

# Down syndrome and hidradenitis suppurativa (HS)

Hidradenitis suppurativa (*Hi-drad-en-i-tis sup-per-ah-TEE-vah* or HS) is a chronic condition with recurrent painful bumps and draining sores of the skin. Sometimes it can look like acne. It more commonly affects the skin folds, such as the underarms, buttock crease, and groin area. When severe, it can appear in other parts of the body as well. HS seems to be more common in people with Down syndrome.

## WHAT CAUSES HS?

The cause is not completely clear. HS is not an infection and is not contagious. It is not caused by poor hygiene. The immune system and local factors play a role in the disease. People with Down syndrome have three copies of chromosome 21, and this can lead to changes in the immune system and skin that make HS more common. There might be other genetic factors that contribute, and it might run in families.

## WHEN DOES HS START?

HS can develop as a child, teenager, or adult. HS can start at a younger age in people with Down syndrome.

## WHAT DOES HS LOOK LIKE?

HS can range from mild to severe. It can look like multiple comedones ("blackheads") to painful bumps and abscesses that heal with scarring. Painful bumps can go on to form draining tunnels ("sinus tracts") under the skin. Deep bumps or tracts often leave scars. The tunnels can drain pus or blood, which can result in a bad smell.

## HOW IS HS DIAGNOSED?

The diagnosis is made by your child's doctor examining their skin. Since HS is more common in Down syndrome, it is recommended that a doctor look for signs of HS every year starting around age 10. Your doctor may check for infection of the skin before making this diagnosis. Other tests are often not necessary.

## HOW LONG DOES HS LAST?

The individual bumps and sores may last for weeks or months. They may keep coming back. In most cases, HS is considered a chronic, long-lasting condition. Each patient is different and the bumps may get better or worse over time.

## WHAT ARE THE TREATMENTS FOR HS?

While there are many treatment options, HS can be very hard to treat. It may take time to find the best treatment plan for each person. Medicines take weeks to months to work. Be patient, and do not stop a medication without first discussing with your doctor.

Friction can make HS worse. Ask your doctor for recommendations on bandages and clothing to reduce friction with the skin. Avoid closely shaving the areas where you have HS.

Dietary changes and a healthy lifestyle may help reduce skin-on-skin friction through weight loss and may improve HS.

## TIPS FOR MANAGING HS

- » See your child's dermatologist or other doctor regularly. They are your partners in helping them feel comfortable in their own skin!
- » Make sure your doctor asks about how your child's HS feels. How does it bother them? Does it hurt? Knowing these answers can help the medical professional come up with a helpful treatment plan.
- » Wear loose, comfortable clothes. Do not closely shave the areas of HS. Rubbing and friction can make HS worse.
- » Healthy eating and exercise may improve HS.
- » Wash affected areas gently. Do not scrub the areas, and always use clean washcloths.
- » Do not pop the "pimples and bumps" as this can make them worse. Warm compresses or soaks can help the bumps to drain gently.
- » Avoid having the areas with HS cut into or drained, unless you are seeing a surgeon specifically for the HS.
- » For severe pain or a sudden change in the condition, call your doctor.

# TREATMENT OPTIONS

## >> Topical therapy:

Topical medicines are placed directly on the skin of affected areas. Some of these medicines contain antibiotics, benzoyl peroxide, chlorhexidine, or retinoids (vitamin A creams commonly used for acne). They are often prescribed in combination with each other.

Talk with your child's doctor about their bath/shower routine and who helps with this. Since these areas may be hard to reach, a support person who helps during bath time may be able to help apply these medicines. Together, you can make a topical plan that is comfortable and easy to remember. In addition, some patients find diluted bleach baths (swimming pool baths) helpful.

## >> Oral antibiotics:

Antibiotics can be taken by mouth to help improve symptoms. They usually need to be taken for an extended period of time. An example of a commonly used antibiotic is doxycycline. Discuss risks and benefits with your child's physician. Talk about any stomach symptoms they might have such as celiac disease, gastrointestinal reflux, or constipation and how antibiotics might affect this.

## >> Hormonal therapy:

Females with HS may notice that their HS changes with their menstrual cycle. Some forms of birth control can help regulate the hormones and thereby help manage HS. A pill called spironolactone can also block these hormones to improve symptoms. Your doctor can discuss the risks and benefits of hormonal therapy with you.

## >> Oral retinoids:

Oral retinoid medications like isotretinoin and acitretin are sometimes used to help HS. Your doctor will discuss risks and benefits with you, but the most common side effects are dryness.

## >> Biologic therapy:

More severe cases of HS that have not responded to other treatments may benefit from adalimumab. Adalimumab is a medicine that is injected into the body (a "shot") to decrease inflammation. The shot is given once a week. It is FDA approved for HS in children 12 years of age and older. Adalimumab has risks and benefits that should be discussed with your doctor.

## >> Injections:

Corticosteroids (potent anti-inflammatory medications) can be injected into bumps to help decrease swelling, inflammation, and pain. This can help make bumps go away faster, but sometimes multiple injections are needed. Injections are not a way to prevent new HS bumps. Discuss risks and benefits with your doctor. Ask about ways to make injections hurt less such as topical numbing creams and other distraction tools. Ask if your doctor has a Certified Child Life Specialist (CCLS) at the clinic to help make the injections more comfortable.

## >> Laser hair removal:

Laser hair removal can be helpful for HS and reduce the risk of worsening HS through shaving. Laser hair removal can be painful and often multiple treatments are needed. As mentioned in the "Injections" section, ask your doctor about ways to make laser hair removal hurt less.

### RECIPE FOR BLEACH BATHS (SWIMMING POOL BATHS):

- » 1/4 cup bleach to a half tub of water
- » Soak for 5-15 minutes, 2-3 times a week.



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