

Diagnosed With HES? What to Know

What Is HES?

Hypereosinophilic syndrome -- or HES -- is a group of rare blood conditions that happens when you have too many eosinophils. Eosinophils are a type of white blood cell that is an important part of your immune system, your body's natural defense system. Most people normally have less than 500 eosinophils/microliter (μL) in their blood. But people with HES often have more than 1500 eosinophils/ μL for 6 months at a time or longer and with no cause for the high, long-lasting number.

HES can affect anyone at any age. Some types can run in families, while others can be from infections, certain cancers, or health problems. But in most cases, the cause of HES is unknown.

Many things can increase your eosinophils -- such as infections, allergies, or medicines -- so your doctor will rule out other causes first when diagnosing HES. They may also do blood, allergy, and genetic tests, as well as imaging tests, such as X-rays and other scans, to check for HES. Your doctor may also recommend testing your bone marrow, the spongy tissue inside your bones where eosinophils are made.

How HES Can Affect Your Body

Over time, the extra eosinophils in your bloodstream can enter various parts of your body and damage different organs and tissues. The most common are the skin, lungs, heart, and nervous system. If not treated, HES can be life-threatening.



HES can also cause many different symptoms depending on which parts of the body are affected, such as:

- Skin rashes, sometimes with swollen itchy lumps or hives
 - Mouth sores
 - Weight loss
 - Dizziness and memory loss or confusion
 - Cough and shortness of breath or trouble breathing
 - Fatigue (tiredness)
 - Muscle and joint pain
 - Fever
 - Stomach pain, vomiting, and diarrhea
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Treating HES

The goal of treatment is to lower your eosinophil count to control symptoms, prevent organ and tissue damage, and improve your quality of life. Treatment can include medicines, procedures, or joining a clinical trial. Which treatment your doctor may recommend will depend on your symptoms and how severe your HES is and its cause.

Types of medicine that may be used can include steroids, chemotherapeutic agents (such as antimetabolites or certain inhibitors), or targeted therapy approved for certain types of HES such as imatinib or mepolizumab. Be sure to talk to your doctor or pharmacist before starting any treatment about side effects that may happen and how to manage them.

Making a Treatment Plan With Your Doctor

HES can affect different people in different ways. So you and your doctor will make a plan together to treat and manage your HES based on your individual needs and symptoms. And because HES can affect many different body systems and organs, your doctor may also recommend that you see certain specialists to help, such as a hematologist, oncologist, immunologist, infectious disease specialist, cardiologist, or pulmonologist.



Questions you can ask your doctor about HES can include:

What tests will I need and how often?

What treatments are available, and what are their side effects?

How can I make sure I have the best quality of life possible?

Are there specialists I should see?

Is there a clinical trial I may be eligible for?

What should I do if I start to feel stressed or depressed?

Where can I find additional information or resources?