



SARCOIDOSIS

Disease Overview

FOUNDATION FOR SARCOIDOSIS RESEARCH

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THE FOUNDATION FOR SARCOIDOSIS RESEARCH IS DEDICATED TO PROVIDING RESOURCES TO PATIENTS, PHYSICIANS, AND RESEARCHERS. THIS BROCHURE PROVIDES INFORMATION ABOUT SARCOIDOSIS TO HELP GUIDE IN UNDERSTANDING THE FULL SCOPE OF THIS RARE BUT DEVASTATING DISEASE. WE PARTNER WITH MANY PROFESSIONAL ORGANIZATIONS AND INDUSTRY TO ENSURE EXCELLENCE IN INFORMATION, RESOURCES, AND RESEARCH INITIATIVES.

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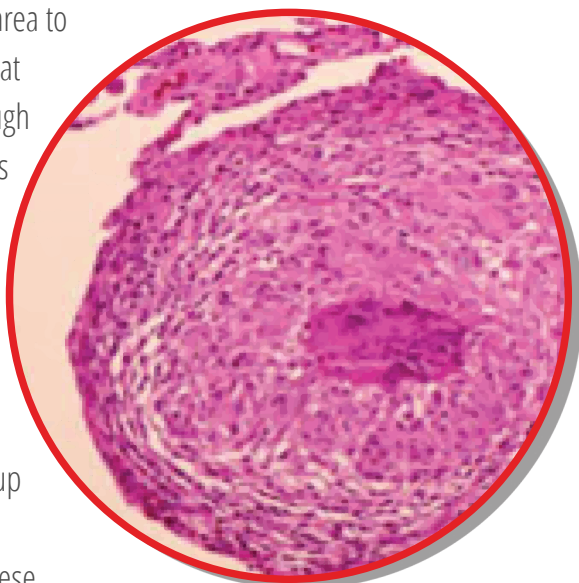
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WHAT IS SARCOIDOSIS?

Sarcoidosis is an “inflammatory” disease that can affect almost any organ in the body. When the body functions in a healthy way, inflammation in the body can be a good thing. For instance, when you accidentally cut the tip of your finger, your finger becomes red, swollen, and warm to the touch – inflamed – because your blood carries special cells and chemicals to the area to destroy any harmful substances that may have entered your body through the cut. In a few days, the cut heals and your finger returns to normal.

But sometimes, inflammation gets out of control. The immune system goes into overdrive, and instead of protecting the body, inflammatory cells sometimes group together and form lumps called granulomas. When too many of these clumps form in an organ, they can interfere with the organ’s function.



Lung granuloma, courtesy of Daniel Culver, DO, and Carol Farvor, MD, of the Cleveland Clinic

Sarcoidosis can affect almost any organ in the body, including the heart, skin, liver, kidneys, brain, sinuses, eyes, muscles, bones, and other areas. Sarcoidosis most commonly targets the lungs and the lymph nodes, which are an important part of the immune system. Sarcoidosis that affects the lungs is called pulmonary sarcoidosis. Ninety percent or more of people with sarcoidosis have lung involvement.

In some cases, sarcoidosis can resolve itself without causing serious damage to the body. However, for some people, the disease can be ongoing as well as cause permanent damage to the body. For pulmonary sarcoidosis, some cases result in permanent lung damage. Medical treatment may ease symptoms, improve organ function, and limit damage to the body. However, treatments that work on some patients may not on others, and often the drugs used in treatments can cause other issues. More research is needed for additional treatment options.

SARCOIDOSIS CAN AFFECT ALMOST ANY ORGAN IN THE BODY, INCLUDING THE HEART, SKIN, LIVER, KIDNEYS, BRAIN, SINUSES, EYES, MUSCLES, BONES, AND OTHER AREAS.

Sarcoidosis can go into remission, a period when the disease no longer causes symptoms or problems in the body. More than half of the people who have sarcoidosis will experience remission within three years of their diagnosis, and two-thirds will go into remission within 10 years of diagnosis. Sarcoidosis symptoms can return after remission, but this is not common. Return of disease symptoms and activity after one or more years of remission occurs in less than five percent of patients.

WHAT ARE THE COMMON SYMPTOMS?

Many people who have sarcoidosis have very few or no signs or symptoms of the disease. In these cases, it is diagnosed in part when a chest x-ray is done for another reason, and it is found to be abnormal.

Because sarcoidosis so often affects the lungs, the most common symptoms of sarcoidosis include shortness of breath and chronic cough. Because sarcoidosis can affect the entire body, a wide variety of symptoms can be seen with sarcoidosis. Other symptoms of sarcoidosis include:

- ☐ Fatigue
- ☐ Unexplained weight loss
- ☐ Night sweats
- ☐ Overall feeling of sickness
- ☐ Swollen lymph nodes
- ☐ Irregular heart beat
- ☐ Swollen legs
- ☐ Headaches
- ☐ Visual problems
- ☐ Weakness or numbness of an arm, leg, or part of the face
- ☐ Painful or red, raised bumps on the legs or arms
- ☐ 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
- ☐ Fever

HOW DOES SARCOIDOSIS AFFECT THE DIFFERENT ORGANS OF THE BODY?

LUNGS



LYMPH NODES



SKIN



EYES



HEART



BRAIN AND
NERVOUS SYSTEM



BONES, JOINTS,
AND MUSCLES



SPLEEN



LIVER



KIDNEYS AND
URINARY TRACT



SALIVARY GLANDS



SINUSES





LUNGS

The lungs are the most commonly affected organ in sarcoidosis. Ninety percent or more of people with sarcoidosis have lung involvement, whether they have symptoms or not.

- ✓ Dry coughing
- ✓ Trouble breathing, wheezing, or pain with breathing
- ✓ Chest pain, tightness, or discomfort
- ✓ Coughing up blood (which is rare), especially in the early stages of sarcoidosis.

Some of the lung problems caused by sarcoidosis – usually only in the most serious cases – can include:

- ✓ *Interstitial lung disease* (also called pulmonary fibrosis), which occurs when inflammation causes scar tissue to form on the lungs, leading to reduced oxygen levels in the blood and shortness of breath.
- ✓ *Fibrocystic disease*, which is an advanced form of lung disease that causes scars that block airways.
- ✓ *Pulmonary hypertension*, which is high blood pressure in the arteries of the lungs caused by scar tissue that narrows or blocks them. The hypertension makes the heart work harder to pump blood through the vessels, which can weaken the heart muscle and hinder its ability to deliver oxygen to the lungs
- ✓ *Bronchiectasis*, which makes the airways in the lungs unable to clear out mucus. The mucus then builds up, creating an environment where bacteria will grow. Over time, the airways become inflamed, stretched out, and scarred, making it harder for the lungs to move air through them.
- ✓ *Aspergilloma*, which is a clump of fungus that forms in healed lung scars and enlarged airways, and can cause bleeding in the lungs.



LYMPH NODES

Sarcoidosis affects the lymph nodes in up to 90 percent of people with the disease. Lymph nodes are glands found throughout the body that make and store white blood cells. When sarcoidosis inflammation targets these glands, they become enlarged. Swollen lymph nodes can be uncomfortable, but they rarely cause medical problems unless they press on organs or blood vessels.

Most commonly, it is the lymph glands in the chest that are affected, but this can be hard to detect without an x-ray. Some of the other places affected by enlarged lymph nodes (they appear as swollen lumps) include:

- ✓ Neck
- ✓ Under the chin
- ✓ Armpit
- ✓ Groin



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Unlike during a cold or the flu, swollen lymph nodes in these areas are not usually tender when associated with sarcoidosis.



SKIN

Roughly a quarter of people with sarcoidosis will develop skin problems related to the disease. Often, these skin problems can indicate the seriousness of the case of sarcoidosis.

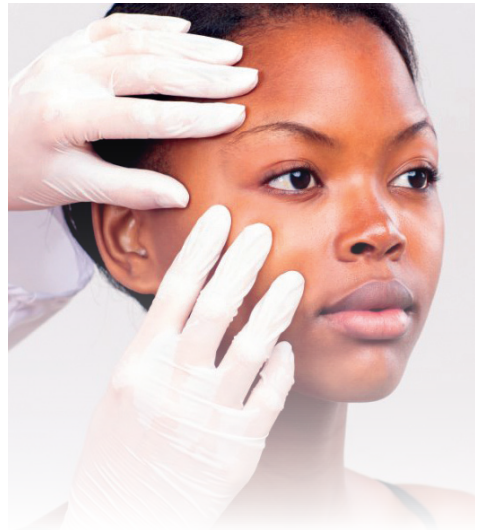
Skin problems might include:

- ✓ *Erythema nodosum*, which causes raised, red, and tender bumps to form on the skin, usually on the front of the legs.

Nearby joints are often swollen and painful. Erythema nodosum usually goes away on its own in six to eight weeks, even without treatment. Often, the presence of erythema nodosum is a good sign, indicating the type of sarcoidosis that also goes away on its own after a few months or years.

- ✓ *Lupus pernio*, which is an uncommon skin condition that causes hard, reddish-purplish bumps to form on the cheeks, nose, lips, and/or ears. These bumps do not go away on their own and often come back when treatment is stopped. They are usually associated with chronic sarcoidosis. In some cases, the sores are disfiguring and can damage underlying cartilage and bone.

- ✓ Other bumps on or under the skin, rashes, sores, scaling, and/or changes in old scars or tattoos that do not go away and are rarely painful or itchy. These skin problems are associated with the kind of sarcoidosis that lasts a long time.



EYES

Sarcoidosis affects the eyes in a quarter or more of people with the disease. In many cases, these problems go away on their own within a year. Many eye problems are treatable with various options.

Eye symptoms can include:

- ✓ Burning, itching, and/or pain
- ✓ Dryness
- ✓ Tearing
- ✓ Red eyes
- ✓ Vision problems, such as seeing black spots or having blurred vision
- ✓ Sensitivity to light
- ✓ Small, pale yellow bumps on the eye



Eye problems caused by sarcoidosis might include:

- ✓ *Uveitis* (the most common eye problem), which is inflammation of the middle membrane – or the uvea – of the eye.
- ✓ *Dry eye syndrome* (also called keratoconjunctivitis), which occurs when the tear ducts are blocked by inflammation.
- ✓ *Tear gland enlargement* (also called lacrimal gland enlargement), which occurs when the tear glands are swollen by inflammation and granulomas.
- ✓ *Glaucoma, cataracts, and blindness*, which are rare but serious problems that can occur if uveitis goes untreated.



HEART

Researchers estimate that sarcoidosis of the heart, or cardiac sarcoidosis, affects more than 10 percent of people with sarcoidosis in the United States, and perhaps as many as 25 percent. Because heart problems can be very serious, everyone who has sarcoidosis should be screened for cardiac sarcoidosis.

Some people with heart involvement might notice symptoms, but many people will feel no obvious effect, even in late-stage disease.

Heart symptoms might include:

- ☑ Irregular heartbeats, which can feel like palpitations and/or skipped beats
- ☑ Shortness of breath, coughing, chest tightness, and/or wheezing (although these symptoms can also be associated with lung problems)
- ☑ Swelling in the legs, which usually occurs only in late-stage sarcoidosis of the heart
- ☑ Feeling lightheaded or fainting

The problems caused by cardiac sarcoidosis can include:

- ☑ *Arrhythmias*, which are abnormal heartbeats or rhythms.
- ☑ *Heart blocks*, which are the blockage of electrical impulses that regulate the heart rate, impairing blood flow to the rest of the body.
- ☑ *Heart failure*, which occurs when the heart is unable to pump enough blood through the body, causing blood and fluid to back up in the lungs and elsewhere.
- ☑ *Pericarditis*, which although rare, can cause inflammation of the covering of the heart, as well as chest pain.

- ✓ *Heart valve problems*, which can prevent blood from flowing through the heart correctly.
- ✓ *Heart attacks*, which can occur when a blockage prevents blood and oxygen from reaching part of the heart.



BRAIN AND NERVOUS SYSTEM

Sarcoidosis affects the brain and nervous system in up to 15 percent of cases. Although it can affect almost any part of the nervous system, the cranial nerves, which are important nerves at the base of the brain, are commonly involved.

Brain and nervous system symptoms can include:

- ✓ Facial palsy (also called Bell's palsy), which causes drooping and/or paralysis on one side of the face (the most common nervous system symptom)
- ✓ Headaches
- ✓ Eye pain and redness
- ✓ Blurry or double vision
- ✓ Blindness
- ✓ Weakness, numbness, tingling, and/or pain in the face, arms, and/or legs
- ✓ Arm and/or leg paralysis
- ✓ Seizures
- ✓ Behavior and mood changes, irritability, memory loss, and hallucinations (which are rare)

The problems caused by sarcoidosis of the nervous system can include:

- ☑ *Nerve inflammation and/or damage*, which results in many of the symptoms described above, depending on which nerves are affected. For example, facial palsy is a result of damage to a nerve or nerves at the base of the brain.
- ☑ *Peripheral neuropathy*, which is a condition that impairs the nerves' ability to transmit messages between the brain and spinal cord and the rest of the body. It can cause the weakness and numbness described previously.
- ☑ *Masses of granulomas in the meninges*, or more rarely, in the brain, which cause the headaches, vision problems, and muscle weakness described previously. These masses can also cause meningitis, hydrocephalus, neuroendocrine disorders, and coma (see below).
- ☑ *Meningitis*, which is inflammation of the meninges, the membranes that surround your brain and spinal cord.
- ☑ *Hydrocephalus*, which is excess cerebrospinal fluid in the skull. It might occur with or after meningitis.
- ☑ *Neuroendocrine disorders*, which affect how the nervous and endocrine systems interact (the endocrine system makes and secretes hormones). When sarcoidosis damages an area at the base of the brain called the hypothalamus, it can lead to neuroendocrine disorders, such as hypopituitarism (an underactive pituitary gland).
- ☑ *Coma*, although this is rare.





BONES, JOINTS, AND MUSCLES (MUSCULOSKELETAL SYSTEM)

Sarcoidosis affects the bones and joints in up to a third of people who have the disease. Granulomas can even form in the bone marrow, a problem that occurs in up to 10 percent of cases. Muscle symptoms are somewhat less common than bone symptoms.

Musculoskeletal symptoms might include:

- ☑ *Early-onset arthritis*, which causes joint pain, stiffness, and/or swelling that usually occurs in the first six months of the disease, begins suddenly in one or both of the ankles and/or feet, and sometimes involves the knees, toes, fingers, wrists, and/or elbow joints. It often accompanies erythema nodosum (described previously in SKIN), and it usually goes away on its own in a few weeks or months.
- ☑ *Late-onset arthritis*, which usually occurs six months or more after sarcoidosis develops, is less painful and affects fewer joints than early-onset arthritis (usually the knees and/or ankles, or sometimes the fingers or toes). It is often associated with chronic skin symptoms (described previously in SKIN) rather than erythema nodosum. This type of arthritis can last for a long time, a lifetime, or it may come and go. It usually does not go away for good without treatment like early-onset arthritis does. It can cause permanent joint damage and should be treated even when it is not painful.
- ☑ Bone cysts (which are rare)



- ☑ Muscle aches or muscle pain (also called myalgia)
- ☑ Muscle weakness

Problems caused by musculoskeletal sarcoidosis can include:

- ☑ *Permanent bone and joint damage*, which occurs from the formation of granulomas and cysts on the bones or from chronic arthritis. Such damage is rare, but when it does occur, it often affects the hands.
- ☑ *Bone thinning* (also called low bone density or osteopenia), which occurs when microscopic holes develop in the bones, making them weaker and more prone to fracture.
- ☑ *Chronic myopathy*, which is a general term for muscle weakness or muscle disease that lasts a long time or a lifetime. It is uncommon, but when it does occur, it is more likely to affect women.





SPLEEN

The spleen is a large organ on the left side of the body under the ribs that produces and filters red blood cells and some types of white blood cells. Along with the lymph nodes, the spleen is part of the lymphatic system, which regulates blood cells and plays a role in immunity.

Sarcoidosis of the spleen does not usually cause symptoms, but possible symptoms may include:

- ☑ Pain on the upper left side under the ribs
- ☑ A sensation of pressure in the same area
- ☑ Feeling tired



Some of the problems sarcoidosis might cause when it affects the spleen include:

- ☑ *Spleen enlargement* (also called splenomegaly), which occurs when inflammation and the formation of granulomas cause the spleen to swell.
- ☑ *Anemia*, which occurs when blood does not contain enough healthy red blood cells to carry sufficient oxygen to the body's tissues, and can cause fatigue.
- ☑ *Leukopenia*, which occurs when there are not enough white blood cells circulating through the body, and makes the body prone to infections.
- ☑ *Thrombocytopenia*, which occurs when the body does not have enough of the circulating blood platelets necessary for blood clotting.



LIVER

Between 50 and 80 percent of people with sarcoidosis develop granulomas in the liver. However, the disease rarely causes serious liver problems, and most people do not even realize when their liver is affected.

Liver symptoms may include:

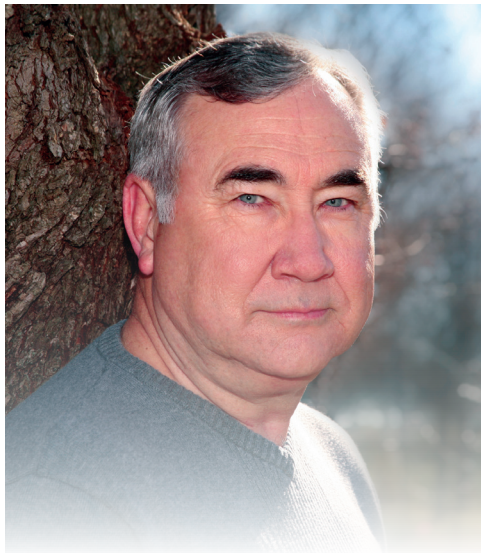
- ☑ Fever
- ☑ Feeling tired or fatigued
- ☑ Itchy skin
- ☑ Jaundice, which causes skin and eyes to look somewhat yellow
- ☑ Pain on the upper right side under the ribs

The liver problems caused by sarcoidosis might include:

- ☑ *Liver enlargement (also called hepatomegaly)*, which occurs when inflammation and granulomas on the liver cause it to swell.
- ☑ *Abnormal liver enzyme levels*, which is a common problem, but not usually a serious one.
- ☑ *Portal hypertension*, which is a rare complication defined as high blood pressure in the main blood vessel that carries blood to the liver. When pressure on this vein prevents normal blood flow, the blood must return to the heart through other blood vessels. These blood vessels become swollen and fragile due to the extra load.
- ☑ *Cirrhosis*, which is a rare condition that occurs when inflammation and granulomas scar the liver.



KIDNEYS AND URINARY TRACT



Sarcoidosis rarely attacks the kidneys directly. However, sarcoidosis can cause the body to overproduce vitamin D, which in turn causes the body to absorb too much calcium and can lead to kidney stones. Although they are uncommon in sarcoidosis, kidney stones can be painful when they break loose from the kidney and pass into the bladder, so patients are advised to be checked for excess calcium before kidney stones have the chance to develop.

Kidney and urinary tract symptoms include:

- ✓ Pain in the back or side, just under the ribs, which can be caused by large kidney stones.
- ✓ An increased urge to urinate, which is also caused by kidney stones.

Kidney problems caused by sarcoidosis might include:

- ✓ Too much calcium in the blood (also called hypercalcemia), which occurs in roughly 10 percent of people with sarcoidosis.
- ✓ Too much calcium in the urine (also called hypercalciuria), which occurs in roughly a third of people with sarcoidosis.
- ✓ Kidney stones, which are fairly uncommon.
- ✓ Loss of kidney function or kidney failure, which is often due to excessively high calcium levels in the blood or urine.



SALIVARY GLANDS

Sarcoidosis causes enlargement of the salivary glands in some people. This inflammation is sometimes painful and can cause dryness in the mouth. It can also make the cheeks look swollen. These symptoms are not serious, and they are usually treatable.



SINUSES

Sarcoidosis can also cause inflammation of the sinuses (called sinusitis). Symptoms include a runny nose, stuffiness, and sinus pain or headache. The sinusitis associated with sarcoidosis is often chronic and can be very troublesome, although it is rarely serious. Medication can relieve some of the symptoms.



WHAT ARE THE CAUSES?

No one knows exactly what causes sarcoidosis. The fact that someone is more likely to develop the disease if someone in his or her close family has sarcoidosis suggests that genetics play a role. Researchers have not yet found a gene or genes linked to the development of sarcoidosis, but they continue to look.

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.

WHAT ARE THE RISK FACTORS?

Sarcoidosis can affect people of any age, race, and gender. However, the disease mostly strikes adults between the ages of 20 and 30. It is most common in African Americans and people of Northern European – particularly Scandinavian – descent.

The disease is slightly more common in women than in men.

The disease manifests differently in different groups of people. While the lungs and lymph nodes are affected in almost everyone who has sarcoidosis, African Americans and people of Japanese descent are more likely to have eye involvement than Caucasians.

Skin lumps are most likely to affect people of Northern European descent, and those with a Japanese background seem prone to sarcoidosis-related heart problems.

HOW TO PREPARE FOR YOUR DOCTOR APPOINTMENT

It is critical to see a health care provider to examine all possible sarcoidosis-related issues. Because sarcoidosis usually involves the lungs, it may be diagnosed with a chest x-ray. However, sarcoidosis can be difficult to diagnose in some cases because



it may not involve the lungs and may have a wide variety of symptoms. You can help your health care provider by compiling a list of your symptoms, including when they appeared and what, if anything, makes them worse or better.

Your health care provider will want to know as much as possible about your overall health and medical history, so bring the following information to your appointment:

- ❑ **A complete list of your medications, supplements, and vitamins:** Include all prescription and over-the-counter medications and supplements, even herbal and natural remedies. If possible, bring the bottles and containers with you to your appointment so your health care provider can see exactly what you are taking.
- ❑ **Your medical history:** If you have medical records at another clinician's office, ask to have copies sent to your current health care provider.
- ❑ **Family history:** Has anyone in your family ever been diagnosed with sarcoidosis or had symptoms of sarcoidosis? Is there a history of other lung, skin, or heart problems?
- ❑ **Questions:** Write down any questions you may have, so that you do not forget to ask them when you are at your appointment. Visit the www.stopsarcoidosis.org site for Awareness Campaign information to see the Sarcoid Five, which are good questions with which to start.

WHAT ARE THE COMMON TESTS AND DIAGNOSIS METHODS?

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 those diseases.

Tests commonly used to look for sarcoidosis include:

- ☑ **Chest x-ray:** A chest x-ray is a painless test that allows your clinician to look at your lungs and airways. Although more than 90 percent of people with sarcoidosis will have abnormal x-rays, many other conditions can cause abnormal x-rays too. Often, a clinician will notice signs of sarcoidosis on an x-ray that was ordered for other purposes.
- ☑ **CT scans:** uses x-rays to create cross-sectional pictures of the body. During a CT scan, the patient lies on a narrow table that can slide in and out of a tube-shaped scanner. It is important to stay still during the exam, so that the machine can take clear pictures. Because your muscles, bones, and lungs move with every breath, you may be asked to hold your breath for brief periods. Some CT scans require the use of contrast, a special dye that helps certain things show up more clearly on the resulting pictures. If your exam requires the use of contrast, a health care provider will tell you when and how the contrast will be administered. Some types of contrast are given through an IV. Others are ingested before the exam.
- ☑ **Lung function tests (also called pulmonary function tests or PFTs):** Your health care provider may have you breathe out into a mouthpiece that is attached to a spirometer, a device that measures the amount and speed of air you blow out. This test gives information about how well your lungs are working. Other equally painless tests may be prescribed. Lungs affected by sarcoidosis generally do not work as well as healthy lungs.

- ✓ **Lung biopsy:** If your chest x-ray, lung function tests, and symptoms suggest pulmonary fibrosis, your health care provider may obtain a sample of lung tissue. The tissue can be analyzed in a laboratory to see if it shows signs of sarcoidosis. Pulmonary specialists can obtain lung tissue samples with bronchoscopy. This procedure is usually done in a hospital, but does not require admission. A bronchoscope is a thin, flexible tube that is threaded into your airways and lungs through your nose or mouth. Specimens are obtained through this tube. Medication will be used to numb your throat before the procedure, and you will be given medication to help you relax.
- ✓ **Other biopsies:** If you have bumps or lesions on your skin that may be related to sarcoidosis, your health care provider may take tissue samples and send them to the lab for analysis. Lymph nodes are also sometimes used for biopsy.
- ✓ **Blood tests:** Many people with sarcoidosis make excess amounts of vitamin D and/or a chemical called angiotensin-converting enzyme. Blood tests can be used to detect high levels of these substances. However, other conditions also cause elevated levels of vitamin D and angiotensin-converting enzymes, so these tests cannot be used to diagnose sarcoidosis. Blood tests can also be used to check blood levels and to look for evidence of liver or kidney damage.
- ✓ **MRI (magnetic resonance imaging):** Like x-rays and CT scans, MRI tests provide a glimpse inside the body. MRIs can be used to look for signs of sarcoidosis in the brain, spinal cord, heart, bones, and other organs.
- ✓ **Nuclear imaging:** These tests use radioactive dye to help clinicians see blood flow through various body organs. The dye is injected into your veins before the scan. After a period of time, your body is scanned with a special camera that can detect the radiation from the dye. Nuclear imaging tests are sometimes used to help diagnose sarcoidosis of the heart.



- ❑ **PET scan (Positron emission tomography):** This imaging test also uses a radioactive substance to provide information about an organ's functioning. PET scans are often used to help diagnose cardiac sarcoidosis or to find a good spot for a biopsy.
- ❑ **Heart rhythm monitoring:** Your health care provider may use electrocardiography (often called ECG or EKG) to get information about the functioning of your heart. Up to 50 percent of people with sarcoidosis will have an abnormal EKG, so additional testing might be needed to see whether the changes are worrisome.
- ❑ **Echocardiogram:** An echocardiogram is an ultrasound of the heart. It uses ultrasound waves to look at the heart. (Pregnancy ultrasounds use the same technology to provide a look at the fetus.) Your health care provider might order an echocardiogram to see how the heart is pumping blood.

WHAT ARE COMMON TREATMENTS?

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.

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.

Types of medications used to treat sarcoidosis include:

- ☑ **Corticosteroids:** Corticosteroids reduce inflammation. They are not the same as anabolic steroids, the type of steroid that is sometimes abused by athletes. Corticosteroids are the primary treatment for sarcoidosis. Treatment with corticosteroids relieves symptoms in most people within a few months. The most commonly used corticosteroids are prednisone and prednisolone. People with sarcoidosis may need to take corticosteroids for many months. Because these medications can cause side effects (including weight gain, insomnia, mood swings, acne, difficulty regulating blood sugar, and bone loss), your health care provider will gradually decrease your dose of medication after you start to take it. The goal is to stabilize symptoms without unnecessary exposure to more corticosteroids than you need to control the disease.

The following list of commonly prescribed drugs for the treatment of sarcoidosis reflects the prescribed treatments that are used by physicians for patients with sarcoidosis. Please note that this list is for information only – use of these drugs is determined by your own physician who develops an individual treatment plan for each patient based on multiple factors. Each patient should discuss their specific options with their own physician(s).

- | | |
|---|--|
| <input type="checkbox"/> Adalimumab (Humira) | <input type="checkbox"/> IGIV (Carimune, Flebogamma, Gamunex, Gammagard, Octagam, Privigen) |
| <input type="checkbox"/> Adrenocorticotrophic hormone (H.P. Acthar Gel) (FDA-approved for sarcoidosis) | <input type="checkbox"/> Leflunomide (Arava) |
| <input type="checkbox"/> Azathioprine (Azasan, Imuran) | <input type="checkbox"/> Methotrexate (Rheumatrex, Trexall) |
| <input type="checkbox"/> Certolizumab Pegol (Cimzia) | <input type="checkbox"/> Methylprednisolone (Medrol, Solu-Medrol) |
| <input type="checkbox"/> Chloroquine (Aralen) | <input type="checkbox"/> Mycophenolate Mofetil (CellCept) |
| <input type="checkbox"/> Cyclophosphamide (Cytoxan, Neosar) | <input type="checkbox"/> Pentoxifylline (Pentoxil, Trental) |
| <input type="checkbox"/> Etanercept (Enbrel) | <input type="checkbox"/> Prednisone, Dexamethasone (Deltasone, Prednicot, Rayos, Sterapred) |
| <input type="checkbox"/> Golimumab (Simponi) | <input type="checkbox"/> Rituximab (MabThera, Rituxan) |
| <input type="checkbox"/> Hydroxychloroquine (Plaquenil, Quinoprex) | <input type="checkbox"/> Thalidomide (Thalomid) |
| <input type="checkbox"/> Infliximab (Remicade) | |
| <input type="checkbox"/> Inhaled Steroids (Advair, Aerobid, Aerospan, Alvesco, Asmanex, Flovent, Pulmicort, Qvar, Symbicort) | |

☒ **Immune system suppressant medication:** Because sarcoidosis may be the result of an overreaction of the immune system, suppressing the immune system may ease symptoms and prevent further organ damage. When corticosteroids are not effective, your provider may talk with you about starting other medications, including methotrexate, azathioprine, and mycophenolate mofetil (CellCept). Other medications may help a few patients who do not respond to other therapies. They may include cyclophosphamide and biologic response modifiers (biologics or TNF-blockers).

☒ **Antimalarial drugs:** These medications were originally used (and are still used) to treat malaria. As a treatment for sarcoidosis, these drugs are most likely to be effective in people who have skin symptoms or a high level of calcium in their blood. Hydroxychloroquine (Plaquenil) and chloroquine (Aralen) are antimalarial drugs that are used to treat sarcoidosis. Both can cause stomach irritation and eye problems.

People with severe or advanced lung sarcoidosis may need oxygen therapy. In a few cases, lung transplantation – the replacement of a diseased lung or lungs with a healthy donor lung – is used to treat severe lung sarcoidosis.

WHAT LIFESTYLE CHANGES CAN HELP?

Staying as healthy as possible increases your odds of living a full, satisfying life with sarcoidosis. A well-balanced diet (high in vegetables, fruits, whole grains, and low-fat proteins) provides your body with the nutrients it needs to stay healthy. Regular exercise keeps you fit and improves your body's ability to efficiently use oxygen. Adequate rest decreases stress and increases feelings of well-being.

If you smoke, quit. Smoking causes additional damage to the lungs. It is not easy to stop smoking, but your health care provider can help. He or she can prescribe medication to help you stop smoking, and can also refer you to local classes and support groups that will help you stop smoking.

See your health care provider for regular appointments. It is also important to schedule routine eye exams. Sarcoidosis – and some medications used to treat sarcoidosis – can affect and damage the eyes. Regular eye exams help detect eye changes so that steps can be taken to preserve eye health and vision. Ask your health care provider how often you should have your eyes professionally examined.



**VISIT OUR WEBSITE FOR
MORE INFORMATION AT
WWW.STOPSARCOIDOSIS.ORG.**

WHAT ARE SOME RESOURCES FOR COPING AND SUPPORT?

A diagnosis of sarcoidosis can cause stress, uncertainty, anxiety, and depression. These emotions are a normal response to life-altering information. It is possible to live well with sarcoidosis, but doing so may require some changes to your usual lifestyle. It is natural to grieve the loss of your “healthy” self after receiving a disease diagnosis.

Remember that many cases of sarcoidosis resolve without treatment, and that treatment can be used to control sarcoidosis symptoms and prevent complications.

Most people with sarcoidosis live full, active, healthy lives. If you are struggling, either physically or emotionally, talk to your health care professional. Support groups can be helpful for patients and families living with sarcoidosis. The Foundation for Sarcoidosis Research hosts an online support group called Inspire that is invaluable for connecting with other patients. In addition, FSR maintains a list of support groups throughout the country and can connect you with a group to help offer support.



Because sarcoidosis most often strikes people in their 20s and 30s, many people with sarcoidosis wonder if the disease will affect their ability to have children. If you have sarcoidosis and are interested in having children, talk to your health care provider. Sarcoidosis behaves differently in everyone; your health care team can provide you with information tailored to your health and treatment. Your health care team will also consider your desire to have children when planning your treatment. Some sarcoidosis medications are safe to take during pregnancy, while others are known to cause birth defects. Many people with sarcoidosis have gone on to have healthy children.

HOW CAN I FIND A DOCTOR WHO TREATS SARCOIDOSIS?



Some primary care and family doctors can diagnose and treat sarcoidosis, but it is advisable for patients to see a specialist(s) right away.

Your doctor might also be able to refer you to a local sarcoidosis specialist, or you can contact a nearby academic medical center or hospital and ask for the department which treats sarcoidosis. A few U.S. hospitals have centers dedicated specifically to sarcoidosis, but in most places, the department that handles sarcoidosis will have a broader scope. In some centers, it will be the pulmonary and critical care department; in others, it might be the internal medicine or rheumatology department.

**FSR PROVIDES A PHYSICIAN
FINDER DIRECTORY TOOL AT
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You might need to see other specialists too, depending on which of your organs are affected and how seriously. In many cases, treating sarcoidosis requires a team approach that includes you, your primary care doctor, and one or more specialists. Specialists include pulmonologists, who treat lungs; cardiologists, who treat the heart; rheumatologists, who treat many bone and joint problems; gastroenterologists and hepatologists, who treat the liver; endocrinologists and urologists, who treat different kidney and hormone problems; ophthalmologists, who treat eye problems; and dermatologists, who treat skin problems.

WHAT CAN PATIENTS DO TO HELP FIND ANSWERS AND TREATMENTS FOR SARCOIDOSIS?

As a person living with sarcoidosis, you know better than anyone that more answers are needed for treating this disease. Your information that you can provide to physicians and researchers is critically needed to find these answers.

One of the most valuable gifts a patient can offer to themselves and other patients is to join the FSR Patient Registry. This registry is a survey that asks questions about your experience and history with sarcoidosis. It gathers information about patients which will inform doctors and researchers about the disease overall. Your name and contact information will never be shared.

**REGISTERING IS EASY AND
FREE. PLEASE DO IT TODAY!
GO TO: WWW.STOPSARCOIDOSIS.ORG.**

HOW DOES THE FOUNDATION FOR SARCOIDOSIS RESEARCH HELP?

While progress has been made in understanding the symptoms and better diagnosing the disease, little is known about the cause of sarcoidosis or who is susceptible to the disease. With increased research, discovering the cause, improving treatment, and finding a cure may be well within our reach.

The Foundation for Sarcoidosis Research is dedicated to supporting and collaborating for increased research as well as for comprehensive education and communication for patients.

PLEASE VISIT WWW.STOPSARCOIDOSIS.ORG.

The Foundation for Sarcoidosis Research 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 funded numerous domestic and international research efforts and has worked diligently to provide resources to thousands.



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