



## National Sarcoidosis Prevention Month

### Committed to your health and our community

#### Understanding Sarcoidosis

Sarcoidosis is a disease which, despite many years of research, still has no known specific cause. Sarcoidosis is not a cancer and is not a contagious disease – in some cases it seems to run in families. Medical textbooks twenty years ago listed the disease as being primarily one of African American women and patients of Scandinavian descent. We now know that, although Sarcoid seems to be more prevalent in these populations, and there may be a genetic predisposition in these populations, the disease is by no means limited to these groups. More and more Caucasian men and women (of eastern European and Scandinavian descent), Puerto Rican patients, and African

American men are being diagnosed. Sarcoidosis is not a death sentence! In fact, once diagnosed, your doctor's first question will be to determine how extensive the disease is, and whether or not to treat at all – in many cases the choice will be to do nothing but watch carefully and allow the disease to go into remission on its own. It is also not uncommon to have a patient present to a doctor with evidence of disease in the past which was not previously recognized – in those cases where the disease can be shown to be in remission, no treatment may be suggested. 60-70% of newly diagnosed cases will go into remission with or without treatment – evidence of the disease such as nodules or

## IN THIS ISSUE

WE WILL BE CLOSED  
SUNDAY, APRIL 21ST. WE  
WILL REOPEN MONDAY,  
APRIL 22ND AT 9 AM. HAVE  
A SAFE AND HAPPY EASTER.



Scarring on a chest CT scan may remain forever – but symptoms and disease activity will not recur.

20-30% of patients may experience disease recurrence of varying severity or continued disease without periods of remission despite treatment.

Unfortunately there is no way to predict which patients will remit and which will go on to have long term difficulty – however, the bottom line is that most patients with sarcoidosis will go on to lead a full, healthy and productive life.

### **What is Sarcoidosis?**

Following exposure to some still unidentified trigger, a patient's immune system is "turned on" in a way that creates a particular pattern of inflammation. The inflammation can affect any organ in the body, but the lungs and skin are the most common. If the inflammation is allowed to continue, the end result will be scarring of the tissue. The goal of treatment is to interrupt the inflammation so that a damaging scar does not form. Scar formation is more important in certain organs – such as the lungs, eyes, heart and brain/brain coverings/nerves – disease

involving these organs would be treated with anti-inflammatory medications. Joint and muscle discomfort would also be addressed with anti-inflammatory medications. Skin involvement is more unsightly than dangerous but also can be treated – many times, very effectively by injecting medication directly into the skin lesion. Some sarcoid patients may have difficulty with calcium metabolism which, for the most part, can be managed with diet changes.

### **What triggers that cause the immune system to "turn on"?**

Despite many years of research, including a recent, large, multicenter attempt to find commonality in the exposure histories of sarcoid patients, no single material has been identified. It seems clear that the offending agent is inhaled by sarcoid patients as opposed to entering the body by mouth or by contacting the skin. Molds, certain chemicals, and inert particulates have all been implicated. There seems to be a disproportionate number of cases in healthcare workers, fire fighters and aircraft servicemen, but this may be a consequence of more

frequent health screening in these groups. Interestingly, there has been an unusual increase in the number of cases diagnosed in New Yorkers following the 911 disaster – the affected patients cut across all demographic groups.

### **How would I know if I have sarcoidosis?**

Patients present differently – shortness of breath with activity, cough without sputum production, and wheezing are some of the most common symptoms.

Swelling and pain in the ankles, wrists, and knees is also fairly common. A skin rash may be seen most commonly on the legs, scalp, or face – but any body part can be involved. The "rash" is a raised/lumpy area that does not itch nor does it come and go quickly the way a viral rash would. Sometimes patients experience profound fatigue, unexplained weight loss, daily fevers and excessive sweating especially at night. Patients with any or all of these symptoms should consult with their doctor.

### **What do I do if I am diagnosed with sarcoidosis?**

The decision to treat or not to treat sarcoidosis at a given time is

critical. The chance of multiple organ involvement must be considered. Therefore, it would be wise to seek out a doctor/healthcare system with a special interest in sarcoidosis and the ability to approach the disease from a multi-disciplinary perspective – involving the appropriate expert specialists when needed – providing the long-term follow-up to monitor remission status, disease recurrence, and response to treatment. Sarcoidosis is a disease of unknown origin that causes the immune system to overreact, which can lead to health issues, including lung damage, skin rashes and eye disease, and can affect other organs of the body. With good medical care, most cases of sarcoidosis are controlled and do not cause lasting damage to the body. However, it is important for people living with sarcoidosis to assess all of their options through an open dialogue with their physician. “Sarcoidosis continues to perplex both patients and doctors. Each case of sarcoidosis is unique, which makes it difficult to diagnose because symptoms vary and often

mimic those of other diseases. While many patients do not experience serious health problems, 30 to 40 percent of people living with sarcoidosis have a persistent condition that may require personalized treatment,” said Doreen Addrizzo-Harris, MD, CHEST Foundation President-Elect & Trustee. “We are excited to be expanding our awareness campaign this year and hope to provide patients, caregivers and clinicians with even more information, tools and treatment options.” With good medical care, most cases of sarcoidosis are controlled and do not cause lasting damage to the body. However, it is important for people living with sarcoidosis to assess all of their options through an open dialogue with their physician. To enable this discussion, Seek Answers. Inspire Results. Offers people living with sarcoidosis and their caregivers a simple toolkit available at [chestnet.org/sarcoid](http://chestnet.org/sarcoid) to help them understand and manage their condition as well as resources to create awareness and spark conversations in the community. These tools include the “Sarcoid

Five” – a list of five questions designed to start patient-doctor conversations to help people living with sarcoidosis understand treatment options and create a personalized plan to control their individual condition.

“Many people with pulmonary sarcoidosis think they have the flu or a respiratory infection before they’re diagnosed with sarcoidosis. Although sarcoidosis can affect many different organs, it most commonly affects the lungs. Symptoms of pulmonary sarcoidosis can include cough, shortness of breath, chest pain or wheezing,” said Albert Rizzo, MD, FACP, FACCP, Senior Medical Advisor to the American Lung Association. “A chest X-ray taken at these times of symptoms can be suggestive of pulmonary sarcoidosis and appropriate referral to a pulmonary specialist may be in order. “In addition to the toolkit, all three partners will be offering in-person and online opportunities to connect with healthcare providers, as well as other patients and caregivers through webinars, online support communities and Foundation for Sarcoidosis Research Patient

Conferences throughout the United States. The campaign also encourages people to increase public awareness for this disease by equipping patients with resources to spark conversations in their “We are proud to partner with the American Lung Association and the CHEST Foundation this year as we continue to help patients navigate this complex condition,” said Ginger Spitzer, Executive Director of Foundation for Sarcoidosis Research. “By working together to ensure that individuals living with sarcoidosis are well-resourced and engaging all stakeholders as partners in raising public awareness for sarcoidosis, this campaign assures patients and their loved ones that they are not alone.” During the month of April, join in the conversation by updating your social media profiles and using the hashtag #SarcoidStories to help raise awareness. For more information, visit [Chestnet.org/sarcoid](http://Chestnet.org/sarcoid), or call the American Lung Association’s free Lung HelpLine to talk to a certified respiratory therapist.

### Types of medications used to

**treat sarcoidosis** 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. Learn more about corticosteroids and questions you can ask your doctor before starting treatment.

### 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.

