Sarcoidosis is a disease that causes your immune system to overreact, which can lead to health issues. It can cause lung damage, skin rashes, and eye disease and can affect other organs of the body.

Learn About Sarcoidosis

Sarcoidosis is a disease of unknown origin that can cause lung damage, skin rashes, and eye disease and can affect other organs of the body.

Key Facts

- Sarcoidosis causes your immune system to overreact, which can cause health issues. People with sarcoidosis have clusters of inflamed tissue called “granulomas” in different places in their bodies.
- Sarcoidosis often improves without treatment.
- Sarcoidosis occurs more often in African Americans than in whites, and African Americans may experience more severe symptoms.

What Is Sarcoidosis?

While no one knows what causes sarcoidosis, it is associated with increased immune system activity. This causes clusters of immune cells called granulomas to infiltrate your organs and lymph nodes. Sarcoidosis most commonly affects your lungs, but it can affect any organ in your body. People over the age of 20 and women are more likely to develop sarcoidosis. Many patients never have symptoms, and the disease is diagnosed only because a chest x-ray is taken for another reason. In most of these cases, the disease improves by itself. However, your overactive immune system may lead to problems with different organs of the body and lead to cough, shortness of breath, night sweats, joint pain, and fatigue. Up to 30% of patients with sarcoidosis have symptoms improve without treatment.

How Sarcoidosis Affects Your Body

If you have sarcoidosis, the increased inflammation in your body may cause flu-like symptoms, such as night sweats, joint pain, and fatigue. This inflammation can lead to scar tissue in your lungs, while also making them function more poorly. Many people with sarcoidosis also have skin and eye damage in addition to lung disease. Occasionally, those with sarcoidosis develop granulomas and inflammation in their hearts, which can trigger abnormal heart rhythms and heart failure.

How Serious Is Sarcoidosis?

Although sarcoidosis can affect anyone, African Americans have a higher incidence of sarcoidosis than do white Americans.

Many people diagnosed with sarcoidosis never have symptoms, but it can cause shortness of breath and loss of lung function and sometimes permanently damage your lungs. In very few cases, sarcoidosis can be life-threatening if it causes heart or severe lung disease. If your symptoms last more than 2 years despite treatment, your disease is considered chronic, and the symptoms may worsen your quality of life. A few people with severe heart or lung disease require heart or lung transplants. You also may have sarcoidosis flare-ups, even after your disease has been inactive.
Sarcoidosis Symptoms, Causes, and Risk Factors

Sarcoidosis can be tricky to diagnose. It’s often confused with other diseases when you first see your doctor. A chest x-ray taken for other symptoms may lead your physician to send you for further testing. People with abnormal chest x-rays should be referred to a pulmonary specialist for evaluation.

What Are the Symptoms of Sarcoidosis?
Many people with sarcoidosis think they have the flu or a respiratory infection before their disease is diagnosed. Sarcoidosis can affect many different organs, but it most commonly affects your lungs.

Common symptoms of sarcoidosis include:
- Cough
- Shortness of breath
- Chest pain
- Night sweats
- Fatigue
- Wheezing or abnormal breathing
- Feeling congested

Sarcoidosis also can cause the following:
- Skin rashes or raised bumps on the skin
- Joint pain or stiffness
- Eye irritation, dryness of the eyes, and sometimes blurry vision
- Fast heart rate or lightheadedness
- Kidney stones
- Increased levels of calcium in the bloodstream
- Abnormal liver function

What Causes Sarcoidosis?
The exact cause of sarcoidosis is unknown. Some research suggests that an infection or exposure to something in the environment can trigger the immune system to overreact? While no specific gene mutation has been shown to cause sarcoidosis, it sometimes runs in families, and there may be a genetic tendency to develop sarcoidosis. Sarcoidosis isn’t contagious, so you can’t catch it from someone else like you could a cold or flu.

What Are the Risk Factors?
- People of African and Scandinavian descent are slightly more likely to develop sarcoidosis.
- Women are more likely to develop the disease than men.
- Some exposures to dusty or moldy environments have increased risk of developing sarcoidosis.
- People between 20 to 40 years of age are more likely to develop sarcoidosis than others.

When to See Your Doctor
Most people who have sarcoidosis have no signs or symptoms of the disease. In these cases, it is diagnosed when a chest x-ray is done for another reason, and it is found to be abnormal.

However, you should contact your doctor if you think you have the flu or are experiencing any of the symptoms above.

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.

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.
Diagnosing and Treating Sarcoidosis

If you have sarcoidosis, you may have symptoms for several months to years before your disease is diagnosed. Many people think they’re tired or short of breath because of some other reason. Specialists such as dermatologists (skin doctors), rheumatologists (joint doctors), and pulmonologists (lung doctors) often diagnose sarcoidosis after they see you and run tests.

What to Expect

Your doctor will probably run routine tests, including drawing your blood, pulmonary function testing, and performing a chest x-ray if it was not already done, if you have a new cough that lasts more than a few weeks, or new shortness of breath.

If you have abnormal chest x-ray findings that show enlarged lymph nodes or spots on your lungs, you may be sent to a lung specialist or surgeon for a biopsy specimen (a sample of your lung tissue). This sample can help doctors understand what’s causing your symptoms and abnormal x-ray results. Because other diseases or some infections can cause enlarged lymph nodes similar to those found in sarcoidosis, it’s important that the disease be properly diagnosed, so you can get the right treatment.

After your doctors get the results from your tests, a specialist will discuss the results with you and decide on a treatment plan that would be best while causing the least amount of side effects. Many patients require no treatment at all but should be followed by a specialist regardless. Specialists who treat sarcoidosis should see you in a follow-up visit after you start treatment. You may have your blood retested to monitor the side effects from your sarcoidosis medications.

How Is Sarcoidosis Diagnosed?

There is no blood test that can accurately diagnose sarcoidosis. If you have a skin rash, sarcoidosis sometimes can be diagnosed by a biopsy - a skin specialist will remove a pinch of skin tissue and examine it under a microscope. Because infections can also cause granulomas that look similar to sarcoidosis, your doctor will test your lung or skin sample for infections such as tuberculosis to rule out other potential causes of your symptoms.

■ Bronchoscopy is a procedure performed by lung specialists on people with abnormal chest x-ray results. The goal is to get a lung or lymph node tissue sample to help make a diagnosis. For this procedure, you’ll be given medication through an IV that will make you sleepy. After spraying your nose or mouth with a local anesthetic to numb the area, a small scope with a camera at the tip is inserted, and more local anesthesia is sprayed through the scope to numb the windpipe and airways. Small pieces of lung or lymph node tissue are collected through the scope and sent to the lab for testing.

■ Mediastinoscopy is rarely needed if a bronchoscopy does not make a diagnosis. This procedure is done in a hospital where an anesthesia doctor puts you completely to sleep. A lung surgeon makes a small incision above your breastbone, a camera is used to look down into your chest, and lymph nodes may be removed and sent to a lab for testing.

■ Skin biopsy is a procedure done in a dermatologist’s office if you have skin rashes or bumps. The doctor numbs the skin near your rash with a needle and numbing medication. They then take a small sample of your skin and send it to the lab for testing.

How Is Sarcoidosis Treated?

After you’re diagnosed with sarcoidosis, your doctor will review your test results with you to determine if you need treatment and which kind to try. Many patients with sarcoidosis have minor or no symptoms and it goes away by itself, in which case no treatment may be needed. All patients with sarcoidosis should have breathing tests, electrocardiogram, blood tests, and an eye
examination to uncover possible problems that may need to be addressed, even if there are no symptoms.

**Breathing tests:** A respiratory therapist will coach you through this test that involves blowing into a tube. The test shows how much lung function you have and can also show how well you have responded to treatment after you’ve started taking medication.

**Chest CT (“CAT”) scans:** A computed tomography scan shows your lung tissue and lymph nodes in your chest.

**Eye examinations:** Ophthalmologists can sometimes tell whether sarcoidosis is affecting your eyes.

**ECG and Echocardiogram:** These are tests of the heart to be sure that the heart is beating normally.

**Laboratory tests (blood and urine tests):** These tests can help doctors see if you have inflammation in your body and high blood calcium levels. The tests also spot potential side effects from medications to treat sarcoidosis.

If a specialist recommends that you should have some form of treatment for sarcoidosis, they often use medications that turn down your immune system’s activity. These medications work in different ways and can have different side effects. It is important to tell your doctor if you feel different after starting one of these new medications and to get your scheduled lab work completed on time.

**Corticosteroids,** such as prednisone, are medications that turn down the immune system’s activity and can improve symptoms of cough, shortness of breath, eye irritation, skin rashes, and joint pain. Prednisone can have side effects such as weight gain, sleeplessness, thinning of the bones, and sometimes vision changes. It may also cause high blood pressure and diabetes. You may be treated with prednisone for a period of time and then tapered off this medication as your symptoms improve.

**Other medications:** Methotrexate is a medication that is used with or sometimes instead of prednisone. It is taken once a week, orally or as a shot under the skin. Antimalarials, usually used to treat malaria, may help with sarcoidosis that involves the skin or joints. Anti-TNF medications are also used to treat rheumatoid arthritis, and may be given intravenously or injected under your skin for sarcoidosis. All of these medications may have side effects and require close monitoring and adjustments by your specialist.

**Living With Sarcoidosis**

If you’ve been diagnosed with sarcoidosis, you might feel anxious and unsure about your health or have symptoms that interfere with your daily routine. After you’re diagnosed with sarcoidosis, it’s important to find a specialist who has experience with sarcoidosis. It can also be helpful to find a community or support group of others with sarcoidosis.

**What to Expect**

People with sarcoidosis can have very different symptoms from each other. Many people with sarcoidosis have breathing problems, but after treatment starts, symptoms may improve over several months. If sarcoidosis affects more than one organ, you may need longer treatment or combinations of medication. If your eyes are affected, you need to see an eye specialist to keep from losing your vision. Always talk to your doctor about any new or worsening symptoms you experience. With good treatment and follow-up, your symptoms may improve, and you may feel more like yourself.

**Managing Sarcoidosis**

If you have sarcoidosis, you may need to work with doctors and specialists in different areas of health care to manage your disease and symptoms. Often starting a new medication can come with new side effects. Make sure you talk about your symptoms with your doctor. Because many of these
medication side effects go away after you adjust to the medication, your doctor may ask you to keep taking the medication for a while longer to see if your sarcoidosis improves. If your symptoms last a long time (even with medication) and you cannot work, make sure to discuss this with your doctor.

Depression and anxiety affects many people with any illness, including sarcoidosis. Tell your doctor if you have these feelings. Treatment for anxiety and depression may actually make your sarcoidosis treatment more effective.

**Finding Support**
Surviving and living with sarcoidosis requires help from your health-care providers, your family, and your friends. Those who understand the disease can be a vital resource for people with a new diagnosis who don’t know what to expect, and several national and regional organizations exist to help you find answers.

The Lung Association recommends patients and caregivers join our Living with Lung Disease Support Community to connect with others facing this disease. You can also call the Lung Association’s Lung Helpline at 1-800-LUNGUSA to talk to a trained respiratory professional who can help answer your questions and connect you with support.

Learn more at:
- Foundation for Sarcoidosis Research (FSR): stopsarcoidosis.org
- Bernie Mac Foundation: berniemacfoundation.org
- Sarcoidosis Network Foundation, Inc.: sarcoid-network.org

**Questions to Ask Your Doctor About Sarcoidosis**
Making notes before your visit, as well as taking along a trusted family member or friend, can help you through the first appointment with your doctor.

- What parts of my body are affected by sarcoidosis?
- What medications should I take and how do they work?
- What side effects could I expect from my medications?
- How will we follow up to see if my sarcoidosis is responding to treatment?
- How long should I take my medicine before we decide whether it’s working or if I need a different medicine?
- What should I look for as a sign that my disease is improving or getting worse?
- What is the best way to get in touch with you if I need to tell you about new problems before the next appointment?
- How will you communicate with other doctors who are treating my sarcoidosis?
- How might this disease affect my quality of life?
- Will sarcoidosis prevent me from working?

Some of these questions will not apply to all people with sarcoidosis. Some are hard to answer in one visit and may take more time to answer. A good working relationship with a doctor who understands your disease is the beginning of finding solutions to living with sarcoidosis and keeping or returning to the lifestyle you enjoy.

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