of sadness or worry can be worsened by chronic pain.
Pain Management Specialist	Pain management specialists help to treat chronic pain with medications and procedures. They may offer therapies that can decrease the need for pain medicine.
Palliative Care Specialist	Palliative care specialists focus on your overall wellbeing, living with serious illness, as well as the wellbeing of your loved ones. They may help you cope with the suffering that HS causes and help you manage symptoms like pain or fatigue that affect your quality of life.

## IV. Managing HS Pain

There are many ways to manage HS pain.

**The most important factor in reducing progression of HS pain is better control of the disease. Therefore, pain management begins with optimal disease control.**

Though finding the right medications may take time, it is important to work with your dermatologist to come up with an effective treatment plan. Finding an effective treatment plan may involve trying different medications to see which one works best for you. During this time, it is important to stick with the treatment plan for long enough to judge if it is really working. It is also important to tell your provider whether or not you are satisfied with the results. Many medications used to treat HS take three to four months of regular use before you will see the greatest improvement.

HS may also worsen over time. Your dermatologist will want to see you regularly to understand how you are doing, and to adjust your HS medications if needed. Though changing medications and taking time from work to attend visits can be difficult, it is important to remember that better treatment of your HS can also reduce your pain.

Your dermatologist may work with a team of healthcare professionals to manage your HS pain. This may include your primary care provider, mental health professionals, pain management specialists, palliative care providers, or a clinical pharmacist. [Table 20.1](#) highlights the role these providers may play in treating your HS. Working with these providers to develop a pain management plan is important, and may decrease the need for urgent care or emergency room visits. You, however, are the most important member of the care team. Communicating your symptoms and describing your pain are critical to ensuring they are addressed and properly treated. Please also see [Chapter 13](#) for more information regarding multidisciplinary care.

Acute pain may be treated with medications or procedures. Examples of medications used to treat acute pain include ibuprofen (Advil®) and acetaminophen (Tylenol®). Other treatments for acute HS pain include steroid injections into actively flaring sites and lancing swollen abscesses (a proce-

**Table 20.2. Communicating with Healthcare Professionals about Pain**

Proposed Step	Details
Describe the pain	<p>Explain your HS pain:</p> <ul style="list-style-type: none"> <li>• How severe is your pain, from 0 (no pain) to 10 (worst imaginable pain)?</li> <li>• How often is your pain bad enough that you need medications?</li> <li>• Describe how the pain feels (see terms in <a href="#">Figure 20.1</a>).</li> </ul>
Describe how the pain has impacted your life	<p>To help your provider understand the impact that pain has on your life, it may be helpful to give specific examples including:</p> <ul style="list-style-type: none"> <li>• Ability to focus on and complete schoolwork</li> <li>• Ability to attend work and perform job functions</li> <li>• Physical function, such as ability to walk upstairs, go grocery shopping, or cook for yourself</li> <li>• Effects on your mood and relationships</li> <li>• Number of visits to the emergency department or urgent care on account of your pain</li> </ul>
Discuss the treatments you have tried in the past.	<ul style="list-style-type: none"> <li>• Tell your provider what has previously worked</li> <li>• Tell your provider what has not worked</li> <li>• It is also important to share if you are using high doses of over-the-counter medications, medications that were not prescribed for your HS pain, or other drugs</li> </ul>

dure called “incision and drainage”). Many people with HS have also found relief with home-based strategies like applying warm or cool compresses to the skin or applying over-the-counter menthol ointments (for example, Vick’s VapoRub®). When

applying warm or cool compresses, avoid using very hot or very cold temperatures, as these may cause skin damage. Skin affected by HS is often less sensitive to temperatures compared to unaffected skin; using heating pads or putting ice directly on affected areas may damage the skin.

Although its use for HS has not been studied, topical use of cannabidiol (CBD) oil or cream is sometimes used to help relieve pain and discomfort. CBD is a chemical that is found in marijuana and hemp plants. It does not cause a “high” feeling; this is caused by a different chemical called tetrahydrocannabinol (THC). As none of the over-the-counter CBD products (hemp) have been approved by the FDA, there is no regulation of their purity or dosage. Do not apply these products to open wounds unless directed.

Treating chronic pain often requires combining multiple strategies, which may include the use of long-term medications. When using medications for a long period, it is important to consider their long-term effects. All medications, prescription or over-the-counter, can have side effects.

Because of possible side effects or your other existing health conditions, it is important to stick to the dosage and frequency instructions on medication labels, or as instructed by your doctor. When you need higher doses of over-the-counter medications or if you require prescriptions to properly address your pain, your healthcare team will help decide what amounts are safe. Paying close attention to warnings is important, and your doctor or pharmacist can help. It is important to discuss all medications you are taking with your healthcare team, even if they do not require a prescription. **Table 20.3** describes important safety precautions when taking pain medications.

To know what to expect, you may want to ask your medical team how quickly your pain medications will begin working. If the medicines do not work within the expected time, you should tell your healthcare provider so they can make changes to the plan that meet your pain needs. **Table 20.4** lists common types of pain medications and highlights safety precautions. This list is not exhaustive and we recommend discussing safety of all medications with your healthcare team.

In addition to medications and procedures, there are other strategies that may help reduce pain from HS. These include psychotherapy to

**Table 20.3. Pain Medication Safety Precautions**

### Important Points for Safe Use of Pain Medication

- Discuss all pain medications you are using with your healthcare provider. This includes over-the-counter medications, prescription medications, and other substances.
- Stick to the medicine dose suggested on the medication labels or recommended by your doctor. Higher doses can be unsafe, even if over-the-counter.
- To avoid throat or stomach irritation, most pain medications should be taken with a full glass of water and food.
- Only take pain medicines for the length of time recommended by your medical provider.
- Do not combine pain medicines with alcohol.
- Do not take medication prescribed to other people.
- Pay attention to warning labels on all over-the-counter medications, and stop use if you are experiencing side effects.

manage anxiety or depression known to worsen pain, as well as deep breathing, acupuncture, and mindfulness techniques.

Anxiety, depression, and feelings of distress often occur with HS pain and are important to address. Pain from HS may also cause feelings of distress, hopelessness, or sadness. These feelings and diagnoses may worsen pain. Working with a mental health professional or taking certain medications used to treat anxiety or depression may help your pain.

### V. Developing a Pain Plan

People living with HS should work with their medical team to develop a pain management plan. Pain management plans are individualized plans that patients develop together with their providers to encourage shared decision making and address chronic and acute pain needs.

The chronic pain plan includes medications and

strategies for dealing with long-term pain from HS, and may include medications, psychotherapy, and complementary strategies as discussed above. The acute pain management plan may involve procedures like steroid injections to active areas, drainage of unopened abscesses, as well as short courses of medications. The plan should include names of medications, safe doses, and guidance concerning how long the medications should be used. **Table 20.5** includes suggested components of an individualized pain management plan that you may want to discuss with your provider.

You may work with any trusted member of your medical team (like your primary care provider or palliative care specialist) to develop an individualized pain management plan. The plan should include input from your dermatologist and be shared with all members of your treatment team.

HS pain does not have to control your life. And we hope that the information in this chapter will help you work with your medical team to achieve better pain control.

Table 20.4. Common Pain Medications and Considerations

Medication Type	Use	Considerations
<b>Topical Agents</b> Types: <ul style="list-style-type: none"><li>• Lidocaine</li><li>• Prilocaine cream</li><li>• Ibuprofen foam</li><li>• Menthol based products (Ex: Vicks VapoRub®)</li></ul>	These are placed directly on the skin to provide temporary pain relief. Lidocaine and prilocaine products help to numb the skin, while ibuprofen foam controls pain.	<ul style="list-style-type: none"><li>• Do not use for longer than the recommended time.</li><li>• May cause skin irritation.</li></ul>
<b>Acetaminophen / Paracetamol (Tylenol®)</b>	Medications that decrease pain perception in the brain.	<ul style="list-style-type: none"><li>• May cause liver damage if used at high doses, or for extended periods of time.</li><li>• High doses may even lead to death.</li></ul>
<b>Non-Steroidal Anti-Inflammatory Medications</b> (Examples: aspirin, ibuprofen, naproxen, diclofenac, indomethacin)	Medications that decrease inflammation and pain.	<ul style="list-style-type: none"><li>• Increases chances of stomach ulcers or gastrointestinal bleeding.</li><li>• Take with a full glass of water and food to avoid irritation to your throat or stomach.</li><li>• Can worsen some forms of high blood pressure.</li><li>• Can cause kidney injury.</li></ul>
<b>Gabapentinoids</b> (Examples: gabapentin, and pregabalin)	Medications prescribed for chronic neuropathic pain.	<ul style="list-style-type: none"><li>• Can cause dizziness or confusion</li><li>• Higher risk of falls in the elderly</li><li>• Do not suddenly stop taking this medication. These medications must be decreased over time to avoid symptoms.</li></ul>
<b>Selective serotonin reuptake inhibitors (SSRIs) / Serotonin-norepinephrine reuptake Inhibitor (SNRIs)</b> (Example: duloxetine)	Medications used to treat depression and anxiety that have also been shown to improve chronic neuropathic pain and overall coping.	<ul style="list-style-type: none"><li>• May cause a rare condition called serotonin syndrome, sexual side effects, or other psychiatric effects in some people.</li><li>• May interact with other psychiatric and pain medications.</li><li>• Effects are often not seen before six weeks (about one and a half months).</li><li>• Do not suddenly stop taking this medication. These medications must be decreased over time to avoid symptoms.</li></ul>

Table 20.4. Common Pain Medications and Considerations

Medication Type	Use	Considerations
Tricyclic Antidepressants (TCAs) (Example: Amitriptyline)	Medications used to treat depression and anxiety that have also been shown to improve chronic neuropathic pain.	<ul style="list-style-type: none"> <li>Side effects may include dry mouth, constipation, urine retention, dizziness, or weight gain.</li> <li>Higher doses may cause heartbeat abnormalities, fast heart rates, and even death.</li> </ul>
Opioid Analgesics (Examples: hydrocodone, oxycodone, and morphine)	For severe, acute pain that doesn't respond to other medications.	<ul style="list-style-type: none"> <li>If used for a long time, you may develop tolerance which will require higher doses.</li> <li>Higher doses may increase symptoms like constipation, drowsiness, decreased heart rate, and decreased breathing which can lead to death.</li> <li>Best used along with other pain management strategies or medications, and over short periods of time.</li> </ul>
Cannabis-based products	These medications have limited evidence but have been reported to provide pain relief when applied directly to the skin in some cases.	<ul style="list-style-type: none"> <li>Be sure to utilize preparations with known ingredients.</li> <li>We recommend purchasing from a well known compounding pharmacy or other licensed retailer.</li> </ul>

Table 20.5. Components of Individualized Pain Management/Shared-Decision Making

Pain Management Plan Components	Things To Discuss with Your Provider
Long-Term Medications	<p><b>Dose, duration, side effects, and precautions</b></p> <p><i>Your plan should include any long-term pain medications that you are currently taking, because this may affect which medications will work best for acute pain episodes.</i></p>
Procedures for Acute Pain (Examples include steroid injections to active areas and drainage of swollen abscesses)	<p><b>Who should I contact for urgent procedures or urgent care?</b></p> <p><i>Examples include a local primary care physician, dermatologist, emergency room, or wound care facility.</i></p> <p><i>You will need to check with your providers to determine if appointments are available for urgent pain needs.</i></p>
Medications for Acute Pain (This may include over-the-counter medications or prescription medications)	<p><b>What medications should I take if I am experiencing acute uncontrolled pain? (Dose, duration, side effects, precautions)</b></p> <p><b>Who should I contact if I need a prescription for my acute pain?</b></p> <p><i>Some providers may have a patient portal or patient assistance number for urgent requests. Other providers may opt to provide you with a prescription for acute pain management to have on-hand, should you experience severe acute pain.</i></p>

Table 20.5. Components of Individualized Pain Management/Shared-Decision Making

Pain Management Plan Components	Things To Discuss with Your Provider
<b>Alternative Strategies</b> (This may include strategies such as deep breathing, mindfulness, and acupuncture)	<b>Who should I contact if I am interested in learning more about alternative strategies?</b> <i>A primary care physician or other member of your treatment team may be able to provide you with a referral to behavioral practitioners, counselors, or other health professionals who specialize in these areas.</i> <i>You may also check with your health insurance policy to see what practitioners are covered under your plan.</i>
<b>Contingency Plans</b> (This should address what to do if medications are not working for severe acute pain, or if you need urgent procedures or appointments and are unable to reach your regular providers)	<b>Who should I contact if my medications are not addressing my severe acute pain?</b> <b>When should I go to the Emergency Room?</b>

## VI. Questions and Answers

### Question 1

**What should I do if I am experiencing uncontrolled HS pain?**

#### Answer

First, follow the pain management plan you have discussed with your healthcare team and adhere to the medications discussed. If you do not have a pain management plan, we recommend reaching out to a trusted member of your healthcare team to determine the best and safest management of your disease and pain symptoms.

### Question 2

**What if the medications I have been prescribed are not working to control my pain?**

#### Answer

Do not suffer in silence. Contact your dermatologist or other healthcare team members to discuss more adequate treatment options. This may include increasing or changing your HS medications, the addition of pain medications, or other pain management strategies.

### Question 3

**What if I am experiencing severe HS pain and am unable to reach my healthcare providers?**

#### Answer

In this case, it is best to seek urgent medical attention. Do not take excessive amounts of over-

the-counter or prescription pain medication, as they may cause serious harm when used inappropriately. After the pain crisis, it is important to contact your HS healthcare team to discuss better disease management and pain management strategies. If you do not have an HS team, we recommend that you establish care with a primary care provider and dermatologist.

### Question 4

**Will I always have pain?**

#### Answer

Some HS pain is due to damage caused by long-term disease, and may require long-term treatment. Other pain is more acute and will improve with better disease control. Talk to your healthcare provider about ways to manage both kinds of pain. Pain that is debilitating and prevents you from completing daily activities should be discussed for better control.

### Question 5

**How long will it take for my pain medications to work?**

#### Answer

The time that it takes for pain medications to take effect varies by medication. Most over-the-counter pain medicine begins working within 45 minutes. Some prescription medications, such as duloxetine or gabapentin, may take weeks to build

up in your system and provide maximal relief. Pain medicines may not take away the pain completely. For more specific information about the medications you are taking, talk to your health-care provider.

#### **Question 6**

**My HS pain is not being treated adequately, what should I do?**

#### **Answer**

If your pain is not being treated adequately, begin by trying to explain the ways in which your pain impacts your daily life and tell your medical provider that you would like treatment for your pain. Work with your medical team ahead of time to develop a pain management plan to address both your chronic and acute pain needs ([Table 20.5](#)). It is important to note that some medications, such as narcotics, have increased risks with long- term use, and your medical providers will likely try to help you find alternatives when necessary. Remain open to trying alternative therapies that your medical providers suggest for pain management, and let your provider know if those approaches are not working.

It is also important to develop relationships with healthcare providers you trust, and with whom you have a positive relationship. If your provider is unwilling to address your needs, you may consider the addition of a patient advocate or a second opinion. You may also request referral to a pain management or palliative care specialist to provide expertise that will contribute to the shared decision making between you and your medical team.

Authors: **Forrest Roberson, Katherine Jicha, Christopher Sayed**

## Chapter 21

# The Right Surgery for the Right Time

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- I. Introduction
- II. Types of Surgery
- III. Recovery After Surgery
- IV. Post-Operative Care
- V. Surgery Benefits
- VI. Conclusion
- VII. Questions & Answers

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## I. Introduction

Medications and lifestyle changes can help HS in a lot of ways, but oftentimes HS is not completely controlled by medications. In these cases, surgery can be helpful for treating stubborn tunnels and scars. Surgery is most often recommended as a treatment option for lesions that have been present for months or years; surgery is usually not initially suggested for newly formed lesions that are likely to heal on their own. Surgery can also be an option for people that dislike medications or have had unpleasant side effects from them in the past. However, the risk of recurrence and need for more surgery may be higher when medications are not also included in the treatment plan to manage your HS.

## II. Types of Surgery

**There are two main types of surgery for HS: deroofing and excisions.**

### Deroofing.

**Deroofing (or unroofing) is when the healthcare provider removes all or most of the skin overlying a tunnel or pocket to expose the inside and remove pus or inflamed skin.**

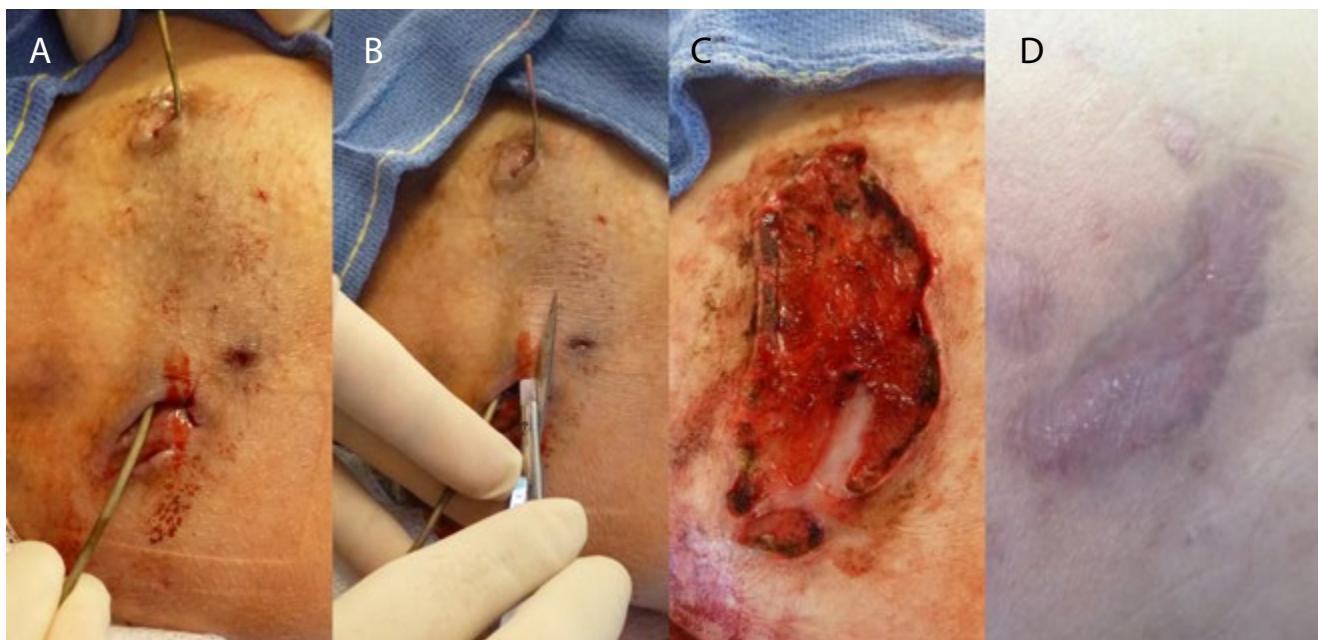
This leaves a shallow wound that does not penetrate the full thickness of the skin. This procedure can be done in a clinic using local anesthesia where you are injected with numbing medicine, but may also be performed in an operating room using general anesthesia where you are put to sleep for the surgery.

Once the area is numb, the healthcare provider will use a scalpel, scissors, or other surgical tools to remove the top of the lesion and clean out any inflamed material. Your dermatologist may use a scraping tool called a curette to remove some of the material in the tunnel. A small metal rod may be used to probe the area and make sure no tunnels remain. The deroofing site will usually be left to heal on its own, as stitches can trap diseased skin or other debris under the surface and lead to the formation of more tunnels or pockets ([Figure 21.1](#)).

### Excision.

**The other main HS surgical technique is excision, which involves removing the entire lesion including the underlying skin layer.**

Excisions can be performed on single lesions or on body sites, such as an armpit. Just like the deroofing procedure, an excision can be performed in a clinic with numbing medicine or in



• **Figure 21.1:** Deroofing procedure: A. After numbing the skin a metal rod (probe) is used to explore the tunnel, B. The surgeon uses scissors to remove the top of the lesion, “deroofing” the sinus tract, C. Immediately after deroofing the wound is left open to heal, D. 12 weeks after deroofing the wound is healed.

the operating room while under anesthesia. Because excisions are deeper, the resulting wound may be larger. Unlike deroofings, excisions do not leave part of the tunnel at the bottom of the wound so it may be possible for an excision wound to be stitched up ([Figure 21.2](#)).

The decision to stitch the wound may depend on factors like size and location. Larger wounds are harder to pull together, and may lead to stitched wounds that feel tight and restrictive. It is unclear if stitching excision wounds increases risk of recurrence compared to letting the wound heal by itself, and some doctors prefer to avoid it. In some cases, surgical repair of excisions can be performed with skin grafts taken from another part of your body. Your healthcare provider may also choose to use a “flap” which rotates and/or pulls skin from beside the surgery site to cover the wound. This can allow a large wound to be closed, but may result in a bigger surgical wound and longer recovery. Excisions are also discussed in [Chapter 22](#).

### III. Recovery After Surgery

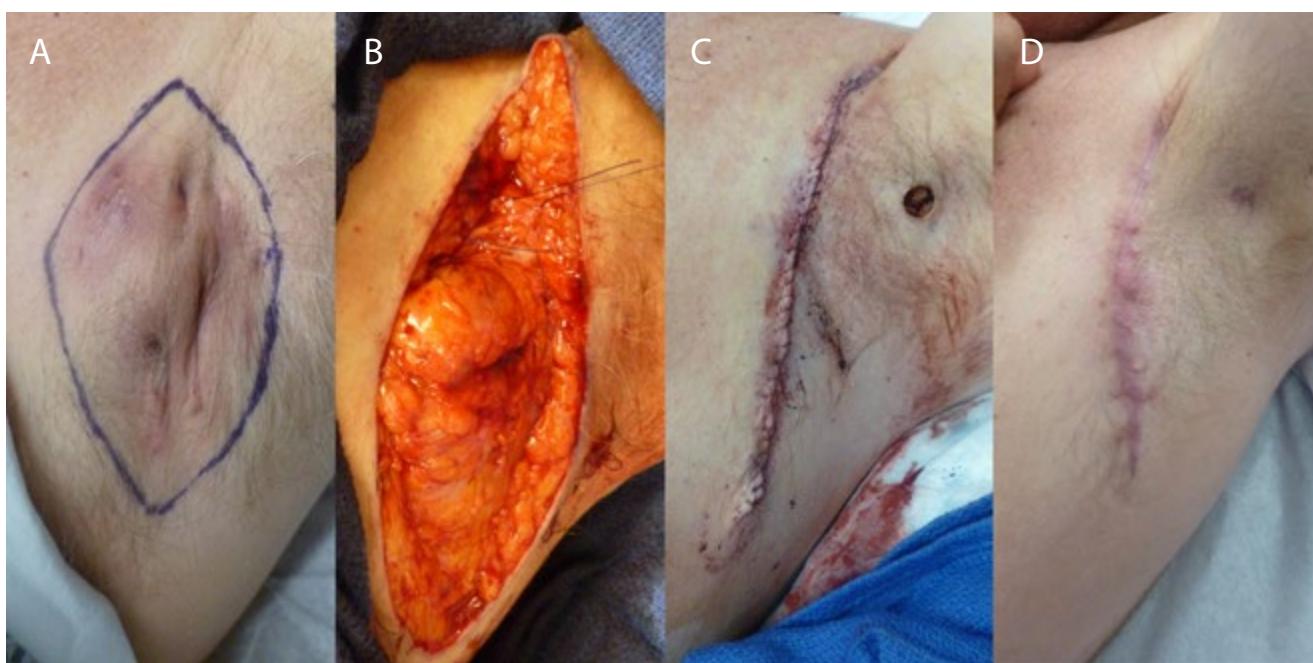
For most people with HS, the pain is worst in the first three to five days following surgery, though many people feel the surgical pain is not much worse than a bad HS flare. You may require extra pain medication and time to recover on those days. Pain is typically managed well with over-the-

counter medications like acetaminophen/paracetamol (Tylenol®) or non-steroidal anti-inflammatories like ibuprofen (e.g., Advil®). For smaller procedures, most people can return to work in a few days. With larger procedures, it may require a few weeks to recover. Most wounds heal over three to six weeks as the edges pull together to form a scar. While recovery has its challenges, most people with HS have experience with wound care and feel like they can handle it well.

### IV. Post-Operative Care

It is important to keep the wound covered and protected after surgery. It may be helpful to wear loose clothing for the first few days so that your clothes do not rub the area. Once the scar has formed, your doctor may have you perform stretches to ensure that the wound heals properly and does not restrict movement. The pain, swelling, and typical wound discharge should gradually improve each day. If it worsens, you should let a healthcare provider know in case there is an infection that requires attention. A small amount of bleeding on the bandage may also occur, but you should notify your healthcare provider if the wound bleeds through the bandage.

For deroofing procedures, wounds typically only need petroleum jelly (e.g., Vaseline®) and a nonstick dressing applied directly, but doctors may



• [Figure 21.2](#): Excision of HS: A. The surgical site is outlined, B. The skin has been excised down to the fat layer, C. The wound is stitched together, D. 12 weeks after surgery the wound is healed in a curved scar.

have different suggestions for wound care. Dressings should typically be changed at least daily after gentle cleansing, as suggested by your doctor.

For very large wounds, it is possible that your doctor will use a special vacuum-assisted closure (VAC) technique, which seals a small suction tube in the wound under a sticky seal. This or other drain types may require additional care. In some instances, a second surgery is planned following the first procedure to close a wound, once it has healed to a smaller size.

## V. Surgery Benefits

One of the greatest benefits of surgery is that it can remove stubborn tunnels and scars that respond incompletely to medication.

Since HS is a disease that can fluctuate between periods of activity and inactivity, it is possible for HS to come back at or nearby the surgery area. Risk of recurrence can depend on several factors, including the severity of your disease, how many locations are affected, how long you have had HS, where your lesions are located, and what kind of surgery is performed. Factors that increase the risk of recurrence include younger age, more affected areas, more severe disease, and surgery in the genital area. However, many people with HS with these traits still have excellent results.

Varying rates of recurrence have been reported following surgery, which may be influenced by the factors above. With deroofing, reported rates of recurrence ranged from 14-27%. With excisions, recurrence rates were reported between 13-33%. This means that, with either surgery, there is around a 70-85% chance that lesions will not return in the area that was operated on. If you do get more lesions, it does not mean that the surgery has failed. Part of the nature of HS is that it does tend to recur, but recurrences after surgery are typically not as severe.

Given the high rates of success, most people with HS are pleased with their surgical results. 90% of people with HS who underwent deroofing procedures would recommend the procedure to others. Similarly, 92% of people with HS who had a wide excision would recommend it to others, and 50% reported that the surgery had a medium

to major positive impact on their lives.

## VI. Conclusion

Ultimately, it is important to remember that surgery is a shared decision between you and your doctors.

You should voice your goals and concerns so that you feel comfortable with the timing and size of the procedures, though sometimes decisions may be influenced by what procedures your surgeon has experience with. Not all dermatologists are familiar with surgery for HS, so a referral might be needed.

It is important to remember that surgery is just one part of managing HS. Especially in severe cases, medication can be key to helping reduce inflammation and prevent surgical complications, allowing for better wound healing.

## VII. Questions and Answers

### Question 1

My regular healthcare provider does not perform these surgeries. What kind of healthcare provider typically performs surgeries? How can I find a surgeon that can help me?

### Answer

Some dermatologists can perform these surgeries, but some do not feel comfortable with it. Thus, it may be helpful to find a surgeon that specializes in HS. You can find a list of HS specialty clinics on support websites like HS Foundation (<https://www.hs-foundation.org/hs-specialty-clinics>). You can also ask your main HS healthcare provider if they have any recommendations. Sometimes social media and online support groups can be helpful in identifying local surgeons, though we recommend using these resources with caution. For larger surgical procedures, and when people prefer to be under general anesthesia (fully asleep), it is more likely that a general surgeon or plastic surgeon would perform the proce-

dure. Furthermore, specialized surgeons may be involved in surgeries performed on certain locations on the body, such as a urologist for the groin or colorectal surgeon for areas near the anus.

### Question 2

**Who is a good candidate for surgery?  
What could make me a bad surgical candidate or prevent me from getting surgery?**

#### Answer

Surgery is typically best for people who have not achieved good control of their disease through medication alone. Their lesions have typically been present for months or years, such as tunnels or sinus tracts that repeatedly become inflamed.

Some surgeons may feel uncomfortable operating on people with HS who smoke, have poorly controlled diabetes, or are very overweight. While studies have not clearly shown that these factors create major problems with healing for HS patients post-surgery, many surgeons are concerned that these factors could complicate wound healing. Certain conditions might also increase the risk of complications relating to general anesthesia.

### Question 3

**Is there anything that I can do before surgery to improve my outcome?**

#### Answer

Good control of inflammation related to HS can help make HS surgical procedures easier and help healing go more smoothly. Skin that is very inflamed may heal more slowly. Using medications when needed to control your HS before surgery and during healing is usually helpful.

If you want to ensure the best recovery, stopping smoking may be helpful. There are numerous ways to help you quit smoking — just ask your healthcare provider. Most studies of surgery for HS included many patients that smoked, and

the majority of those patients still benefited. Quitting smoking may be helpful, but surgery can still be beneficial when quitting has been hard.

Having good control of your diabetes can also help to ensure that your wounds heal properly. Your primary healthcare provider can do a quick blood test to check how well your diabetes is managed, and they can work with you to adjust your medications as needed. Patients with diabetes can still heal well from surgery, but improving control of diabetes may help speed the healing process after surgery for HS.

### Question 4

**If surgery works well, why not just get all areas affected by HS surgically removed as a cure?**

#### Answer

Sometimes surgery alone can be very effective. This is most often the case for people with HS that rarely develop new lesions and just have a few stubborn areas with tunnels that keep getting inflamed. In a case like this, surgery alone could be considered.

For many people with HS, however, there is a mix of old and new lesions, and removing old ones will not necessarily keep new ones from forming. Thus, it is usually best to stabilize HS with medicines first, then pursue surgery for areas that do not completely improve. Some people with HS who do not have good control of new flares end up having many procedures over time as new areas continue to pop up.

### Question 5

**Will I need to stop my medications before or after the surgery?**

#### Answer

Most people with HS can continue their medications without interruption, but it is important to review all your medications with your healthcare provider be-

fore undergoing surgery. Some medications used to treat HS may suppress your ability to fight infection, which can be important following surgery. However, having your disease well-controlled can reduce the risk of surgical complications. Notably, the “SHARPS” study found that adalimumab (Humira®) does not impact healing and can be continued during surgery. Your provider will consider these factors and help you to make a plan that is best for your situation.

Authors: **Stephanie R. Goldberg**

## Chapter 22

# Surgical Excisions

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- I.** Introduction
- II.** How the Procedure Works
- III.** Wound Closure
- IV.** Benefits of Surgical Excisions
- V.** Questions and Answers

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## I. Introduction

You might be considering surgery or perhaps surgery was recommended to you by a healthcare provider. Surgery, when combined with medical management, can be a helpful option for patients with HS. There are many different types of surgery, all of which - when combined with medical management and lifestyle changes - can lead to an improved quality of life. This chapter focuses on surgical excisions (which were briefly described in [Chapter 21](#)).

## II. How the Procedure Works

A surgical excision is a procedure where HS tunnels and affected areas are removed down to the level of subcutaneous tissue, or "fat." This surgery can be done in an outpatient office under local anesthesia (or numbing medicine), although bigger surgeries are performed in the operating room with the patient asleep under general anesthesia. There are many different physicians that perform this type of surgery, including some dermatologists, dermatologist surgeons, general surgeons, plastic surgeons, and gynecologists. If you are trying to find a health care provider who can do this, an important question to ask when you call to schedule an appointment is: "Does this clinic do surgery for HS?" Surgery requires patience and trust in your physician.

Once surgery for HS is performed, and the diseased tissue is removed, there is typically a wound, much like a hole, in the skin. The post-surgery wound can be big or small, depending on how much of the HS-affected areas are removed. Some people prefer to have a large excision done at one time, and others decide to have a series of smaller excisions done over a longer period of time. It is a personal decision to discuss with your surgeon. The wounds can be dealt with in different ways and one approach is not necessarily better than the other.

## III. Wound Closure

One way to close a wound after a surgical excision is by letting it heal by what is called "secondary intention healing," or basically just letting it heal on its own from the inside out, without using

stitches. This can be done with wound dressing with either moist gauze, petrolatum jelly (e.g., Vaseline®), bacitracin, or specialized wound care products. Wound care and dressings are further discussed in [Chapter 15](#). The body is amazing, and patients with HS often discover that they heal very well after surgery. What was once a large wound can shrink down over the course of a few months to a scar that is only a fraction of the size of the original wound.

Some wounds can be closed at the time of surgery. This involves the placement of stitches (also known as "sutures") to hold the skin and tissue together, and sometimes there is a drain placed that you go home with to keep fluid from building up under the skin during the healing process. The stitches are typically removed at a later time in the office, although sometimes dissolvable stitches are used underneath the skin that go away by themselves.

A third way to close the wound is to do something called a flap. A flap involves taking tissue from next to the wound, or any other area of the body, to close the hole. Not everyone needs a flap and there are many other options.

Many patients considering surgery ask if they will need skin grafts, and this is a fourth way to close the surgical wound. Skin grafts are a great way to cover a wound quickly once the wound has healed enough. The surgery is typically done in an operating room and under general anesthesia, which means you will go to sleep for the surgery. Skin is taken from an area such as the back or the thigh, and placed over a wound. This is typically done weeks after the original surgery.

For a skin graft to work, it does not matter whether the wound has been treated with daily wound care or with a wound vac. The wound just needs to have a good base of what we call healthy granulation tissue (i.e., the bright red tissue) and has healed enough based on the surgeon's evaluation. The skin graft is placed over the wound and attached using sutures or staples. Either a spongy bolster dressing (a type of dressing that is sewn on top of a skin graft) or a wound vac is then placed for approximately five days, and then the dressing is removed during your post-op clinic visit to see if the skin is sticking to the wound as intended.

Most of the time, skin grafts work really well, and the wound is officially closed at the five day mark. But there is always the chance that the skin graft may not survive on the wound, leaving you with a wound that needs to close. In that case, you will also have another wound on your thigh or back from where the skin was taken and that can be very painful, both physically and emotionally. If the skin graft does work well, typically there will be a patterned look to the skin once it has healed, meaning it will not look like your smooth typical skin. This occurs because small holes are made in the piece of skin that is taken from another part of your body for the skin graft. This allows surgeons to use a smaller piece of skin to cover a bigger wound. Talk to your surgeon about whether this is the right option for you.

#### IV. Benefits of Surgical Excisions

Surgical excision of affected HS skin is one of the easiest ways to get back to your regular life quickly—while the wounds are healing, many people are able to work, take care of family members like children, cook, drive, and even exercise. Another option on how to manage the wound after excision is to place a wound vac on the wound. A wound vac is a specialized sponge attached to a suction canister that pulls fluid out of the wound and helps the wound close. The benefit of the wound vac is that the dressing only needs to be changed every three or so days. The downside, however, is that you are attached to a little portable machine, so there can be some painful “pulling” or “tugging” sensations, and it requires a special nurse to change the wound vac. It is important to remember that every surgeon has a sense of what works best with how they do their surgeries, and to have discussions about post-surgical care.

Talk to your healthcare provider about whether you are a good candidate for surgical excision of your HS. Your healthcare provider will help determine which technique is most appropriate for you—sometimes, it involves excisions, combined with other techniques like deroofing (see *Chapter 21*) in certain areas. The most important thing to remember is that it is important to first establish the goal of surgery before picking the type of surgery.

Surgery to treat HS can have different goals. One goal might be to remove as much of the diseased skin as possible. Another goal might be to remove the areas causing the most pain or drainage, especially in people who have severe HS and many affected areas. Think about what your treatment goals are and work together with your healthcare provider to figure out if surgery is right for you.

#### V. Questions and Answers

##### **Question 1**

**I've been in so much pain with this disease. Is surgery painful?**

##### **Answer**

All surgery requires a period of healing so there can be pain. However, the post-op pain during the temporary healing period is different from the chronic recurring pain of HS. For instance, patients often report that – after surgery – they no longer experience the gnawing, dull, pressure-like pain they previously felt in the area where the disease was removed. Most patients find surgery worthwhile and report being happy with the outcome of their procedure(s).

There are strategies to help manage the post-op pain during the wound healing process. If your wound is very sensitive the first few weeks during wound care, ice packs can be helpful. Ice packs placed by and around the wound for about 10 minutes at a time work well to help numb the area and decrease inflammation. They can also trick your brain into focusing on the cold instead of the pain. Keep in mind that your healthcare provider will inject numbing medicine into the wound at the time of surgery which will help decrease post-op pain. They may also give you some pain medication to help you manage your pain when you first go home. Following that, many patients find that over-the-counter pain medications are sufficient for pain management.

**Question 2**

**Will my HS come back after surgical excision?**

**Answer**

Surgical excision works very well to remove HS in a specific area. Since HS is a disease with systemic inflammation and can occur in a lot of different areas of the body, it is possible to still develop HS lesions around the excised area or in completely different areas of the body. Keep in mind that if you do develop more disease, it does not mean that the excision was unsuccessful.

Authors: **Barry I. Resnik, Sydney R. Resnik**

## Chapter 23

# Procedures in the Office

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- I. Introduction
- II. Botulinum Toxin Injections
- III. Chemical Peels
- IV. Cryoinsufflation
- V. Incision and Drainage
- VI. Intralesional Steroid Injection
- VII. Deroofing and Surgical Excisions
- VIII. Staged Carbon Dioxide (CO<sub>2</sub>) Laser Marsupialization
- IX. Questions and Answers

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## I. Introduction

While it is more appropriate for some procedures to be performed under general anesthesia, there are a number of procedures that can be done at the doctor's office. This chapter covers HS treatment procedures that can be performed in the office.

## II. Botulinum Toxin Injections

Botulinum toxin is in a class of medicines called neurotoxins. This class now includes brands like Botox®, Myobloc®, Dysport®, Jeuveau®, and others. These medications are injected through the skin. Botulinum toxin injections work by putting up a temporary wall between our muscles and the nerve signals we use to move them, which temporarily paralyzes the muscles. Our bodies break down the walls over time, which means injections need to be done repeatedly to maintain the effect. These medicines are traditionally used to reduce wrinkles that form during facial muscle movement and also used for migraine headaches.

As our scientific knowledge advances, doctors are finding new ways to use neurotoxin to treat various diseases, including HS. Botulinum toxin injections were first used to help HS patients by reducing the amount of sweating in areas affected by HS. It was found that pain and irritation from HS decreased and the effect lasted about 10 months. Use of these injections in people with HS, with disease severity ranging from mild to severe (Hurley I to Hurley III), has since been reported several times, but with varying effect. The doses have varied as well.

It is generally considered something that may work for some patients with HS but not necessarily for others, but will not make HS symptoms worse. The brand name of the botulinum toxin does not seem to affect results. The injections are pin-pricks and the medicine itself does not sting or burn. However, as botulinum toxin injections for HS may not be covered by insurance plans, it can be expensive.

- **Botulinum Toxin Injections: Patient Selection.**

People with mild HS (Hurley I) are the most appropriate candidates.

- **Botulinum Toxin Injections: Post-operative Care.** No post-operative care is required.

## III. Chemical Peels

Chemical peeling involves using liquids like trichloroacetic acid, glycolic acid, and resorcinol to strip off the superficial skin layers in a controlled fashion, allowing the skin to heal in a better way. Chemical peeling is most often used to rejuvenate sun-damaged skin. It can also help reduce pre-cancerous spots.

Topical resorcinol has been studied in patients with HS and found to be beneficial. Please note that it is currently only available from specialty compounding pharmacies in the United States, so your doctor would need to find a specialty pharmacy that is able to make the resorcinol cream or ointment in order for you to access the medication. Please see *Chapter 16* for further information.

- **Chemical Peels: Patient Selection.** Anyone with HS may benefit from topical resorcinol. However, it is likely that people with mild (Stage I) or moderate (early Stage II) disease will benefit most.

- **Chemical Peels: Post-operative Care.**

No postoperative care is required.

## IV. Cryoinsufflation

This technique was originally intended for people with HS lesions that would benefit from a systemic treatment but who could not tolerate or did not want systemic therapy (for example, pregnant women). Liquid nitrogen is used to treat HS sinus tracts/tunnels. Liquid nitrogen is a gas that dermatologists often use to treat warts and other lesions. It is very cold at -190 degrees Celsius. Skin cells are easily damaged at this low temperature. A special attachment with a thin tube or needle on one end is placed on a liquid nitrogen spray bottle. The area to be treated is numbed with lidocaine, and the thin tube/needle is placed into the opening of an HS tunnel. The liquid nitrogen is then sprayed into the tunnel in short bursts. The gas expands through the entire tunnel and any interconnected tunnels before passing out distant tunnel openings. The extreme cold causes injury to the lining of the tunnels, hopefully resulting in tunnel closure when healed. Each tunnel usually requires at least two treatment sessions. Potential side effects include pain, formation of ulcers, or rarely, air embolism.

In the authors' experience, this procedure has worked well in areas with around 1-3 tunnels.

- **Cryoinsufflation: Patient Selection.** People with any stage of HS are possible candidates.
- **Cryoinsufflation: Post-operative Care.** The treated sites are bandaged. Any pain afterwards can be treated with acetaminophen/paracetamol (Tylenol®) or other pain medications if needed and the occasional ice pack.

## V. Incision and Drainage

This procedure is used for swollen and tender bumps in the skin called boils or abscesses. These generally contain pus, and the best treatment is to release the pus. The boil is numbed with a lidocaine injection, and a sharp scalpel or punch tool (a small round cookie-cutter like instrument, typically measuring 3 to 4 millimeters in diameter) is used to make an opening in the top of the boil. Pressure is used to push the pus out of the boil. Sometimes, the inside of the boil is rinsed with water to clean the area and a packing made of cotton string gauze is placed inside the wound. The packing can be removed the next day, and the area cleaned and re-bandaged.

- **Incision and Drainage: Patient Selection.** People with any stage of HS are possible candidates.
- **Incision and Drainage: Post-operative Care.** The treated sites are bandaged. Any pain afterwards can be treated with acetaminophen/paracetamol (Tylenol®) or other pain medications if needed and the occasional ice pack.

## VI. Intralesional Steroid Injection

Steroids are medicines that have a great deal of effect against inflammation and can act like a blanket on a fire, putting out the flames and bringing sometimes significant relief within hours. Your healthcare provider can inject a steroid solution (typically called triamcinolone or Kenalog® solution) directly into inflamed HS bumps to decrease inflammation and pain.

- **Intralesional Steroid Injection: Patient Selection.** People with any stage of HS are possible candidates.
- **Intralesional Steroid Injection: Post-operative Care.** There is no specific care needed after this procedure.

## VII. Deroofing and Surgical Excisions

Please see [Chapter 21](#) for information regarding deroofing. Information on surgical excisions can be found in [Chapter 21](#) and [Chapter 22](#).

## VIII. Staged Carbon Dioxide (CO2) Laser Marsupialization

This procedure was developed based on the knowledge that HS is a disease of the skin and is not found in fat or muscle. Knowing the bounds of the disease helps the surgeon remove as much of the disease as possible without taking healthy skin.

The light wavelength put out by a carbon dioxide (CO2) laser is absorbed by water. It can penetrate no deeper than the skin. It also helps reduce bleeding by sealing off blood vessels as it cuts through the tissue. The surgeon defines the area by touch and maps out the borders of the disease in the involved area, then uses the CO2 laser to cut around that border.

The active HS lesions are removed off the underlying healthy tissue with the laser. Care is taken so that no HS-affected skin remains at the base. Once the HS affected area is removed, a metal probe is used to explore the borders looking for hidden tunnels. If any are found, they are also removed. The area is then bandaged and allowed to heal by itself (secondary intention healing). Healing can take up to three months, but patients can typically still function during the healing period with little/ manageable pain, and patients are encouraged to go about their daily lives. The chances of HS coming back in the area remain extremely low, and the resulting scars are generally much preferred to the HS-involved skin that was removed. This procedure can be done under local anesthesia in the office or under general anesthesia at a surgery center.

- **CO2 Laser Marsupialization: Patient Selection.** People with any stage of HS are candidates.
- **CO2 Laser Marsupialization: Post-operative Care.** Care after the surgery involves petrolatum (Vaseline®) ointment, non-stick pads, gauze, and tape applied to the area and changed daily. The areas gradually become smaller as they heal. Healing generally takes about 3 months even for large areas. However, in some cases, longer healing time is needed.

## IX. Questions and Answers

### **Question 1**

**How would I know if I would benefit from neurotoxin injections?**

#### **Answer**

If you feel like your HS gets worse with sweat, neurotoxin injections may be beneficial for both reducing sweating and for your HS. Studies have also shown that neurotoxin injections may be helpful in people with HS even if excess sweat is not present. Please discuss with your health-care provider to see if you are a good candidate for this procedure, though keep in mind that it may not be covered by insurance.

to try to help reduce the pain of injection. Using a small vibrational unit during injections can also distract from injection pain.

### **Question 2**

**Will Staged CO2 Laser Marsupialization cure my HS?**

#### **Answer**

No. This procedure can remove HS affected areas that will always be potential sources for flare, reducing the burden of disease. In some cases, CO2 laser can surgically remove all the existing HS lesions and offer disease remission in the treated areas. However, disease control using medications will still be needed to prevent new HS lesions from occurring.

### **Question 3**

**Will insurance cover staged CO2 Laser Marsupialization?**

#### **Answer**

This procedure is not currently covered by insurance. This status may change at any time.

### **Question 4**

**Injections (such as numbing medicine injections and steroid injections) are so painful, especially when done on an already tender boil. Is there any way to lessen the pain?**

#### **Answer**

Yes. Numbing cream or an ice pack can be placed on the area before the injection

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## Chapter 24

# Laser Therapy

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- I.** Introduction
- II.** Hair Reduction (Nd:YAG Laser Treatment)
- III.** Carbon Dioxide Laser Therapy
- IV.** Post-CO<sub>2</sub> Laser Healing and Care
- V.** Photodynamic Therapy
- VI.** Questions and Answers

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## I. Introduction

In cases where HS is not sufficiently well controlled by medication, the added use of laser therapy in combination with medications can be helpful to better manage the disease. Especially for patients with moderate to severe HS, laser therapy may be recommended as a treatment option. Some benefits of laser therapy include its limited adverse side effects and ability to be performed in a clinic setting without the need for general anesthesia.

While LASER is popularly used as a single term, it is actually an acronym for Light Amplification by Stimulated Emission of Radiation. A laser is a medical device that uses multiple colors and wavelengths of focused light to treat various skin disorders, including HS.

Many different types of lasers have been developed. Each type of laser has unique properties and varying effects. This chapter outlines the basic principles of laser devices and how lasers and lights can benefit patients with HS. The role of the Nd:YAG laser, carbon dioxide (CO<sub>2</sub>) laser, and photodynamic therapy in the management of HS is discussed.

## II. Hair Reduction (Nd:YAG Laser Treatment)

While we do not fully understand the exact cause of HS, current research indicates that HS develops when a hair follicle (which refers to the base of the hair) becomes clogged with keratin (a type of protein in the skin, hair, and nails).

Hair follicles clogged from excessive keratin, sweat, and bacterial growth lead to painful and swollen bumps. The plugged hair follicles can rupture and lead to an inflammatory response. People with HS experience this inflammation as pain and drainage. Given that hair follicles play an important role in the development of HS, lasers that reduce hair follicles may be a good treatment for select people with HS.

One of the most popular laser devices used to reduce hair follicles is the Nd:YAG laser. This type of laser can penetrate deeper into the skin than other lasers, using a beam of intense light that targets the hair follicle roots. The laser light released from the Nd:YAG device produces permanent,

heat-causing damage to the follicle. Treatment with the Nd:YAG device may stop hair growth more effectively for some individuals than others.

There are many benefits to this type of treatment. These include reduction in disease severity, reduction in symptoms (e.g., less pain and/or drainage), reduction in the number of HS flare-ups, and decreased reliance on systemic medications. Another advantage of this type of laser treatment is its ability to be performed in a clinic without the need for general anesthesia.

It is important to note that there are factors to consider to help determine if the Nd:YAG laser is an ideal treatment option for a patient. This type of laser may not be appropriate for patients with severe HS (Hurley stage III) due to the presence of scar tissues and sinus tracts. Hair reduction laser procedures are primarily limited to patients with clinical stage I and stage II disease as a result. Additionally, because the laser works by targeting hair pigment, it is best suited for patients with fair skin and dark hair.

There are minimal risks associated with hair reduction procedures when performed by a trained dermatologist who is board-certified by the American Academy of Dermatology, but there may still be side effects. Although the treated area is numbed (with the use of a numbing medication called lidocaine), it is not uncommon for patients to experience discomfort and stinging during the procedure. Some patients have reported that the sting from a laser procedure feels similar to the sting of a rubber band snapping on the skin. However, this varies among individuals.

One of the common side effects that people may experience after hair reduction laser procedures include skin discoloration (such as brown or white discoloration at the site of treated area). Some people may also experience an increase in pain and inflammation in the first week following treatment. Please discuss with your healthcare provider if this occurs.

Additional laser devices that are less utilized for hair reduction and less studied compared to the Nd:YAG laser include the intense pulsed light (IPL) therapy, long pulsed Alexandrite laser, and non-Q switched ruby laser. Of these other lasers, the Alexandrite and IPL have the most promise, but more research needs to be done.

### III. Carbon Dioxide Laser Therapy

Carbon dioxide (CO<sub>2</sub>) laser therapy is effective for the treatment of persistent HS lesions, and for locating and removing HS sinus tracts/tunnels that may not be otherwise visible. This procedure is typically used for patients with moderate to severe disease (e.g., Hurley stage II-III). A benefit of the CO<sub>2</sub> laser procedure is that the procedure can be performed in the clinic.

CO<sub>2</sub> laser therapy allows areas to be carefully examined after the removal of affected tissue, which facilitates the discovery and subsequent removal of hidden lesions (e.g., tunnels).

After HS lesions are treated with CO<sub>2</sub> laser therapy, healing occurs naturally without any sutures or wound closure. This process is called secondary intention healing (SIH). Due to this process, new lesions are less likely to form in the treated areas. In fact, several studies done on the use of CO<sub>2</sub> laser therapy for HS showed that there is around a 90% chance that lesions will not return in the area that was treated. In rare cases, CO<sub>2</sub> laser procedures result in complications, such as bleeding, discomfort, delayed healing, and infection.

Given the high success rates, most patients with HS are satisfied with the outcome of their CO<sub>2</sub> laser therapy. When asked about the visual appearance of the areas treated, many patients report being pleased with what they consider an aesthetically pleasing outcome. Staged CO<sub>2</sub> laser marsupialization is discussed in [Chapter 23](#).

### IV. Post-CO<sub>2</sub> Laser Healing and Care

As discussed, lesions treated with CO<sub>2</sub> laser therapy will heal naturally. This is especially beneficial for lesions located in areas with high friction such as axilla (armpit) and genitalia, as this type of healing reduces the likelihood of HS lesions returning.

It is important to note that natural healing, or secondary intention healing (SIH), is gradual and may take several weeks to months. Regardless of where the treated lesion is located, SIH is often successful. While bleeding and infection are all possible, these risks are rare.

Immediately after the procedure, the wound is covered with dry or ointment-infused dressings. The ointment used is often petroleum jelly (e.g.,

Vaseline). In addition to the dressing, a covering bandage attached with surgical adhesive tape or gauze underwear is also used. After the procedure, patients are instructed to leave the wound dressings on for 2-3 days. After that, the wound is cleaned and rinsed with tap water. From there, the wound dressing should be changed as needed until healing is complete.

With clear instructions from their healthcare provider, patients are usually able to perform their own dressing changes with minimal discomfort. Pain can also be managed with a short course of opiates, and patients are instructed to alternate between acetaminophen/paracetamol (Tylenol<sup>®</sup>) and ibuprofen (e.g., Advil<sup>®</sup>). Reducing pain during the recovery period is essential, since changing wound dressings can be painful. Patients should follow up with the healthcare provider who performed the CO<sub>2</sub> laser therapy one week after the procedure and again six weeks after. General principles of HS wound care and dressings are further discussed in [Chapter 15](#).

### V. Photodynamic Therapy

Photodynamic therapy (PDT) is a well-known treatment used to treat various dermatologic conditions. PDT works by selectively killing targeted cells. A topical medication (e.g., 5-aminolaevulinic acid) is applied to the lesion, which gets activated by light. This allows PDT to produce a chemical reaction that is toxic to bacteria.

Research shows that bacteria play a role in HS. Bacteria can cluster together and form a tight layer covering HS lesions called biofilm. Research shows that PDT is able to kill bacteria in the biofilm, making it a promising therapy. PDT can specifically help treat HS by reducing the amount of bacteria present in the lesions, which in turn reduces the inflammation and symptoms (i.e., drainage, odor, pain). This means that, following PDT therapy, patients will usually experience symptom relief such as less pain and less discharge.

While PDT therapy is generally safe, it is not appropriate for everyone. People who have a history of lupus, a history of porphyria, or allergies to the topical medications used in PDT are not good candidates for this form of treatment.

## VI. Questions and Answers

### Question 1

#### Are all people with HS good candidates for laser hair reduction?

##### Answer

Laser hair reduction works by targeting the pigment of the hair. It is the color contrast between hair and skin that enables the laser to focus and target the hair follicle. Laser hair reduction works best on individuals with fair skin who have dark-colored hair. For individuals with darker skin, laser hair removal can be effective if they have light-colored hair. However, individuals with darker skin that have dark-colored hair may not benefit from this procedure due to lack of color contrast between the skin and the hair follicle. Similarly, this procedure may not be suitable for people with fair skin and light-colored (white/grey) hair.

### Question 2

#### Does insurance cover laser hair reduction?

##### Answer

Most health insurance in the United States does not cover laser therapy. However, based on the specific insurance policy and the patient's unique conditions, laser therapy may be covered. The average out of pocket cost typically varies between \$200 to \$1,000 per session. On average, people require three laser treatment sessions, but some people may need more sessions. These sessions take place once every 4-6 weeks. Keep in mind that initial improvement might not be noticeable until after one month.

### Question 3

#### Can lasers help HS scars?

##### Answer

A form of CO2 laser therapy called fractionated CO2 laser therapy was shown to reduce scars associated with HS lesions. Fractionated CO2 laser therapy works by focusing microscopic beams of light

into deeper layers of the skin. This creates "micro-wounds," or tiny holes within the skin. This process stimulates the production of new collagen, tightens the new skin, and smooths out the scar. It is important to note that scars cannot be completely removed. Instead, fractionated CO2 laser can minimize scar appearance and thickness.

In order to minimize the formation of new scars, it is generally recommended to massage the surgically treated areas (after they have healed from surgery) within the first two years of having had a surgical procedure.

### Question 4

#### How does Intense Pulse Light compare to CO2 laser?

##### Answer

Intense Pulse Light (IPL) releases light of different colors (known as wavelengths) while a laser device releases light of a single color (or wavelength). IPL is able to target and remove affected lesions through the conversion of light to heat. Although promising, current research is limited regarding the use of IPL in the treatment of HS.

### Question 5

#### Can Alexandrite laser be used for hair removal?

##### Answer

Similar to the Nd:YAG laser, the Alexandrite laser can also target hair follicles, making it a suitable therapy for hair removal in HS. However, research investigating its efficacy in treating HS is limited. Current research indicates that the Nd:YAG laser remains a superior option for hair reduction.

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## Chapter 25

# The HS Toolbox

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- I.** Introduction
- II.** Your HS Toolbox and Your Doctor
- III.** HS Toolbox Medicines
- IV.** Non-Medicines in Your HS Toolbox
- V.** Questions and Answers

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## I. Introduction

Why is it that the same HS treatment can be very helpful for some people while only slightly helpful or not helpful at all for others? This is because HS is a heterogeneous disease, which means it may have different causes and triggers in different people. Given this, it can be helpful for both healthcare providers and people with HS to view the options for HS treatment as a “toolbox”.

The tools used by different people with HS may differ since their HS may be triggered by different things. For example, for some people, hormones may be a strong driving force for disease activity, in which case, starting a medication that targets hormones would be beneficial.

Having a variety of tools in the HS toolbox is valuable because different tools are appropriate for different situations. Sometimes the situation for a person with HS changes, so the tools used to treat their HS also needs to change. This chapter discusses how to think about the tools available in the HS toolbox.

## II. Your HS Toolbox and Your Doctor

If your HS is triggered by a combination of causes, you may need a combination of different types of medicine to get the best results. Currently, choosing the best therapy or combination of therapies to treat HS typically involves some trial and error.

You may need to try different treatments to find what works best to control your HS. Because of this, working with a healthcare provider who is knowledgeable about HS can be really helpful because they are familiar with the HS toolbox. They can help choose tools that are best for you, taking into consideration the specifics of your case (for example, your HS disease severity and any treatment preferences).

## III. HS Toolbox Medicines

The HS toolbox is made up of a wide variety of treatment options listed by medical experts in guidelines and reviews based on clinical studies and expert opinion. These treatment guidelines and reviews are accessible through the Hidrad-

enitis Suppurativa Foundation’s website ([www.hs-foundation.org](http://www.hs-foundation.org)).

It is important to keep in mind that different treatment options are appropriate for different disease severities. Some treatments, such as oral antibiotics like doxycycline, do not seem to work as well for people who have severe HS (such as Hurley Stage 3) as they do for people with mild HS (Hurley Stage 1). On the other hand, adalimumab is only approved for people with moderate to severe HS.

When it comes to combining therapies from the HS toolbox, sometimes it is helpful to combine medicines of the same type while other times it is helpful to combine different types of medicines. For example, sometimes combining two or three antibiotics together may be more helpful than just treating HS with one antibiotic. For women with menstrual HS flares, taking an oral contraceptive pill (also known as a birth control pill) and spironolactone together may work well. Both of these medications work to target the hormonal component of HS.

There are also successful examples of combining two different medicine types from the HS toolbox. One example of this is the combination of oral antibiotics with a biologic, such as adalimumab (Humira®). For some people, taking doxycycline may be enough to control their disease. However, for those who find that doxycycline helps them but not enough, their healthcare provider may suggest combining it with adalimumab, and then continuing adalimumab long-term since oral antibiotics are not a long-term treatment.

There are no firm rules about how long a medicine should be tried before giving up on it, or before adding on another medicine to try to get better results. Please see [Chapter 12](#) for more information on HS treatment goals and how to manage your treatment expectations.

## IV. Non-Medicines in Your HS Toolbox

In addition to medicines, the HS toolbox also has other tools that can help with HS. Depending on your situation, surgery and/or laser treatment may be tools from the toolbox that are helpful, likely in combination with medicines (please see [Chapter 21](#) for further information about HS surgeries). Additionally, lifestyle modifications, such as not

smoking, weight management, and diet adjustments may be good for your general health and may help with HS. It can be challenging to stop smoking or make diet changes, so it is important not to feel guilty or blame yourself if you struggle to make lifestyle modifications. Some people with HS report finding it easier to make lifestyle changes after they have started medicines that get their HS under control to the point where they have more energy to work on lifestyle changes.

## V. Questions and Answers

### Question 1

**Some of the medications I've tried didn't work, so why would my healthcare provider recommend them again?**

#### Answer

It is possible that your healthcare provider had forgotten, or did not notice in reviewing notes for the visit, that you have already tried the medication. This is especially likely if it has been a long time since you took this medicine, or if another HCP prescribed it. Before your doctor visits, it can be helpful to refresh your memory of your treatment history: remembering which medicine(s) you have tried, at which doses, for how long, whether they helped at all, and whether they caused any side effects.



This process can be made easier with the use of an HS symptom tracker, such as the HS App that will be available soon, which is discussed in *Chapter 26*.

It is also possible that your healthcare provider may recommend a medicine again because they think that in the past you did not try it for a long enough time or at a high enough dose.

Another possibility is your healthcare provider may think a medication that did not work for you previously may help when taken in combination with another medicine. Some treatments may not work as well by themselves, but can help another medication work better.

### Question 2

**What can I do to decrease my “medication burden”?**

#### Answer

Many people with HS feel that they have a great number of medications (to apply and/or to take) and it can become a source of frustration. This is understandable: taking lots of medicines is burdensome and can feel like a lot of work. It is important to be transparent with your healthcare provider about how you are feeling about your treatment plan and to voice any concerns you have. It may be helpful to ask your healthcare provider if you can add on one treatment at a time if you are worried about becoming overwhelmed. Generally, it is easier to take pills once a day than twice or three times a day—check to see if it is okay for you to take your medicines together, and to take them once per day.

### Question 3

**Why did my healthcare provider recommend taking more than one type of medication for my HS?**

#### Answer

Your healthcare provider may prescribe several medicines in hopes of targeting different potential causes of HS and having the medications work together to optimally benefit you. When you say to yourself “This medicine did not work,” ask yourself if you are sure that the medicine did not help, even a little.

### Question 4

**Are the risks of side effects higher if I take more than one medication for HS?**

#### Answer

Yes, unfortunately the risks from taking two medicines together may be equal to, or sometimes greater than, the risks of taking each medicine separately. Situations where risks of two medicines together are greater than either medicine by itself include: (1) if one medicine causes the blood level of the other medi-

cine to rise, even if you do not change the dose of the other medicine, or (2) if both medicines have a similar effect on your body (for example, if both are suppressing your immune system).

When adding a new medicine, it is important to check with your healthcare provider or pharmacist to see if the risks of any side effects are higher from combining the new medicine with your other existing medicines.

Keep in mind that just because the risk of side effects is higher does not automatically mean it is a bad idea to combine medicines. For example, it is possible that the extra benefit from combining medicines is much greater than the extra risk.

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## Chapter 26

# Tracking Your HS

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- I.** Introduction
- II.** HS Tracker Benefits
- III.** How to Start an HS Tracker
- IV.** Questions and Answers

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## I. Introduction

When you have a complicated chronic condition like HS, it can be challenging to keep track of your treatment history as well as thoroughly cover all the topics and concerns you hope to discuss with your doctor during your visits. It can also be difficult to accurately communicate what your experience with your HS has been like and how your disease has been trending between doctor visits. Additionally, triggers can be hard to identify as well.

**An HS tracker or journal is a tool that can help solve these problems as a simple, organized, and visual way to keep track of your HS journey.**

**An HS tracker can make it easier for you to track the course of your disease, identify potential triggers, and better evaluate your treatment response.**

This chapter covers the benefits of keeping an HS journal as well as recommendations around what to consider including in your journal.

## II. HS Tracker Benefits

Starting an HS journal can be a great way to keep track of your HS symptoms and to accurately relay to your healthcare provider what has been going on between visits. Although it would be ideal to see your doctor every week and keep them updated on your symptoms, the reality is that you are going to see them a few times a year, and during those visits you want to have a good way to express how you have been doing since you last saw them.

A journal can help your HS treatment journey in many ways, including:

- Keeping track of symptoms:** It can help you keep track of your HS symptoms like flares, pain, itch, drainage, and how often you are getting new boils.
- Keeping track of progress:** It can help you and your healthcare provider understand how your HS is trending. It can help you identify if your condition is overall worsening, which may indicate a need to re-evaluate your treatment plan. You would also have a record of your positive progress, like if you started a new medication that has been helping decrease

flares. It can be easy to forget the progress you have made after time has passed, so a journal can be a helpful reminder of how far you have come.

**Identify potential triggers:** It can help you identify different things that may be triggering your HS symptoms like certain foods, stress, weather, menstrual periods, clothing, etc.

**Agenda for your next doctor's visit:** It can be hard to remember everything you want to discuss with your doctor during your office visit, but keeping an HS journal can help you to remember the points you want bring up and questions you want to ask your healthcare provider.

A journal can also help your healthcare provider in many ways, including:

**Productive doctor visits:** A journal can be a more time-efficient way for your healthcare provider to understand what has been going on. They will be able to look through your notes and focus on things that they have identified are important and need more attention. This will lead to a more productive visit.

**Shared-decision making:** A tracker can help you and your doctor make thoughtful joint decisions, such as what medications to start or stop and what referrals to make based on how you have been doing.

## III. How to Start an HS Tracker

**An HS tracker should be a collaborative effort between you and your doctors. The first thing to do is to consult with your healthcare provider to determine what would be helpful to track between visits.**

Through a collaborative effort, it will be easy for you to track your progress and for your doctor to go through your notes during the visit.

The best HS journal is going to be one that is easy for you to use and one that you will be consistent with updating. An HS journal can be in a notebook, a printout template, or your electronic device like your phone or laptop.



You can also consider using the HS mobile app, which is designed specifically for people with HS. It will be available in an app store soon.

Some basic information to record in your HS tracker are dates, your HS symptoms (such as flares, pain, and itch), and the intensity of your symptoms (for example, mild, moderate, or severe). It is also important to write down any medications, supplements, and topical products that you start and stop. You can also choose to record other factors that can potentially affect HS, like stress levels, certain foods, and exercise, etc. **Table 26.1** lists examples of helpful things to

Table 26.1. HS Tracker Example Template

HS Tracker Items to Record	
Date	<ul style="list-style-type: none"> <li>Date, month, and year of each entry</li> </ul>
HS Symptoms	<ul style="list-style-type: none"> <li>Location of active boils</li> <li>Pain levels</li> <li>Itch levels</li> <li>Drainage levels</li> </ul>
HS Flares	<ul style="list-style-type: none"> <li>Location of any new boils or old boils that have reappeared</li> <li>Number of new boils</li> </ul>
Medications	<ul style="list-style-type: none"> <li>Start and stop date of all medications and supplements you are taking</li> <li>Topical products that you are using and number of times a day they are used</li> </ul>
Food Triggers	<ul style="list-style-type: none"> <li>List of foods that you ate that could potentially trigger your HS (which may include dairy, Brewer's yeast, simple carbohydrates, etc.)</li> <li>List of foods that you have noticed trigger flares</li> </ul>
Stress Levels	<ul style="list-style-type: none"> <li>Rate your stress level on a 1-10 scale</li> </ul>
Exercise	<ul style="list-style-type: none"> <li>Type of exercise you performed</li> </ul>
Other	<ul style="list-style-type: none"> <li>Other thoughts of what you feel may have an impact on your HS</li> <li>Notes on how your HS is impacting your quality of life</li> </ul>

include in your journal. You can always modify your journal to include or exclude things based on what is working for you and your doctor.

An example of a basic HS journal template can be found at the end of this chapter. It may give you inspiration for your own HS journal. Keep in mind it is just a sample and you are encouraged to tailor your journal based on what you know is important for you to track and also based on a conversation with your healthcare provider.

## IV. Questions and Answers

### Question 1

**How do I track my HS symptoms and flares?**

#### Answer



First, decide which method you are going to use to keep track of your HS symptoms like a notebook, printout sheet, electronic device such as your phone or laptop, or the HS App, a free comprehensive app that is coming soon, please visit the [hspatientguide.com](http://hspatientguide.com) website for updates!

Then decide with your doctor what information would be helpful to record. Sample items to include in an HS journal are listed in **Table 26.1**. Then you are ready to start recording!

### Question 2

**How can I tell what factors may trigger my HS?**

#### Answer

An HS journal is a great way to understand what factors may be triggering your HS. Recording potential triggers in your journal – such as stress, mood, food intake, and exercise – can show you patterns of what might be triggering your HS. When reviewing the data in your journal, you may notice certain patterns. For example, you may realize you repeatedly have flares after eating certain foods or after doing certain exercises.

**Question 3**

**How can I track if a medication is working or not?**

**Answer**

Sometimes it can be hard to tell whether a medication is working, especially if you have been taking it for a long time. An HS tracker can help with this since you can look back at your symptoms before you started taking the medication and look at your more recent symptoms to decide if you are having decreasing flares or pain. Showing your healthcare provider your symptoms before and after starting a medication can help you decide - as a team - if the medication is working or not.

**Question 4**

**How do I communicate how my symptoms have been doing in the time between visits?**

**Answer**

An HS journal is a great way to help communicate how you have been doing between visits. Before your appointment, look over your journal since your last visit to determine the topics you want to discuss with your doctor. An example scenario would be if you started adalimumab six months ago and notice you have fewer flares every month. That would be a great progress update to call out.

• **Figure 26.1. Blank Sample Journal Entry**

<b>Name:</b>	<b>Month:</b>		
<b>Number of HS flares this month:</b>			
<b>Flare characteristics</b>			
<b>Location of boil</b>	<b>Pain level (1-10)</b>	<b>Itch level (1-10)</b>	<b>Drainage (1-10)</b>
<b>New medications or supplements:</b>			
<b>Diet notes:</b>			
<b>Exercise notes:</b>			
<b>Other notes:</b>			

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## Chapter 27

# Experiences from People Living with HS

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- I.** My Experience with a Great HS Healthcare Provider
- II.** Working with HS, It Can Be Done
- III.** What is a Community Advocate and a Patient Advocate?
- IV.** How to Be an HS Community Advocate

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## I. My Experience with a Great HS Healthcare Provider

by **Athena Gierbolini**

As with most patients, I have had varied experiences with medical care professionals treating my HS. Most have a very limited understanding of HS, and a very small toolbox for treating this disease. It usually goes something like: antibiotics, bleach bath, incision and drainage if needed, and concludes with a conversation about weight loss and smoking.

**My first encounter with an HS Specialist changed me and my progression of course profoundly.**

Right away, her approach was different than any other healthcare provider I had met. We started with a conversation about my medical history and what medicines I had used that worked and did not work. She paid attention and asked a lot of questions about what types of medications I was comfortable with.

When it came time for the exam, she meticulously went over my skin and explained what was happening in each area. She answered questions and took her time making sure I felt educated and informed on the state of my disease. When she finished examining my skin, we discussed treatment options that included medication and procedures. Surgery had always been off the table for me because I work a lot and I live alone; recovery would be difficult and require lengthy periods of time off, or so I thought. She explained that, in my state of disease, surgery and medications would be best, then offered a surgical option that met my needs. She walked me through what an excision would be like, the recovery process and how beneficial it would be. It was a huge bonus that she would be doing the procedure herself in her office and I would not have to go under general anesthesia, but she would instead use a local (injection) anesthetic.

A few weeks later, I was in the office, undergoing that procedure without any pain. My Hurley Stage 3 (severe) HS was gone, and the post-operative pain was minimal. I was able to do the dressing

changes by myself, and the recovery went exactly as she said it would.

I have gone on to have three more procedures with her, and I am seeing good success with the medication she has prescribed. We plan to get more aggressive with medication as soon as my prescription insurance kicks in. For now, the HS is gone in two areas of my body, and I have so much more freedom to move than I have in a very long time. I feel comfortable communicating with her and addressing my concerns. She is fast in response time, and will accommodate me if I need an unplanned appointment for a steroid shot (intralesional steroid injection).

**It is so important to have a knowledgeable and dedicated healthcare provider to manage this disease.**

My life has drastically improved since my first appointment, and my anxiety has gone down considerably because I know I have a healthcare provider who is fighting this disease right along with me.

## II. Working with HS, It Can Be Done

by Christine Yannuzzi

Trying to maintain a career with HS can be daunting; tips on wound care, odor, dress codes, accommodations, and knowing how to deal with human resources (HR) can help. While it might seem uncomfortable, the best course of action is to start with your HR department and your direct manager. Bringing a guide to HS with you can help by opening up the lines of communication and giving your supervisory team a better idea of what you are dealing with, without having to go into personal details (see resources below). Remember, your personal health information is protected but the more transparent you are, the more likely you are to leave the interaction having achieved your goals.

Addressing your wound care needs at work can be difficult, but being prepared for emergency situations can help. Keeping a “go kit” can make this easier. Some items to include might be extra undergarments, cleansing wipes (witch hazel wipes are great), gauze, lidocaine, small scissors, tape, and medical grade honey (such as Medihoney®) or other healing ointment. You may also want to consider keeping small disposable bags for any soiled items (dog poo bags work great, as they are cheap, small, and often scented).

Dealing with odor can not only be hard, but extremely embarrassing. Mitigating odor by using products such as chlorhexidine wash (Hibiclens®) may help. Wearing loose-fitting clothing can be more comfortable. While talking about odor is far from easy, the more you share with your coworkers, the more understanding they will be. It is important to remember that you ARE NOT at fault.

Trying to adhere to a specific dress code is not always possible for HS sufferers. Certain fabrics, colors, and pieces of clothing can make or break a shift at work. Here again, communication is going to be your best friend. Dress codes are covered by the Americans with Disabilities Act (ADA), and as such, modifications are legally required in most circumstances. A note from your health care provider will most likely be required, and it is important that you discuss with your employer what

reasonable accommodations you need that will also fit in line with the company’s conduct rules. It is important to note that, *If an individual with a disability cannot comply with a dress code that meets the ‘business necessity’ standard or is mandated by federal law, even with a reasonable accommodation, he will not be considered ‘qualified.’ (The significance, n.d.) (Example, wearing a hard hat at a construction zone).*

These same rules apply to your work environment. A more comfortable chair, a standing desk, extra break times, a fan, and flexible hours are just some of the ideas you can discuss with your employer.

For many of us, being able to work outside the home is crucial to our wellbeing. Yet it can feel overwhelming trying to navigate a job with HS, which for many people is a disability. As such, it is important to be aware of your legal rights as an employee. Federal and state laws such as the ADA, Family and Medical Leave Act (FMLA), and Civil Liberties Act are all in place to help protect you. Know your limits, understand your employers’ policies, work toward creative solutions, and, most importantly, talk to your coworkers and management team. Remember, you are your best advocate.

### Resources

- <https://www.ada.gov/>
- <https://www.dol.gov/agencies/whd/fmla>
- <https://askjan.org/>
- <https://www.whatcanyoudocampaign.org/where-to-learn-more/resources-for-job-seekers-and-employees/>
- <https://www.hsconnect.org/copy-of-what-is-hs-cards>

### III. What is a Community Advocate and a Patient Advocate?

by Denise Fixsen

*It's important to know the difference.*

A community advocate differs from a patient advocate. An HS community advocate advocates publicly on behalf of HS; a patient advocate supports and advocates for someone with HS. You can be either kind of advocate for HS, or both, if you desire.

An HS community advocate:

- **Ensures factual information is being provided to the community and clinicians**

We post information daily and under relevant social media posts only: our articles, research, Dermatology list, etc. We also have a clinician section for those not educated in hidradenitis suppurativa, or maybe do not know all the resources available to them.

- **Breaks stigmas**

This is our biggest challenge, and one we must work on diligently. An example of this work is informing people that HS is not a gland illness, or infection of the glands. This stigma set us back decades, and continues to persuade the medical field to say you do not have hidradenitis suppurativa, because your abscesses or nodules are not in the right location. Breaking the stigmas—and there are many—is one of the most important things we can do as Community advocates.

- **Raises true awareness**

This goes with all of the above. However, we go above and beyond with special projects, such as our professional made awareness video, talent section on our website, our tattoo section, warriors sharing their stories, and, of course, on Awareness Week we make a lot of noise.

- **Obtains and shares reliable information and resources for the community**

All of this can be found on our website. We have an HS research section and HS physician article section. All our written material is based on research and or collaboration with physicians, and, of course, informed by decades of experience, which includes attending several sympo-

siums over the years. We also share information from the HS foundation. We screen everything before we share it. Anything but Google.

So those with the illness know and have reliable information. And it is our duty to promote true HS awareness.

**Important:**

When sharing written information with the HS community, stay mindful and ensure that the information you are providing is valuable, factual, reliable, and from reputable sources.

**Patient Advocates - In person or online is more of a hands-on approach**

We help those unable to advocate for themselves, or who may feel lost amid all the information; we can help navigate the system, and help those in need to ensure they understand their options. A patient advocate is someone who is “by their side” (in person or virtually) to ask healthcare providers or healthcare payors (such as insurance companies and or federal/state health programs) the right questions on their behalf, to ensure the patient understands the options, and, in many cases, make sure things happen.

Patient advocates may help with:

- **Doctor appointments.** Finding patients a doctor or going with them during a visit; calling around or emailing finding the right physician that specializes in hidradenitis; going with them on their visit as their advocate; making sure they understood with the doctor was explaining; making sure everything was taken care of, their needs were met, and their questions were answered.

- **Hospital visits/stays.** If someone isn't getting the care they need or deserve, this would be exactly what a patient advocate of the hospital would do: making sure the person you are advocating for is being taken care of is being heard and their needs are being met. If not, it is the Patient Advocate's responsibility to speak to the charging nurse, management, etc.

- ***Surgeries.*** If they are not being heard or not understanding the process, being their Advocate and speaking on behalf, if necessary. Explaining to a surgeon what the patient is asking for and why. Making sure they are being heard when they don't have a voice.
- ***Procedures.*** Making sure the patient and even the medical professionals know all the options. This is where reliable resources are crucial. Once they know all the options, they can discuss the best plan of action.
- ***Insurance companies.*** Help get things covered if they are being denied for things they need. This can be quite a process. The Advocate would have to know what information to provide both to the physician and the insurance company. This also requires you to work with the prescribing provider to ensure they are writing the letter properly able to appeal to, and even work on, outside insurance appeals.
- ***Medical bills.*** Assisting with setting up payment plans or help lower overall costs; working closely with the person you are advocating for; teaching them how to call around to set up payment plans, if they qualify; finding them a charity organization that might be able to help them pay bills.

To be a community or patient advocate takes desire, dedication, and passion. Most importantly, you must fully be educated on the illness. This also includes educating others. Patient Advocacy requires being able to communicate with clinicians, researchers, multiple personality types, and navigate challenging situations. As a patient advocate, there will often be times that you deal with people in desperate situations, which require the ability to listen, help formulate a plan, and follow through on commitments made to others. Being an advocate, especially a patient advocate, is not for everyone.

In most cases, a community advocate doesn't need to be as personally involved to extend their knowledge and understanding on social media or in support groups. Sometimes it's about letting others know you understand and that they're not alone, and just offering reliable information, resources, and opinions.

If possible, please share your personal experiences and journey of being a successful community advocate.

### **My own journey as an HS Advocate**

I have been an HS patient advocate for nearly three decades. I have worked with hundreds of hidradenitis patients and clinicians over the years. Due to several other illnesses, and being bed-bound, I have been doing everything from home, and due to the HIPAA laws, it has become trickier to help others. I have been a community advocate since the days of Yahoo support groups, in 2001.

As of March 2022, I have officially decided to concentrate on our organization, mentor community advocates and retire from patient advocacy altogether. Around 2017, I met the other co-founder of HS Connect, Brindley Brooks, and both of us had a passion to create a safe place where everybody could go for reliable and, most importantly, accurate hidradenitis suppurativa information and resources.

We started the process in 2018 and launched our website in 2019. In 2021, we officially became a 501c 3 (nonprofit organization). We have grown and blossomed into something beyond our dreams. We are averaging 8,000 visitors a month and roughly 10,000 visitors from HS support groups. Our support group is quickly reaching 10k members. And we're continuously growing. We're helping so many that suffer and getting the opportunity to work with amazing organizations, foundations, and HS medical professionals.

### **Resources**

- <https://www.hsconnect.org/post/patient-advocates>

## IV. How to Be an HS Community Advocate

by **Donna Atherton**

Let me begin by sharing the reason for creating the International Association of Hidradenitis Suppurativa Network (IAHSN). At an annual physical, my primary care physician (PCP) and I discussed my ongoing problem with Hidradenitis Suppurativa (HS). My PCP handed me a list of foods (nightshades, sugar, bread) to avoid eating. The list was to help reduce inflammation and flares. I looked at the list and replied, “I can’t eat anything! What can I eat?” She laughed! I drove home thinking about the long list of foods to avoid, against the echoing memory of her laughter.

So when I got home, I created IAHSN on Facebook and Twitter: a place to share information to help others with HS. On that day, I made a commitment to advocate for hundreds, thousands, or even millions of people living with HS. So let me share a few skills that I have learned over the years as a HS advocate. This section will guide you as a new HS community advocate. By using these skills, you can achieve success.

Each action builds on the previous skill, and it is up to you how you take action. Such actions will motivate your growth as an HS community advocate. You will build confidence, knowledge, and skills as a community advocate.

Let’s start with a personal story. Your story should project powerful images that influence the listener. You must speak with power about an issue that will move the listener. You want them to become engaged in your story.

Write a letter and send it to your elected officials. In a few days, follow up with a telephone call. This action is not difficult. Educate officials about what is happening in their district or state. Introduce yourself and share your passion for the issue. This action allows decision-makers to know how best to represent you. In your letter, include your contact information and request a response. Schedule a yearly, in-person meeting with your Senator or their aid. You will be able to discuss your HS advocacy work throughout the year. Don’t forget to leave your pamphlets, brochures, flyers, and business cards.

Promote HS Awareness Week and send a letter to your State’s Governor. Request, in writing, a Proclamation signed by your Governor. This action acknowledges HS Awareness Week in June. Then host or participate in events promoting HS Awareness.

Let people know about HS by hosting a table at an event. This is a great way for community members to get information. Present at a local event or the Chamber of Commerce in your area. This will alert others in the community of your advocacy work. Promote ways of becoming involved as a volunteer, such as health fairs, expos, walkathons, trade shows, and conferences. These are great venues to host a table.

If you feel adventurous, host a walkathon, bike-a-thon, or jog-a-thon. A walkathon brings the community together and promotes awareness in a fun environment.

Fundraising is another way to promote HS community advocacy. You can host a community event. Host a small event and invite family and friends. As the host, provide some light food and drinks. This is a great way to share your successful work in a relaxed setting. Parties can include guest speakers, short videos, or presentations. Hosting a party can highlight the importance of investing in your work to your guests.

At the end of the evening, request a contribution. This allows you to continue your work as an HS community advocate. Another option is to donate the funds to HS nonprofit associations. Lastly, collaborate with other advocates or associations. It’s just that easy!

### Resources

- [https://www.verywellhealth.com/  
how-to-become-a-patient-advocate-or-  
navigator-2614922](https://www.verywellhealth.com/how-to-become-a-patient-advocate-or-navigator-2614922)

Authors: **Brindley A. Brooks, Lucas Swihart**

## Chapter 28

# Experiences from HS Caregivers

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- I. Caring for A Child with HS
- II. Caring for A Partner with HS

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## *I. Caring for A Child with HS*

*by Brindley A. Brooks*

Whether or not you have HS yourself, parenting a child with HS presents unique challenges. You have already taken the critical first step in learning how to advocate for your child by educating yourself!

The toll that HS can take on your child's self-esteem is immeasurable. This disease is not their fault, nor is it yours. Triggers for each person differ greatly—this is not a one-size-fits-all disease. There is no cure, and treatment options are currently limited. Building and maintaining trust with your child about their HS is the best thing you can do.

Helping your child understand the difference between pain and discomfort is important. This is crucial to most everything else having to do with their HS. Empower your child to decide what they can and cannot do; this is especially hard for parents who think they know best (like me)! When they tell you they cannot do something, listen. This doesn't mean not to challenge them, but it does mean they need to determine their limitations. There are many of us who, despite having HS, have successful careers, marriages, kids, and lives.

The teen years are by far the most difficult. The social implications are far reaching: the odor that can accompany abscesses, an abscess draining unexpectedly during school, changing clothes in physical education (PE) class, or the "HS walk" when you have a groin flare.

Being understanding and supportive is often times all you can do, and all your child needs. Be a safe place for your child to land. Be open with your communication, ask questions, look at the wounds. Check in often with your child on their mental health status. Depression rates are much higher amongst HS patients than others.

**Advocating for your child can look like any of the following:**

- Sending a letter to the school outlining the condition, what your child can or cannot do, and why they may ask to use the restroom more than other students.

- Asking your dermatologist for a note to excuse your child from PE during the school year, when they do not feel that they can participate.
- Listening to your child when they tell you what they need and accommodating (as much as possible). If they say they are too uncomfortable to go to school, listen.
- Encouraging them to carry on with life despite their HS, but in relation to what they physically can or cannot do.
- Understanding that, just because an abscess is not large, it does not mean it's not as painful as a large abscess.
- Helping them learn how to cope with the pain that comes with HS is challenging, as the normal pain treatments (such as opioids) are not typically used for children, and can lead to dependency. Finding an alternative pain control method is highly suggested.
- Talking through options with the dermatologist AND your child, their opinion matters. In my experience, some of the proposed treatments can have side effects that may be worse than the disease itself (i.e., Vitamin A derivative treatment) so please familiarize yourself with the treatment options. Do not be afraid to stand up for your child at appointments; it is your responsibility to be as knowledgeable as the doctors you are seeing, to ensure the best care for your child.
- Getting help and support for yourself. For as much support as you offer them, please be sure you have a place to get support for yourself as well. You will need assistance in navigating through this journey with your child, just as much as they need you.

## *II. Caring for A Partner with HS*

*by Lucas Swihart*

Many people do not choose to become a caregiver of an HS patient—it just happens. When I met my now-wife, she was very independent and lived an active lifestyle. Little did I know she also dealt with a serious skin condition called Hidradenitis Suppurativa. She did not try to hide it from me, it was something that she did not even know had a name. Her symptoms started when she was about 15 years old, and she was not diagnosed until she was 38, when the disease became a focal point in all our decisions.

For everything we chose to do, we had to take into consideration if she would be comfortable enough to enjoy it, if it was even possible, and, if we partake in this activity, will it be worth the outcome we will most likely see in the next few days? So I have gone from seeing my wife live with this issue when it was very manageable to seeing her lying in bed crying, unable to find comfort. I chose to stay by her side and help her as much as I was capable of at that time. I hope that the following words I share will shed insight on how you can help your loved one with HS.

**Be Present.** Being with the person, both emotionally and physically, is important, and not an easy role. Emotionally, it can be very draining. It is hard to watch someone continuously be beaten down. Every time we thought we were getting a foot in front of the other, we were taking two steps back. She experienced severe anxiety and depression and, at times, could not leave the house. The life she was used to was slowly being taken away, and, at times, I did not see it. I did not see her emotional turmoil or the anxiety she was facing. I have learned to be empathetic by trying to put myself in her position, to just imagine what thoughts and feelings are going through her head. Be there physically, because they will need you in ways that we do not realize.

**Be Supportive.** While offering support, it is also important to know when to back off. This is easier said than done. Watch and offer assistance to make it easier on them; just remember they may be in

denial, or struggling with how to ask for help. If they snap at you, remember to stay calm and take mental note of what could be done differently, or addressed at a more appropriate time. Instead of coming to the rescue each time, let them try to find a way that works for them.

**Be Understanding.** Remember to be understanding of all the changes your loved one is going through. They are fighting a battle within themselves, and we sometimes get the backlash for things out of our control. I am not condoning verbal or physical abuse, but things may be said that are not directed towards you, but said out of frustration.

**Be Prepared.** So far, we have mentioned the need to be present, supportive, and understanding. I would like to end with being prepared. You must be prepared for everything at all times, from emotional roller coasters (you will never know what will trigger a breakdown), first aid needs, and new life changes. Regarding first-aid needs, be on the lookout for lost gauze when out in public and even at home. You never know where they might fall out. And whatever you do, do not make a big deal with an “Ewwww, is this yours?” Just pick it up or ask nicely, “Did you drop this?” Learn to have a never-ending supply of bandages of all sizes and types, in every vehicle and at home. You will need them at some point. More than anything, keep letting the person you care for know they are still special to you, attractive, and that you love them just the same as the day you first fell in love.

Authors: **Claire Elizabeth Herzog, Rob Leland Shaver,  
Michelle Anne Lowes, Noah Goldfarb**

## Chapter 29

# Pipeline Therapeutics for Hidradenitis Suppurativa

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- I.** Introduction
- II.** What is a clinical trial?
- III.** What is a drug target?
- IV.** How does HS develop?
- V.** Pipeline medical therapies
- VI.** Reference articles
- VII.** Questions & Answers

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## I. Introduction

Research into new drugs for hidradenitis suppurativa (HS) has greatly increased in the last 20 years. New drugs being studied in clinical trials may become good treatment options for helping treat HS in the future. This chapter explains the clinical trial process, what a drug target is, how HS occurs, and reviews the drugs being studied in clinical trials for HS (often called “the pipeline”).

## II. What is a clinical trial?

Clinical trials test new drugs to see whether they are safe and effective for treating a given disease. There are four stages of clinical trials referred to as “phases”. Phase I trials test drug safety and look for harmful side effects. Phase II trials continue to evaluate safety and test whether a drug is effective at treating a specific disease, comparing people taking the drug being studied with people taking a “fake” drug (also called placebo group). Phase III trials test the effectiveness of drugs across larger and more diverse groups of people. In the United States, after the drug has been tested in Phase I through III trials, the drug may be approved by the Food and Drug Administration (FDA). Once a drug becomes approved by the FDA, doctors can prescribe the drug to patients. Phase IV trials take place after FDA approval and entail collecting more information as the drug is used by the larger general population. A detailed description of clinical trials Phases I-IV and a complete list of active clinical trials for HS can be found at [clinicaltrials.gov](https://www.clinicaltrials.gov)

## III. What is a drug target?

Drugs work by binding and blocking “targets” that cause disease. The most common drug targets are called *ligands* and *receptors*. Ligands are small proteins that tell cells to carry out tasks. Ligands convey a message to the cell by binding to their specific receptor on the cell surface. Through ligands and receptors, cells can talk to each other and carry out functions. Problems with ligands or receptors can lead to cells carrying out the wrong functions that may lead to disease.

The immune system is a complex network of cells and proteins that defend our body against

sickness and disease. When prompted, immune system cells release ligands called *cytokines* that bind receptors on other cells. As a result, cells are told to turn on (or activate) inflammation to fight off disease. Our current understanding is that the immune system is overactive in HS, causing inflammation when it is not needed and harming healthy tissue. Drugs used to treat HS can bind to and block cytokines or receptors involved in this process, stopping the inflammation and damage to healthy tissues that we see in HS.

There are many types of drugs, and a general principle is that the structure of each drug determines its overall function. One type of drug is called an *antibody*. Antibodies are special proteins made by the immune system that recognize and block harmful substances in the body, such as bacteria, viruses, and toxins. Antibodies can also be made in the laboratory and given as a drug to recognize and block disease-causing proteins. For instance, an antibody can be made to recognize and block a cytokine known to cause inflammation in HS. In this way, antibodies can be a good treatment for some patients with HS. Many drugs being made and studied for HS are antibodies and are given the ending to their name “-mab” (e.g., adalimumab). Most antibody drugs are given as an injection or an infusion.

## IV. How does HS develop?

Knowing how HS occurs in the body helps researchers decide what targets may be important for new HS drugs to block. The red lumps (“nodules”), boils (“abscesses”), and tunnels that form in HS are thought to start with a plugged hair follicle that widens and bursts open into the skin. Abnormal hair follicle structure, hormones, smoking, increased body weight, and chronic rubbing of the skin may play a role in the hair follicle plugging and bursting. Abnormal levels of bacteria living on the skin and in the hair follicles may also add to the inflammation seen in HS.

Bursting of the hair follicle in the skin starts a series of events that cause the skin to become red, warm, swollen, and painful. The material of the ruptured hair follicle activates cells called *macrophages and dendritic cells*. These important cells act as the “guards” of the immune system and release cytokines that produce inflammation. Some

of these cytokines include tumor necrosis factor alpha (TNF- $\alpha$ ) and interleukins (IL), such as IL-1, IL-17, and IL-36. One of the major effects of these cytokines is calling white blood cells called *neutrophils* to the skin or other sites of inflammation. Neutrophils normally reside in the blood stream but can travel to the skin if they are needed to help fight infection in response to trauma. Neutrophils are the “first responder” cells and they both release toxic substances that may hurt tissues and call even more neutrophils into the skin. Pus forms as a result of neutrophils migrating to the skin and causing inflammation. *Complement* is another system used by the immune system to fight off infections. Proteins that are part of the complement system seem to be abnormally activated in HS. One protein involved in complement, called complement 5a (C5a), recruits even more neutrophils to the skin. The inflammation caused by neutrophils, cytokines, and complement lead to the nodules, abscesses, and draining tunnels seen in HS. Drugs that block the functions of neutrophils, cytokines, and complement may reduce the inflammation thought to cause HS.

## V. Pipeline medical therapies

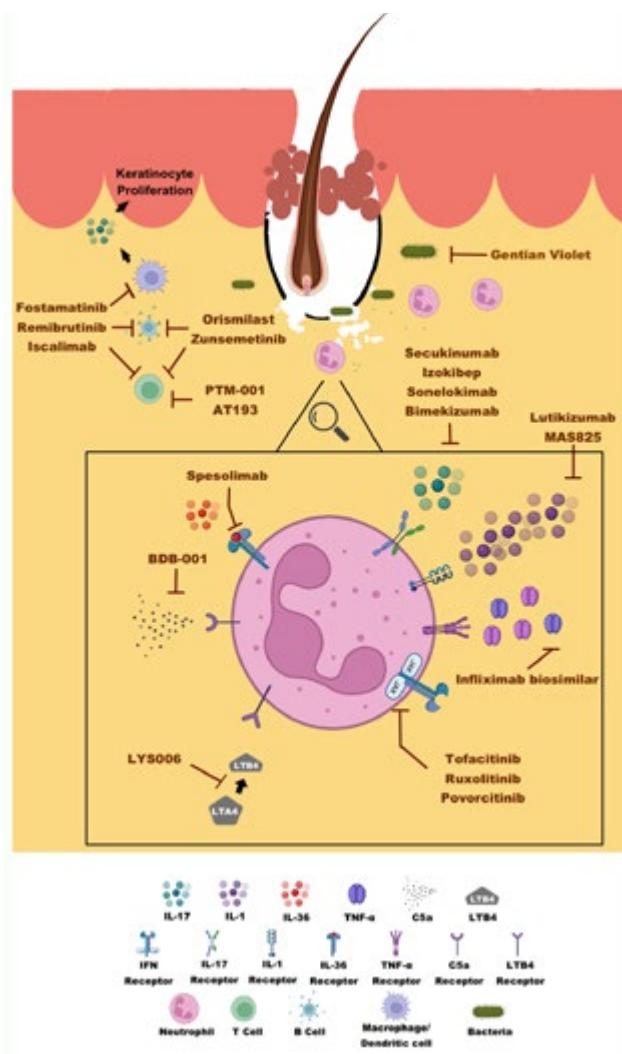
Drugs being studied in clinical trials for HS are described below based on the main target of each drug. Table 29.1 lists those clinical trials for HS that are active, recruiting, or not yet recruiting at [clinicaltrials.gov](https://clinicaltrials.gov) as of January 1, 2023. Drugs being studied that do not yet have a formal name are typically identified by a combination of letters and numbers (e.g., ABC-123). Figure 29.1 illustrates targets of new drugs that are being studied for HS.

**Neutrophils & Complement.** As mentioned above, neutrophils are one of the cell types that are most active and destructive in HS. Large numbers of neutrophils are called to the skin by inflammatory cytokines and some fatty molecules, called lipids. An example of a lipid that recruits neutrophils to the skin is called LTB4. A new oral drug, called LYS006, stops cells from making LTB4 and therefore prevents neutrophils from migrating to the skin and causing inflammation. LYS006 is currently being studied for HS in a phase II trial.

Blocking the complement pathway can also reduce the number of neutrophils called to the skin. There are two drugs that have recently been stud-

ied for HS that block the complement pathway. BDB-001 is monoclonal antibody drug given as an injection that directly blocks C5a to lessen inflammation. The safety of this drug is currently being studied in early phase clinical trials. Avacopan, an oral C5a receptor blocker, and IFX-1 (also called vilobelimab), an injectable drug that blocks C5a itself, both recently completed phase II trials for HS. Press releases from both phase II studies have reported improvement in HS, but not significantly greater than placebo. However, makers of both Avacopan and IFX-1 are committed to further test whether these C5a blockers will be safe and effective for some HS patients.

**Cytokines.** Adalimumab is an antibody drug that is currently the only FDA-approved drug treatment for moderate to severe HS. TNF- $\alpha$  levels are increased in HS and adalimumab blocks this cytokine from causing inflammation in the skin. Infliximab is another antibody drug that blocks



• Figure 29.1

TNF- $\alpha$  that is FDA-approved for rheumatoid arthritis, plaque psoriasis, and inflammatory bowel disease. A small study of 38 patients showed that treatment with infliximab for 8 weeks significantly improved HS compared to placebo. Because of these results and positive results from other small studies, infliximab is sometimes prescribed when HS fails to improve with adalimumab. Though not currently FDA-approved for HS, the North American clinical management guidelines for HS recommends infliximab as a potential treatment option for moderate to severe HS. A new drug that is similar to infliximab, sold under the name Infliximab biosimilar, has just entered the HS drug pipeline and is currently undergoing a phase I trial for HS.

Other cytokines involved in HS inflammation include IL-1, IL-17, and IL-36. There are several drugs in clinical trials that block these cytokines in attempt to stop the inflammation seen in HS.

IL-1 is a cytokine that causes inflammation and is found in high amounts in HS skin and blood. A small study showed that an IL-1 receptor blocker, Anakinra, was effective for HS. Since then, several new treatments aimed at blocking IL-1 have joined the medical pipeline for HS. Lutikizumab, a new antibody drug that binds IL-1 was recently developed and will be studied in an upcoming phase II trial for HS. MAS825, an IL-1 blocker that also blocks IL-18, another cytokine, has previously been studied for COVID-19 infections, and is now in a phase II trial investigating its efficacy for HS.

IL-17 is found in high amounts in HS skin and blood. One IL-17-blocking drug, called secukinumab, is FDA-approved for plaque psoriasis and psoriatic arthritis and has been in the drug pipeline for HS for several years. In Fall 2022, the makers of secukinumab shared the results of two large phase III trials. Excitingly, a significant number of patients treated with secukinumab in these trials experienced improvement in their HS compared with placebo. The makers of secukinumab plan to submit these results to the FDA in 2023 with hope that secukinumab can become the second FDA-approved medical therapy for HS. Bimekizumab, a unique IL-17 blocker showed very good results in a recent phase II trial. Bimekizumab also completed two phase III trials that showed greatly improved signs and symptoms of HS. The results

of these studies have not yet been published, but results have been presented at national meetings and announced in press releases. Currently, the long-term effects are still being studied in a follow-up phase III trial seeing how patients do on the treatment over 120 weeks. Two additional new IL-17 blocking drugs similar to secukinumab, called izokibep and sonelokimab, will be also studied in upcoming phase II trials.

IL-36 is another cytokine that is found in high amounts in HS skin and is thought to contribute to the inflammatory process seen in HS. One antibody drug that blocks IL-36, called spesolimab, received FDA-approval for the treatment of a rare skin condition called generalized guttate psoriasis in October 2022. Spesolimab is currently being studied in a phase II trial for HS. Recently, another IL-36 blocker, Imsidolimab, completed its phase II trial for HS, and unfortunately, was not found to be effective.

**Janus Kinase.** Janus kinases (JAKs) are proteins attached to many cytokine receptors and help relay messages from ligands and receptors to the inside of the cell. There are four different JAK proteins (called JAK1-3 and TYK2) that are attached to many kinds of cytokine receptors. The first FDA-approved JAK blocker drugs were tofacitinib (JAK1-3 blocker) and ruxolitinib (JAK1-2 blocker). Tofacitinib is FDA-approved for treatment of rheumatoid arthritis, psoriatic arthritis, and ulcerative colitis. So far, there have only been three reported cases of tofacitinib being effective for HS. Tofacitinib will be studied in a planned phase II trial for multiple inflammatory conditions in patients with Down Syndrome, including HS. Oral ruxolitinib is FDA-approved for treatment of several bone marrow diseases. Ruxolitinib is also made as a topical medicine. Topical ruxolitinib is FDA-approved for atopic dermatitis and vitiligo and will be studied in two phase II trials for HS. Povorcitinib, a new JAK1 blocker, has finished two small phase II trials and was shown to be safe and effective for treating HS in a small number of patients; a phase III trial is now underway.

**Multiple immune system cells.** Several of the new drugs in phase I and II trials block proteins and receptors that affect many different immune cells and pathways of inflammation. Fostamatanib, Remibrutinib, Zunsemetinib, and Orismilast, are

all oral medications that affect the ability of various immune cells to function. Fostamatanib and Remibrutinib uniquely also affect B-cells, which produce antibodies. Zunsemetinib and Orismilast reduce the ability of immune cells to produce and respond to cytokines, specifically TNF- $\alpha$  and IL-1. While Orismilast reduces inflammation, it does not significantly reduce the immune system's ability to fight off infections. For some people, this may make Orismilast more appealing than other anti-inflammatory drugs. Apremilast, a drug similar to Orismilast, has previously been shown to be effective for less severe HS. Iscalimab is a unique injectable drug that blocks a receptor needed to activate various immune system cells including as macrophages and dendritic cells, as well as B-cells. AT193 is a topical medication that reduces the ability of immune cells to produce IL-17. PTM-001 is an oral receptor blocker that also influences IL-17 production, but more prominently affects cells' ability to produce IL-1 as well as TNF- $\alpha$ .

**Other Drugs.** Gentian violet is an anti-bacterial dye that is cheap and can be obtained over-the-counter (i.e., without a prescription). This topical medicine could be a cost-effective option for patients with HS if it is shown to be effective in clinical trials. Metformin, a drug that is FDA-approved for the treatment of type II diabetes mellitus, has shown promise for patients with HS in small studies. Metformin works by boosting insulin sensitivity and lowering blood sugar, making it a very useful treatment for type II diabetes. Metformin is also thought to reduce inflammatory cytokines that cause disease in HS. A phase III clinical trial is planned to see if metformin could be a good treatment option for patients with HS.

Table 29.2 lists the new non-drug treatments being studied in clinical trials for HS as of January 1, 2023. A detailed review of these treatments is outside the scope of this chapter.

The future of HS treatment appears bright with these promising new therapies being studied in clinical trials, and there is hope that more safe and effective treatment options will become available for patients soon.

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## VII. Questions and Answers

### Question 1

How can I find an HS clinical trial in my area?

### Answer

Visit [clinicaltrials.gov](https://clinicaltrials.gov). Under the section titled “Find a study”, select the status “Recruiting and not yet recruiting”. Next, in the section labeled “Condition or Disease”, enter “Hidradenitis Suppurativa” and select your country and state. The site allows you to search for clinical trials in specific cities and within a certain distance from your home.

Table 29.1. Drugs currently in the clinical trial pipeline for hidradenitis suppurativa

	Drug Name	Route	Target(s)	Sponsor	Phase	Status
Neutrophils/ Complement	LYS006	Oral	LTA4 hydrolase	Novartis Pharmaceuticals	II	Recruiting
	RIST4721*	Oral	CXCR2 receptor	Aristea Therapeutics Inc.	II	Recruiting
	BDB-001	SC	C5a	Staidson (Beijing) Biopharmaceuticals Co., Ltd	I/II	Recruiting
TNF- $\alpha$	Infliximab biosimilar	SC	TNF- $\alpha$	Services Institute of Medical Sciences, Pakistan	I	Active, not recruiting
IL-1	Lutikizumab (ABT-981)	SC	IL-1	AbbVie	II	Recruiting
	MAS825	SC	IL-1/IL-18	Novartis Pharmaceuticals	II	Recruiting
IL-36	Spesolimab	IV, SC	IL-36 receptor	Boehringer Ingelheim	II	Active, not recruiting
	Imsidolimab*	IV, SC		AnaptysBio Inc	II	Active, not recruiting
IL-17	Secukinumab	SC	IL-17	Novartis Pharmaceuticals	III	Recruiting
	Izokibep	SC	IL-17	Acelyrin Inc.	II	Recruiting
	Sonelokimab	SC	IL-17	MoonLake Immunotherapeutics AG	II	Recruiting
	Bimekizumab	SC	IL-17	UCB Biopharma SRL	III	Active, not recruiting
JAK	Tofacitinib (for various indications in patients with Down Syndrome)	Oral	JAK 1-3	University of Colorado, Denver	II	Recruiting
	Ruxolitinib 1.5% cream	Topical	JAK 1-2	Milton S. Hershey Medical Center Incyte Corporation	II	Recruiting
	Povorcitinib (INCB054707)	Oral	JAK 1	Incyte Corporation Incyte Corporation	III III	Not yet recruiting Not yet recruiting

Table 29.1. Drugs currently in the clinical trial pipeline for hidradenitis suppurativa

	Drug Name	Route	Target(s)	Sponsor	Phase	Status
Multiple Immune System Cells	Fostamatinib	Oral	SYK	Rigel Pharmaceuticals	II	Recruiting
	Remibrutinib (LOU064)	Oral	BTK	Novartis Pharmaceuticals	II	Recruiting
	Zunsemetinib (ATI-450)	Oral	MK2	Aclaris Therapeutics Inc.	II	Active, not recruiting
	Orismilast	Oral	PDE4	UNION therapeutics	II	Not yet recruiting
	Iscalimab (CFZ 533)	SC	CD40	Novartis Pharmaceuticals	II	Recruiting
	AT193	Topical	Aryl hydro-carbon receptor	Azora Therapeutics Inc.	I	Active, not recruiting
	PTM-001	Oral	P2X7 receptor	Phoenicis Therapeutics	II	Recruiting
Other Meds	Gentian Violet	Topical	Bacteria	Wake Forest University Health Sciences	II	Not yet recruiting
	Metformin	Oral	Anti-diabetic	Erasmus Medical Center	III	Unknown

Phase I-III clinical trials registered with clinicaltrials.gov for hidradenitis suppurativa that were either active, recruiting or not yet recruiting as of January 1, 2023.

Abbreviations; CXCR, CXC chemokine receptor; C5a, complement 5a; LTA4, leukotriene A4; IL, interleukin; IV, intravenous; JAK, Janus Kinase; SC, subcutaneous injection; PDE4, phosphodiesterase 4; TNF, tumor necrosis factor; MK2, p38MAPK-activated protein kinase 2; SYK, spleen tyrosine kinase

\* While still in clinical trials as of January 1, 2023, at the time of publication these drugs were no longer in the pipeline for HS treatment. The trial for RIST4721 was stopped due to safety concerns. A press release from the company for Imsidolimab stated that the results from their phase II clinical trial did not show that it was effective for HS and the company will be stopping Imsidolimab's development for HS.

Table 29.2. Procedures, wound care, and complementary and alternative medicine (CAM) currently in the clinical trial pipeline for hidradenitis suppurativa

	Name	Sponsor	Status
Procedures	Alexandrite Laser	Wayne State University	Active, not recruiting
	Axillary deroofing followed by serial 1064nm Nd:YAG laser treatments	University of Texas at Austin	Not yet recruiting
	Axillary perforator flap versus secondary wound healing	Assistance Publique - Hôpitaux de Paris	Not yet recruiting
	Botulinum toxin	University of Pittsburg	Recruiting
	Fecal microbiota transplantation for various indications	Odense University Hospital	Not yet recruiting
	Fractional ablative 2940nm Er:YAG laser for HS scarring	Montefiore Medical Center	Not yet recruiting
	Fractional ablative carbon dioxide laser with topical steroids	University of Southern California	Not yet recruiting
	Intralesional diode laser	Zealand University Hospital	Recruiting
Wound Care	Methylene blue, gentian violet, and bovine forestomach	Wake Forest University Health Sciences	Not yet recruiting
	NovaSorb® biodegradable temporizing matrix versus human allograft	Joseph M. Still Research Foundation, Inc	Not yet recruiting
	Observational registry for use of Myriad Matrix™ and Myriad Morcells™ in soft tissue reconstruction for various indications	Aroa Biosurgery Limited	Recruiting
	Petrolatum w/ non-stick bandage vs wet-to-dry dressing post HS surgery	University of North Carolina, Chapel Hill	Recruiting
	Procellera bioelectric dressing vs gauze dressing post deroofing	University of Miami	Recruiting
CAM	Battlefield Acupuncture	Wayne State University	Recruiting
	Mindfulness Training	University of Miami	Not yet recruiting

Phase I-III clinical trials registered with clinicaltrials.gov for hidradenitis suppurativa that were either active, recruiting or not yet recruiting as of January 1, 2023.

Abbreviations. Er:YAG, erbium-doped yttrium aluminum garnet laser; Nd-YAG, neodymium-doped yttrium aluminum garnet; nm, nanometer.

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## Chapter 30

# The Future of HS

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- I.** Introduction
- II.** HS Education and Awareness
- III.** Improvements in Patient Care
- IV.** New Ways to Measure HS
- V.** New Treatment Options
- VI.** The Future

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## I. Introduction

The HS community, including people living with HS, healthcare providers, researchers, and drug company partners, has been working together to help improve care and quality of life for people with HS. The largest survey of HS patients across the world - called the VOICE project - shed light on many unmet needs within the HS community, including low disease awareness, late diagnosis of HS, problems accessing providers who know about HS, limited ways of measuring HS, and insufficient options available to treat HS symptoms (e.g., severe pain). However, several efforts are underway to address these unmet needs within the HS community.

## II. HS Education and Awareness

Many people still do not know about HS.

For most people with HS symptoms, it takes 7-10 years and more than five healthcare provider visits to receive an HS diagnosis.

It is often difficult for HS patients to find a healthcare provider who knows a lot about HS. A possible solution to this is the development of *HS Specialty Clinics* with health care providers who are knowledgeable about taking care of HS patients and who work closely with other types of providers such as pain specialists, nutritionists, and wound care providers.

As of January 2023, there are over 50 HS clinics in the United States, but 27 states do not have an HS clinic (<https://www.hs-foundation.org/hs-specialty-clinics>). The creation of more HS clinics, especially in areas without them, will be of great benefit.

The Hidradenitis Suppurativa Foundation (HSF) is a non-profit organization with a mission to improve the lives of people affected by HS through research, advocacy, and education.

The HSF website ([www.hs-foundation.org](http://www.hs-foundation.org)) has many resources. There is a section for healthcare providers with published HS treatment guidelines, updates on new research about HS, patient handouts on HS for their offices, and resources

for working with insurance companies to obtain HS medications. The HSF website also provides resources for patients, including education about what HS is, the symptoms and causes of HS, treatment options, and explanations of new research results.

To increase education among medical providers, the US and Canadian HSFs have organized an annual scientific Symposium on Hidradenitis Suppurativa Advances (SHSA).

Founded in 2016, this is a meeting that brings together providers from all over the world to share recent research findings and discuss new and better ways of caring for patients with HS. In addition, the HSF has created two new programs to develop the next generation of HS providers: the *HS Mentorship Program* and the *HS Academy* (also known as the HS Resident Symposium). The goal of the HS Mentorship Program is to have young doctors work with and learn from HS experts, to be able to become HS experts themselves. The HS Academy is a conference intended to teach young doctors the skills to best care for their patients with HS. In addition to provider education, the HSF also works to educate patients and the community.

The HSF recently started the HS Spotlight, a yearly program that educates patients about HS. The HS Spotlight has several different types of health care providers talk about pain management, mental health, wound care, and overall wellness in the context of living with HS.

Another exciting educational resource is the 2022 publication of a new textbook called *A Comprehensive Guide to Hidradenitis Suppurativa* to help improve HS patient care by all healthcare providers.



An HS App to help people with HS easily track their condition on their phones will be available in 2023 (please see *Chapter 26* for more information).

In addition to the HSF, there are several other non-profit organizations that provide support and education to patients.

In the last several years, groups such as Hope for HS, HS Connect, and HS Warriors have been founded, among many others. These HS communities have grown to become one of the most important sources of support and education for patients.

Working together, drug companies, the HSF, and several non-profit support groups have increased HS awareness. Through social media campaigns as well as TV and radio advertisements for medications, we are starting to see a rising awareness of HS in both the medical community and the general public. In addition, over the last several years, *HS Awareness Week* (the first week in June) has been recognized by increasing numbers of states throughout the US and Canada.

### III. Improvements in Patient Care

To improve patient care, the US and Canadian HSFs published the *North American HS Management Guidelines* in 2019. These guidelines developed by HS experts give providers the tools to evaluate and care for HS patients. The guidelines tell providers how best to determine HS severity, test for other associated conditions (also called comorbidities) and choose the best treatment options for each patient. They include information on medications, procedures, and wound care - all of which are important components of treating HS. *Comorbidity screening guidelines* for HS were published in 2021 and include recommendations on which associated conditions to look for in HS patients, including joint pains, diabetes, high blood pressure, high cholesterol, and mental health problems. These guidelines are all available on the HSF website. More guidelines are currently being created, including how to best care for people with HS in certain situations (for example, those who are pregnant, have cancer, or have severe heart problems).

Recent research from the *COVID-19 HS Registry* provides important information on how COVID-19 affects HS patients and interacts with HS medications. Patient registries are an important type of research in which investigators collect data on patients who have a condition, and then follow patients over time to evaluate their dis-

ease course and also response to treatments. The COVID-19 HS Registry collected information from HS patients all around the world who developed COVID-19. The registry data showed that the use of biologic therapy was not associated with increased COVID-19 severity in HS patients. This study helped providers give recommendations to HS patients about medication use during the COVID-19 pandemic.

In addition, a recently published *consensus paper* by a group of HS experts provided recommendations on COVID-19 vaccinations, infection risks, and considerations on medication use during the pandemic.

### IV. New Ways to Measure HS

There is a group of patients, physicians and drug company partners who are working together to find new and improved ways of measuring HS and how it affects patients' lives, called **HISTORIC** (which stands for **H**idradenitis **S**uppura**T**iva **c**ORe **o**utcomes **s**et **I**nternational **C**ollaboration).

This group is developing new surveys and tools to measure HS symptoms, HS skin changes, HS pain, and the effect of HS on daily life. These tools will be helpful for new HS studies and eventually for clinical care.

### V. New Treatment Options

Studies show that almost half of HS patients are dissatisfied with the current treatment options for HS. It is therefore extremely important that we find new treatments for patients. There are currently a number of new drugs being studied in clinical trials for HS that are discussed in detail in *Chapter 29*. Currently, most of the research on HS happens in North America and Europe. Work is being done to expand HS research to more countries, as well as include more patients of different racial groups in clinical trials.

Other exciting areas of research include that of complementary and alternative medicine (CAM) practices, including acupuncture and cannabidiol (CBD) to help manage HS pain; the impact of diet and weight management on HS; and possible

genetic influences on HS. The great increase in HS research has been in part made possible due to increasing government funds for HS studies, specifically from the National Institute of Health (NIH). The HSF also gives Danby Research Grants and Translational Research Grants to investigators studying HS. Hopefully, this trend of increasing financial support continues for years to come.

**To move other areas of HS research forward, an exciting new project is underway called HS PROGRESS (which stands for Hidradenitis Suppurativa PRospective Observational REgistry and bioSpecimen repository).**

HS PROGRESS is a large patient registry collecting information and research samples from HS patients across North America.

**The mission of HS PROGRESS is to help HS research through collaboration between patients, health care providers, drug company partners, and researchers in order to improve the lives of people living with HS.**

This registry will help increase our understanding of HS, including what causes HS. It will also help to figure out which patients may develop more severe HS and why patients respond differently to various treatments.

## VI. The Future

Over the last several years, patients, providers, researchers, and drug companies have been working together to address the unmet needs of people with HS. Much progress has been made, though there is still work that needs to be done. Importantly, several clinical trials are currently underway to find new treatment options for patients. There are exciting new drugs and treatment options being studied, providing hope for the future of HS treatment.

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# Hidradenitis Suppurativa

## PATIENT GUIDE

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