



FOR THOSE WHO SEEK ANSWERS **AND INSPIRE RESULTS**

AN INFORMATIONAL TOOLKIT FOR PATIENTS WITH SARCROIDOSIS

Patient education resources supported in part by grants from Mallinckrodt Pharmaceuticals and Pfizer, Inc.



The CHEST Foundation of the American College of Chest Physicians and the Foundation for Sarcoidosis Research have teamed up to launch **Sarcoidosis: Seek Answers. Inspire Results.** – a campaign that encourages people living with sarcoidosis to take a proactive role in their treatment plan. This toolkit will provide patients and caregivers with educational information and content to generate additional awareness and education around Sarcoidosis.

Table of Contents

Informational Video2

Social Assets.....3

Understanding Sarcoidosis - Quick Facts4

Treatment Options - Common Medications5

Sarcoidosis Glossary - Common Terms and Definitions6

The Sarcoid Five - Start the Conversation10

Patient Resources11

Advocacy - Securing a Proclamation.....12

INFORMATIONAL VIDEO

To view a brief informational video about Sarcoidosis, please visit <https://www.youtube.com/watch?v=xLkoPKkl6c0>.



SOCIAL ASSETS

Raise awareness and share your personal story with these social assets! Please feel free use these tools on your social platforms as you see fit. The social assets are provided in jpg format for simple image uploads to LinkedIn, Facebook and Twitter - there are various sizes for each platform, noted on the file, which can be found at chestnet.org/sarcoid. Below are snapshots of what is available by accessing the link:



- 5 Sarcoidosis Factoids
- Patient Quote
- Social Cover Page
- Patient Profile Badges

Please feel free to include the campaign url in your posts for easy access to additional information, chestnet.org/sarcoid and use the following hashtag in your posts to gain momentum [#SarcoidStories](https://twitter.com/SarcoidStories).

In addition, below are some social content examples we will be using during National Sarcoidosis month.

- The [#StopSarcoidosis](https://www.inspire.com/groups/stop-sarcoidosis) Online Support Community is over 25,000 members strong! Join today: www.inspire.com/groups/stop-sarcoidosis
- How does [#sarcoidosis](https://twitter.com/sarcoidosis) affect your life? How long did it take you to be diagnosed? Your answers can help doctors accelerate research! Join the [@FdnSarcResearch](https://twitter.com/FdnSarcResearch)

UNDERSTANDING SARCOIDOSIS

YOU ARE NOT ALONE

WHAT IS IT?



Sarcoidosis is an inflammatory disease wherein the immune system goes into overdrive.



Sarcoidosis can affect almost any organ in the body.



Sarcoidosis causes cells to group together into clumps called "granulomas."

It is not known exactly what causes sarcoidosis.

It is estimated there are more than 200,000 people living with sarcoidosis in the US.¹

SYMPTOMS²

25%
of cases affect the eyes.

35-50%
of cases have respiratory symptoms, such as shortness of breath, dry cough, and chest pain.

90%
of cases affect the lungs and lymph nodes.

25%
of cases affect the skin.

AGE

Sarcoidosis can affect people of any age, but 70% of patients are ages 20 to 40.

ETHNICITY

Anyone can develop sarcoidosis.

For reasons not yet understood by medical science, sarcoidosis is more common among African Americans and people of Northern European – particularly Scandinavian – descent.

TREATMENT

In more than half of cases, sarcoidosis only lasts for 12 to 36 months and resolves without treatment.³

GREAT NEWS: With good medical care, most cases of sarcoidosis are not severe and do not cause lasting damage to the body.

When treatment is needed, however, it is important to understand all of your options.

START THE CONVERSATION
WITH YOUR DOCTOR BY USING

THE SARCROID 5

1. Which of my organs are affected by sarcoidosis?
2. Can I do anything to prevent symptoms?
3. What are all of the treatment options available to treat sarcoidosis?
4. Which treatment is best for me and why?
5. Where can I find support?

To learn more about sarcoidosis, please visit
chestnet.org/sarcoid
stopsarcoidosis.org/awareness

Sources:

¹ Foundation for Sarcoidosis Research website: stopsarcoidosis.org/patient-resources/what-is-sarcoidosis/

² Foundation for Sarcoidosis Research infographic: pinterest.com/pin/477522366711934075/

³ Nunes H, Bouvry D, Soler P, Valeyre D. Sarcoidosis. *Orphanet Journal of Rare Diseases*. 2007; 2(46)


SARCOIDOSIS
Seek answers. Inspire results.

 **CHEST**
FOUNDATION



FOUNDATION FOR
SARCOIDOSIS RESEARCH

SARCOIDOSIS GLOSSARY OF TERMS

A

ACE (Angiotensin-Converting Enzyme) — Levels of this enzyme may be increased in the blood of patients with sarcoidosis. ACE levels in the blood can be elevated in other illnesses and may be normal in patients with sarcoidosis.

Adenopathy — A swelling or enlargement of lymph nodes.

Alveoli — The tiny air sacs in the lung where carbon dioxide and oxygen are exchanged.

Alveolitis — Inflammation of the alveoli.

Anemia — Any condition in which the number of oxygen-carrying red blood cells is lower than normal. Symptoms of anemia include pale skin color, shortness of breath, irregular heartbeat, and fatigue.

Anesthesiologist — A doctor who specializes in anesthesia, sedation and pain control.

Arrhythmia — An abnormal heartbeat.

B

Berylliosis (also known as Chronic Beryllium Disease [CBD]) — A lung disease resembling sarcoidosis that results from increased exposure to beryllium metal, often due to mining or processing jobs.

Biopsy — A sampling of small portions of body tissues to aid in the diagnosis of sarcoidosis.

Bronchoalveolar lavage — Fluid obtained from the lung using a bronchoscope.

Bronchodilators — Medications that cause the bronchial air passages of the lungs to expand, which makes breathing easier.

Bronchoscope — A long, narrow tube with a light at the end inserted in the lung to look at the airways and to take samples for diagnosis of a variety of illnesses.

C

Chest X-ray — A test that provides a picture of the lungs, heart, and lymph nodes in the chest that can aid in diagnosing the presence and extent of sarcoidosis.

CBC (complete blood count) — A blood test that measure red and white blood cells and platelets in the blood.

Chronic sarcoidosis — Having sarcoidosis for an ongoing period of time. The disease is considered chronic when granulomas continue to form and cause tissue scarring of the affected organ.

Conjunctivitis — Inflammation of eye membrane and eyelid.

Cor pulmonale — Poor function of the right side of the heart resulting from disease in the lungs and its blood vessels, making it more difficult for the heart to pump blood through the lungs.

CT (computed tomography) scan — A type of X-ray that provides a more detailed look at the chest than that provided by a standard chest X-ray.

Cytotoxic — Any medicine or process that kills cells. Chemotherapy and radiotherapy are forms of cytotoxic therapy.

D

Diagnosis — The identification of a disease.

Diffusing capacity — A breathing test that addresses how well the lungs can transfer oxygen from the air to the blood.

Dyspnea — Shortness of breath.

E

Electrocardiogram (EKG or ECG) — A test of the electrical activity of the heart.

Enzyme — A substance made by living cells that causes specific chemical changes.

Erythema nodosum — Red, tender bumps that tend to appear on the face, arms, and shins of some patients at the onset of sarcoidosis.

F

Fibrotic tissue — Inflamed tissue that has become scarred.

G

Gallium scan — A test in which a radioactive material is injected into the body to examine the extent of the spread of sarcoidosis in the body.

Genetic — The inherited code for human structure and function.

Granulomas — Clumps of inflammatory cells in tissues. The cells collect because of an abnormal immune system response.

H

Helper T-cells — Class of T lymphocytes that stimulate growth of B cells, cytotoxic T cells, and macrophages.

Heart block — Lack of a coordinated heartbeat due to an electrical activity defect in the heart.

Hilar adenopathy (or lymphadenopathy) — Enlargement of the lymph glands at the root of the lung.

Hypercalcemia — An increased level of blood calcium.

Hypercalciuria — An increased level of urine calcium.

Hypertension (high blood pressure) — Abnormally high arterial blood pressure.

Hypoxia/hypoxemia — A lower-than-normal level of oxygen in the body's blood and/or tissues.

I

Immune response — The reaction of the immune system against foreign substances. When the reaction occurs against the body's own cells or tissues, it is called an *autoimmune reaction*.

Immune system — A complex system of molecules and blood cells that protect the body from germs, such as viruses and bacteria.

Immunoglobulin — A protein produced by plasma cells that is used by the immune system to identify and neutralize foreign objects such as bacteria and viruses.

Immunosuppressive drugs — Drugs that suppress the body's immune system. These drugs can be used to treat autoimmune diseases.

Inflammation — A reaction of tissues to injury or disease, typically marked by four signs: swelling, redness, warmth and pain.

K

Kveim-Siltzbach Test — Skin test for diagnosing sarcoidosis.

L

Lavage — A washing of lungs with a bronchoscope.

Lofgren's syndrome — A form of sarcoidosis that includes enlargement of the lymph nodes and development of raised red lumps under the skin (erythema nodosum), fever, and joint pains. Despite the temporary discomfort, this form of sarcoidosis usually resolves on its own with no treatment.

Lupus pernio — A chronic skin condition seen with sarcoidosis, marked by purple-colored lesions on the cheeks, lips, nose, and ear.

Lymph nodes — Small, bean-shaped organs of the immune system distributed throughout the body tissue.

Lymphocyte — A type of white blood cell that determines the immune system response to infections and foreign substances.

M

Mediastinoscopy — A surgical biopsy of the lymph nodes in the chest cavity.

Meningitis — An inflammation of the tissue of the brain and spinal cord that may occur with sarcoidosis.

Multiorgan (multisystem) disease — A disease that affects more than one part of the body.

N

Nodule — A lump, swelling or mass.

Necrosis — Tissue death.

Nephritis — Kidney inflammation.

P

Paresthesia — Abnormal skin sensations, such as “pins and needles.”

PET scan — A test in which a radioactive material is injected into the body to view the extent of the spread of sarcoidosis in the body.

Portal hypertension — High blood pressure that occurs in the liver.

Pulmonary — Of, relating to, or occurring in the lungs.

Pulmonary fibrosis — Lung tissue scarring.

Pulmonary function tests — Tests that measure how well the lungs are working.

Pulse oximetry — Measurement of the oxygen level in the blood using a device attached to the finger.

Purified protein derivative — A skin test to help to distinguish sarcoidosis from tuberculosis.

S

Sarcoid — A short form of the term *sarcoidosis*.

Sarcoidosis — An inflammatory disease marked by the formation of granulomas (small nodules of immune cells) in the lungs, lymph nodes, and other organs.

Sclera — The outer coating of the eyeball.

Slit lamp examination — An examination of the inside of the eye used to detect problems caused by sarcoidosis.

Spirometry — A breathing test that measures flow of air into and out of the lungs.

T

T-cell — A type of immune cell that can attack foreign cells, cancer cells, and cells infected with a virus.

TH1 and TH2 cells — Types of lymphocytes.

Thrombocytopenia — Low platelet count.

Tumor Necrosis Factor (TNF) — A protein made by white blood cells in response to an antigen or infection. Treatments that suppress TNF have proven effective in treating sarcoidosis.

U

Uveitis — Inflammation of the middle layer of the eye.

SARCOIDOSIS TREATMENT: **YOUR OPTIONS ARE AS UNIQUE AS YOU**

Sarcoidosis is a condition that can affect any organ in the body, although more than 90% of cases affect the lungs and lymph nodes. Because each case is unique, it's important for you to take an active role in your treatment plan.

With good medical care, most cases of sarcoidosis are not severe and do not cause lasting damage to the body. However, when treatment is needed, it is important to know all of your options.

If you have sarcoidosis, it's important to ask questions and, if necessary, follow a tailored treatment plan based on multiple factors.

Common treatments for sarcoidosis include:

Corticosteroids

Reduces inflammation in affected organ(s).

Repository corticotropin injection is the only FDA-approved treatment with an indication specifically for sarcoidosis.

Immune system suppressants

Restrain the immune system, which may ease symptoms and prevent further organ damage.

Antimalarial medications

Helps alleviate skin-related symptoms; often effective for people with high calcium blood levels.

TNF-alpha inhibitors

Often used in autoimmune diseases to treat inflammation; helpful when other medications are ineffective.

Cytotoxic agents

Medicines that kill cells, such as chemotherapy.

Please note that this list is informational only – decisions about treatment are determined by your own physician, working with you. The individual treatment plan for each patient is based on multiple factors.

You are your best advocate. Always talk to your doctor about your condition and the treatment options that are best for you.

ADDITIONAL RESOURCES



chestnet.org/sarcoid



FOUNDATION FOR
SARCOIDOSIS RESEARCH


stopsarcoidosis.org

START THE CONVERSATION
WITH YOUR DOCTOR BY USING

THE 5 SARCOID

The CHEST Foundation and FSR have teamed up to launch **Sarcoidosis: Seek Answers. Inspire Results.** – a campaign that encourages people living with sarcoidosis to take a proactive role in their treatment plan.

To start the conversation with your doctor, here are five questions to bring to your next appointment:

- 
1. Which of my organs are affected by sarcoidosis?
 2. Can I do anything to prevent symptoms?
 3. What are all of the treatment options available to treat sarcoidosis?
 4. Which treatment is best for me and why?
 5. Where can I find support?



FOUNDATION FOR
SARCOIDOSIS RESEARCH

To learn more about sarcoidosis, please visit
chestnet.org/sarcoid • stopsarcoidosis.org/awareness

PATIENT RESOURCES

Patient Registry Video

<https://youtu.be/wfFiNxN5OCE>

Patient Registry

<https://fsr-sarc.patientcrossroads.org/>

Physician's Directory

<https://www.stopsarcoidosis.org/patient-resources/find-a-physician>

Treatment Protocol

<https://www.stopsarcoidosis.org/wp-content/uploads/2014/11/Treatment-Protocol.pdf>

In-Person Support Group Directory

<https://www.stopsarcoidosis.org/directory/?>

Inspire Online Support Community

<https://www.inspire.com/groups/stop-sarcoidosis/>

Patient Education Guide

<http://www.chestnet.org/~media/chesnetorg/Foundation/Documents/SarcoidosisPrimerNEW31215.ashx>

Calendar of Events and Activities

<https://www.stopsarcoidosis.org/awareness>

SECURING A PROCLAMATION FOR SARCOIDOSIS AWARENESS MONTH

City and state proclamations are an excellent way to increase awareness for sarcoidosis! And getting a proclamation is much easier than one might imagine.

Where to Begin

- Find the names and contact information of your elected officials.
 - Visit your town/city's website first. Learn about your elected officials and to which communities/committees they belong.
 - If there is a councilman/woman specifically designated to your community, contact them first. If not, decide who will be the best advocate for your cause.
 - Determine if there is an application process for proclamations
 - Is the application online? Do you submit the request by mail?
 - What is the timeline for securing a proclamation?
- Contact the office of your elected officials. Inquire about the process of obtaining a proclamation, if the information wasn't available online.
 - Know in advance what it is that you want. See page 2 for a sample letter of request and page 3 for a sample proclamation.
 - Make it your own! The only reason your official will care and act is if you speak to why you care about the cause! They'll care too because you are their constituent.
- Request a meeting to discuss your request in more detail. The more personalized your approach, the more likely the official will act to make a proclamation a reality.

Preparing to Meet an Official

- Get to know the government official and/or aide/person you're going to meet
 - To what committees do they belong?
 - How have they voted on issues concerning health care and advocacy?



SARCOIDOSIS
Seek answers. Inspire results.

Learn more about sarcoidosis: chestnet.org/sarcoid • stopsarcoidosis/awareness

- Look for connections you may have with them. Where are they from? Where did they go to school? What issues do they care about?
- Thank them for something they did or voted on.
- Determine what district to which you belong and/or whether you're one of their constituents. If so, be prepared to mention it in the meeting.
- Go in knowing exactly what you want to say and be prepared to explain yourself. Make sure that you mention:
 - April is Sarcoidosis Awareness Month
 - Brief overview of sarcoidosis and why you want to raise awareness. This is a great opportunity to tell your story and share how sarcoidosis affects other citizens in your community!
 - Prepare questions. How will the proclamation be officially presented? Would they be willing to present it at a local event? At a support group meeting? With a press release?
- Bring printed materials with you, when possible. Many materials are available at www.stopsarcoidosis.org/patientresources or email info@stopsarcoidosis.org to receive information by mail.
 - Direct the officials to FSR's website to learn more information.
- Dress professionally and arrive 10 minutes early

Meeting with the Official

- Relax! They work for you!
 - Mention your district and/or whether you're a constituent
 - Eye contact shows confidence and shows you are passionate about your cause.
 - Share your story and those of other patients in your community!
 - Answer questions and discuss your points in detail. If there's a question to which you don't know the answer, tell the official you'll find out and follow up with them.
- At the end of the meeting, thank them for their time and for listening.

- Ask the official when you can follow up with them about securing the proclamation.
- Always follow up a meeting with a letter thanking them again for their time. Call their office after the agreed upon amount of time if you don't hear back.

When a Proclamation is Issued

- Call the office and thank them.
- Ask for the date when the proclamation will be signed. Find out who you may contact in the office to follow up on the process.
- Once you have a date for the proclamation signing, confirm the number of guests who can attend. The office may ask you to submit a list of guests in advance of the presentation.
- Ask about how the office plans to publicize the signing.
 - Offer to support their efforts by preparing a press release and sharing it with local newspapers, radio, and TV stations.
 - Notify physicians and hospitals that treat sarcoidosis patients.
- Take photos! Share your photos on social media, with local media, and with the Foundation of Sarcoidosis Research at info@stop sarcoidosis.org. We will feature them on our website and in social media.

Once you've received a proclamation from your town/city, you can move to the next government level!

- For a city proclamation, start with the mayor's office.
- For a proclamation signed by city councils or state assemblies, start by contacting the office of the chairperson or president.
- For a state proclamation, start with the governor's office.

Sample Proclamation Request Letter

Dear Mayor/Governor/Councilmember_____:

On behalf of the Foundation for Sarcoidosis Research, I am writing to request your proclamation of the month of April as Sarcoidosis Awareness Month in the city/state of _____.

Sarcoidosis is a systemic, inflammatory disease that can affect almost any organ in the body. It occurs when a person's immune system overreacts resulting in the formation of granulomas, microscopic clumps of inflammatory cells. Patients can experience a wide range of debilitating symptoms which can lead to death - the cause remains unknown.

Sarcoidosis Awareness Month offers a rare opportunity to focus attention on this devastating illness.

(Briefly discuss why you care and local activities/support for sarcoidosis)

In recognition of sarcoidosis and 200,000 patients suffering across the United States, we ask that the city/state of _____ issue a proclamation for Sarcoidosis Awareness Month. We would be particularly honored to have you present this proclamation at *(describe the event at which you would like the proclamation read)*.

More information and sample language that might be helpful in drafting a proclamation, is attached. We look forward to working with your office on this important endeavor and in representing our city/state in this major international campaign.

Thank you for your consideration.

Sincerely,

[Signature and title]

Sample Proclamation

Whereas, the month of April marks the occasion of National Sarcoidosis Month observances in the town of Manasquan, focused on generating public awareness and understanding, compassion for those suffering from this disease, and support for medical research.

Whereas, Sarcoidosis is an inflammatory disease that can effect almost any organ of the body.

Whereas, Sarcoidosis causes the immune system, which normally protects the body from infection and disease, to overreact resulting in damage to the body's own tissue.

Whereas, the classic feature of Sarcoidosis is the formation of granulomas which are microscopic clumps of inflammatory cells that group together. If too many of these clumps form in an organ, they can interfere with how that organ functions.

Whereas, the cause of Sarcoidosis is currently unknown.

Whereas, Sarcoidosis can affect people of any age, race, or gender but is most common among adults between the ages of 20 and 40.

Whereas, Sarcoidosis is a multi-system disorder which means that symptoms typically depend on which organ the disease affects. In most cases the disease will affect the lungs.

Whereas, the observance of Sarcoidosis Awareness Month will provide validation to those who suffer from this unknown disease.

Whereas, recognizing Sarcoidosis Awareness Month will provide the people of Manasquan with an opportunity to increase their understanding of this potentially fatal disease.

Whereas, Cathy Wick and the Foundation for Sarcoidosis Research work together to raise awareness every year in Manasquan by hosting an annual benefit to raise money for research.

Whereas, Cathy Wick is currently hosting a support group at Jersey Shore University Medical Center help newly diagnosed patients and their families by not only helping them cope with their illness, but also providing support, both physically and mentally.