



Sarcoidosis (pronounced SAR-COY-DOE-SIS) is an inflammatory disease characterized by the formation of granulomas, tiny clumps of inflammatory cells, in one or more organs of the body. When the immune system goes into overdrive and too many of these clumps form, they can interfere with an organ's structure and function. When left unchecked, chronic inflammation can lead to fibrosis, which is permanent thickening or scarring of organ tissue.

This disorder can affect almost any organ in the body, including the heart, skin, liver, kidneys, brain, sinuses, eyes, muscles, bones, and other areas. Despite the best efforts of researchers for more than a century to better understand this disease, sarcoidosis remains difficult to diagnose with limited therapies. Disease presentation and severity varies widely among patients. In some cases, sarcoidosis will go away on its own, but in others the disease is chronic and can be life-threatening.

# What is sarcoidosis?

## WHO GETS SARCOIDOSIS?

Once thought to be rare, sarcoidosis is now known to be common, affecting people of any age, race, and gender worldwide. Sarcoidosis is most common among adults between the ages of 20 and 40, and slightly more common in women than in men. Disease presentation can vary widely by race or ethnicity:

- most common in African Americans (estimated 2% lifetime risk of developing sarcoidosis) and people of European "particularly Scandinavian" descent.
- African Americans and people of Japanese descent more likely to have eye involvement than Caucasians.
- skin lumps are more common in Northern Europeans
- people of Japanese background seem prone to cardiac sarcoidosis

Research also shows that risk appears to be elevated if someone in his or her close family has sarcoidosis, although researchers have not yet found a gene or genes linked to the disease.

## WHAT CAUSES SARCOIDOSIS?

No one knows exactly what causes sarcoidosis, although our understanding is advancing. Experts currently believe that one or more exposures in people who have a specific genetic makeup can cause the immune response to go into overdrive. Some research suggests that bacteria, viruses, or chemicals might trigger the disease. Such triggers, although usually harmless in most people, might irritate the immune systems of people who are at genetic risk for developing sarcoidosis. More research is needed to more fully understand why sarcoidosis occurs, who might be at risk, and whether it can be prevented.

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## HOW IS SARCOIDOSIS DIAGNOSED?

Sarcoidosis is a diagnosis of exclusion, meaning that doctors will oftentimes have to rule out other possible diseases before confirming that your symptoms are caused by sarcoidosis. There is no objective test which can easily diagnose sarcoidosis. Numerous exams and tests are required to confirm your diagnosis and help your doctor decide on the best treatment options.

Your health care provider will take your medical history and perform a physical examination. Medical tests provide additional information. Because many of the symptoms that occur with sarcoidosis also occur with other diseases, your health care provider may work to rule out other possible explanations.

## WHAT ARE THE SYMPTOMS?

Signs and symptoms of sarcoidosis vary widely depending on the organs affected. While many people who have sarcoidosis have very few or no signs of the disease, others suffer debilitating effects that can interfere with daily life. Because sarcoidosis so often affects the lungs, the most common symptoms include shortness of breath, wheezing, and chronic cough. Other symptoms may include:

- Fatigue
- Unexplained weight loss
- Night sweats
- Overall feeling of sickness
- Irregular heart beat
- Swollen legs
- Headaches
- Visual problems
- Weakness or numbness of an arm, leg, or part of the face
- Discoloration of the nose, cheeks, lips, and ears
- Scaly-appearing skin rash
- Joint pain
- Muscle swelling and soreness
- Arthritis
- Burning, itching, tearing, or pain in the eyes
- Red eyes
- Sensitivity to light
- Blurred vision

Note that this is not an all-encompassing list. Symptoms vary depending on the organs involved.

## TREATMENT OPTIONS

Medical treatment can be used to control symptoms, prevent complications, and improve outcomes in patients with persistent sarcoidosis. If you have sarcoidosis, your health care provider will carefully monitor you to see if your sarcoidosis is getting better or worse, and will adapt your treatment depending on how your body is doing. Many physicians will choose to treat when your quality of life suffers or when there is danger of organ damage or death.

In many cases of sarcoidosis, no treatment is necessary and sarcoidosis may go away without medical treatment. The disease may never reappear or may reappear later in life. However, many other patients need consistent treatment for the ongoing effects of sarcoidosis.

Sarcoidosis is often treated with the help of a multidisciplinary team of health care professionals. Because the disease can affect so many organ systems, you may work with health care providers who specialize in the treatment of the lungs, heart, brain, kidneys, liver, eyes, and skin. At specialized medical centers, these health care providers work as a team to develop a comprehensive treatment plan to control your symptoms and protect your overall health.

There is currently no cure for sarcoidosis.

## THE FOUNDATION FOR SARCOIDOSIS RESEARCH WORKS TO EMPOWER PATIENTS

FSR is the nation's leading nonprofit organization dedicated to finding a cure for this disease and to improving care for sarcoidosis patients. Since its establishment in 2000, FSR has fostered over \$4 million in sarcoidosis-specific research efforts and has worked diligently to provide resources to thousands of patients and physicians worldwide.

Resources include an online physician finder, support groups, patient education materials, patient conferences, and more. We also invite you to join us in working to speed up research!

Learn more and join us in the fight to stop sarcoidosis at [www.stopsarcoidosis.org](http://www.stopsarcoidosis.org).