



# FOR THOSE WHO SEEK ANSWERS AND INSPIRE RESULTS

**An Informational Toolkit for Physicians and Their Patients**

Patient education resources support in part by a grant from Mallinckrodt Pharmaceuticals.



[chestnet.org/sarcoid](http://chestnet.org/sarcoid)



FOUNDATION FOR  
SARCOIDOSIS RESEARCH

[stopsarcoidosis.org/awareness](http://stopsarcoidosis.org/awareness)



[lung.org/sarcoidosis](http://lung.org/sarcoidosis)

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 physicians, their patients, and caregivers with educational information and content to generate additional awareness and education around Sarcoidosis.

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# INFORMATION AND SYMPTOMS

## Informational Video

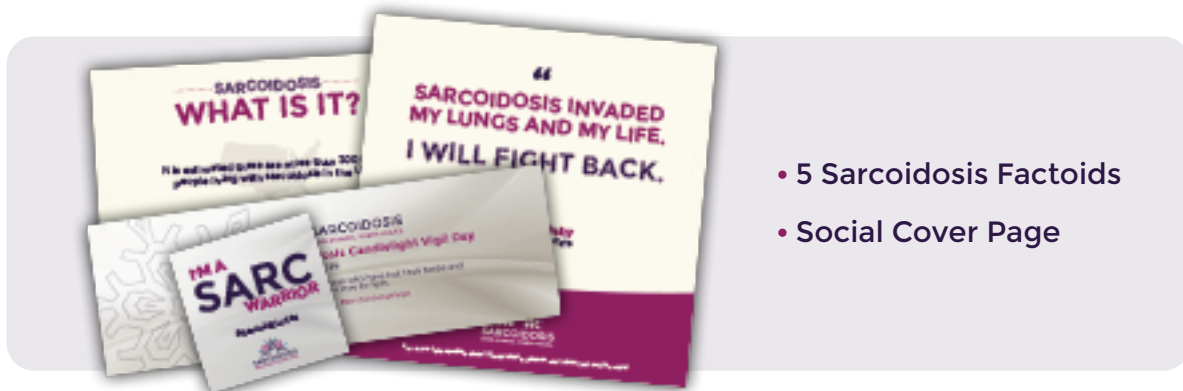
<https://www.youtube.com/watch?v=xLkoPKkI6c0>

## Symptom Navigator Microsite

<http://sarcoidosis.chestnet.org>

## SOCIAL ASSETS

Raise awareness for sarcoidosis with these social assets! Please feel free to 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](http://chestnet.org/sarcoid). Below are snapshots of what is available by accessing the link:



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



## 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



# 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.<sup>1</sup>

## SYMPTOMS<sup>2</sup>

**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.<sup>3</sup>

**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 5  
SARCOID**

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](http://chestnet.org/sarcoid)  
[stopsarcoidosis.org/awareness](http://stopsarcoidosis.org/awareness)  
[lung.org/sarcoidosis](http://lung.org/sarcoidosis)

Sources:

<sup>1</sup> Foundation for Sarcoidosis Research website: [stopsarcoidosis.org/patient-resources/what-is-sarcoidosis/](http://stopsarcoidosis.org/patient-resources/what-is-sarcoidosis/)

<sup>2</sup> Foundation for Sarcoidosis Research infographic: [pinterest.com/pin/477522366711934075/](https://pinterest.com/pin/477522366711934075/)

<sup>3</sup> 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

 **AMERICAN  
LUNG  
ASSOCIATION**

# PHYSICIAN RESOURCES

## Physician's Treatment Protocol

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

## Protocol Mobile App

<http://www.sarcoidosisprotocol.org/>

## Patient Education Guide

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

# 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>

## Support Groups

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

## Calendar of Events and Activities

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