SARCOIDOSIS FACTS

Sarcoidosis (Sar-coy-doe-sis) is a systemic inflammatory disease believed to be brought on by an abnormal response of the body's immune system resulting in inflammation of tissue that clump together and form grain-like lumps called Granulomas in various parts of the body.

Sarcoidosis is considered a multi-systemic disorder because it has the ability to affect any system and organ in the body; the heart, eyes, liver, kidneys, skin and even the central nervous system; including the brain, but it generally originates in or around the lungs.

Sarcoidosis is **not** contagious but it can potentially be fatal due to its erratic behavior in the body coupled with the inability of the medications used to treat the disease to stop the progression of the disease and the fact that there's **NO KNOWN CURE!!**

What Causes Sarcoidosis?

The cause of Sarcoidosis is unknown but researchers believe that Sarcoidosis might be caused by the body's immune system reacting to something environmental such as; Bacteria, Chemicals/Toxins, Dust, Mold or Pathogens that enter the body and possibly even a virus but to date a definite cause remains unclear.

What are the signs & symptoms of Sarcoidosis?

Signs and symptoms of Sarcoidosis vary from person to person; no two people are affected in same exact way (which is why the "snowflake" has become the national symbol for the disease).

Common signs can include but are not limited to:

Persistent coughing, shortness of breath, extreme fatigue, vague feelings of discomfort, fever, weight loss, small red bumps on the face, arms, buttocks or legs, eye irritation, arthritis in the ankles, elbows, wrists and hands but in some cases symptoms may not appear at all.

How is Sarcoidosis diagnosed?

In the early stages of Sarcoidosis symptoms can be minimal to non-existent. Signs of the disease can develop gradually over time or emerge & disappear suddenly.

The erratic characteristics of Sarcoidosis can make it very difficult to diagnose which is why it is frequently detected incidentally through a chest X-ray taken for unrelated reasons.

Oftentimes when signs & symptoms do become present they are mistaken as preludes to other similar diseases such as Lupus, Lymphoma, Tuberculosis, Rheumatoid Arthritis & even heart disease. Sadly, many patients go misdiagnosed for years under the label of these diseases before being properly diagnosed with Sarcoidosis. Therefore a doctor must first rule out other diseases before they can confirm a diagnosis of Sarcoidosis.

Jaz Owens
(818) 850-0223
Asongfoundation@gmail.com

<u>Common test used to help identify Sarcoidosis include</u>:

· **Chest X-ray**
· **Tissue Sampling**
· **Pulmonary Function Test (PFTs)**
· **Mediastinoscopy** - Surgical procedure to examine the inside of the upper chest cavity near the lungs.
· **Blood Test Measuring:**
- Liver Function
- Calcium Levels,
- **ACE Levels**/Angiotensin-Converting Enzyme
A substance produced by the granuloma making cells

· **Slit-Lamp Examination** - Eye Test
· **Electrocardiogram** (ECG) - Tests heart function.

Who is at risk for Sarcoidosis?

Anyone can develop Sarcoidosis! It's no longer considered a rare disease as it has become a common health issue that affects people internationally from all origins, ethnicities, gender & ages (but most commonly detected between the ages of 20 - 40).

Since the first detection of Sarcoidosis in London back in 1877, this disease has spread worldwide but still remains a medical mystery. Sarcoidosis remains one of the least recognized & underserved causes today but silently affects **(an estimated) tens of thousands plus people across the U.S.**

The symptoms of Sarcoidosis may masquerade as other illnesses, but the real ***"Faces of Sarcoidosis"*** stand before you each day as mothers, fathers, husbands, wives, sisters, brothers, sons, daughters & friends fighting to raise the volume on this quiet epidemic through awareness, education & research to help find a cause and a cure!

What medications &/or treatments are used to manage Sarcoidosis?

Currently there isn't an "approved" medical protocol for treating Sarcoidosis; however below is a list of medications that have been used to treat various symptoms & complications of the disease.

- Prednisone or Dexamethasone which are Oral Corticosteroid Medications.
- Hydroxychloroquine & Chloroquine are Oral Antimalarial Drugs which are used to treat Sarcoidosis of the skin, lungs & nervous system.
- Methotrexate & Azathioprine are used instead of or in addition to Corticosteroids to treat pulmonary and chronic Sarcoidosis.
- Cyclophosphamide & Chlorambucil are used in severe stages of the disease, when other medications have failed to be effective.
- Pentoxifylline & Thalidomide have been reported to have beneficial effects of treatment-resistant lupus pernio.

Jaz Owens
(818) 850-0223
Asongfoundation@gmail.com

- Infliximab (Remicade) or Adalimumab (Humira) and Etanercept (Enbrel) are medications given by intravenous injection under the skin once a month, once again in severe cases of Sarcoidosis when other medications have been unsuccessful.
- Colchicine is an oral medication used to treat Sarcoidosis related arthritis.
- NSAIDs (nonsteroidal anti-inflammatory drugs) such as ibuprofen to help reduce inflammation fever and relieve joint pain.

It's important to know that some of these medications can have major side effects and are very toxic but none of them listed or used have the ability to stop the progression of the disease, they can only minimize (mask) the symptoms.

What are the stages of Sarcoidosis & how can a person determine the stage that they're in?

"Stages" as it pertains to Sarcoidosis can be very misleading, as this term does not pertain to all types of Sarcoidosis; it's only significant with respect to Pulmonary Sarcoidosis (lung involvement).

It's important to know that Sarcoidosis cases don't always go from mild to serious in a noticeable manner ... Stage I does not always progress to stage two, three etc. Stages do not imply progression, rather just patterns seen on chest films.

Between Stage I & Stage II there usually aren't significant differences in symptoms, pulmonary function tests or prognosis. Generally, patients in Stages III & IV exhibit the worse symptoms and prognosis but on occasion, their chest film overestimates their symptoms.

There are four (4) Stages of Pulmonary Sarcoidosis:
Stage 0 - Patients display a "normal" chest x-ray.

Stage I - Patients have enlarged lymph nodes in the middle of the chest (Thoracic Lymphadenopathy) but may not exhibit any symptoms & usually don't have any lung involvement.

Stage II - Patients have enlarged lymph nodes/glands in the middle of the chest (Thoracic Lymphadenopathy), abnormal lung findings on chest x-ray films (which means there is lung & node involvement) but they may or may not exhibit any symptoms.

Stage III - Patients have abnormal lung findings on chest x-ray films but the lymph nodes/glands in the middle of the chest are <u>not</u> enlarged. These findings suggests that the disease has progressed and the symptoms are more severe.

Stages IV - Patients have deterioration of the lung with damage to upper lobes and formation of scar tissue (irreversible lung disease). This can be determined by loss of lung function, fibrosis (scarring in the lungs) and progressive dyspnea (difficulty breathing).

Jaz Owens
(818) 850-0223
Asongfoundation@gmail.com
ForLife.wix.com/Sarcoidosis ● Facebook.com/ASongForSarcoid ● Twitter: @ASongForSarcoid

Is Sarcoidosis contagious &/or is it hereditary?

Sarcoidosis is **<u>NOT</u>** contagious and can't be transmitted from person to person like a virus or common cold!

All though there are cases in families where Sarcoidosis has affected more than one family member, it is not a transmittable disease. However, research is still being done to determine if there is a genetic predisposition coupled with certain environmental exposures that might be the causing factor but researchers don't know for sure.

Are there any dietary precautions that I should adhere to living with Sarcoidosis?

An estimated one in ten patients experience high blood calcium levels. This core group of Sarcoidosis patients should avoid calcium rich foods such as milk, & cheese as well as supplements/vitamins containing calcium.

Patients should also be careful about spending time in direct sunlight due to the over absorption of Vitamin D from the sun causing adverse effects.

What is the difference in Lupus & Sarcoidosis?

To fully understand the **differences between Lupus & Sarcoidosis** you have to know that the definition of **Autoimmune is:** A disorder when ones immune system cannot decipher the difference between the body's healthy tissue and foreign invaders (viruses, bacteria & germs) then creates auto-antibodies ("auto" means "self") that causes inflammation, pain and mistakenly **attacks and destroys its own healthy tissue** in different parts of the body.

Lupus is a Chronic Auto-Immune Disease. In people with Lupus something goes wrong with the immune system where it can't tell the difference between foreign substances and the body's healthy tissues causing it to become hyperactive and attack the normal, healthy tissue. This results in symptoms such as inflammation, swelling, and damage to joints, skin, kidneys, blood, the heart, and lungs.

Sarcoidosis is a Systemic Inflammatory Disease of unknown origin but believed to be brought on by an abnormal response of the body's immune system resulting in inflammation.

A normal immune system: Defends your body against harmful substances by sending special cells to protect the organs in danger. These cells release chemicals that recruit other cells to isolate and destroy the harmful substance but during this process inflammation occurs. In a normal immune system, once the harmful substance is gone the cells and the inflammation go away.

In people with Sarcoidosis, the inflammation doesn't go away. Instead, the inflamed tissue clump together and form grain-like lumps called Granulomas (gran-yu-LO-mas) or nodules harboring the ability to affect any part of the body. This results in symptoms such as extreme fatigue, chronic dry cough, joint pain and potential damage to the Lungs, Kidneys, Liver, Joints, Eyes, Skin & Central Nervous System (including the Brain).

Both Lupus & Sarcoidosis are known for their erratic characteristics of patients experiencing alternating periods of being asymptomatic (void of symptoms) and periods of mild to severe flare-ups (exacerbations) without warning.

Jaz Owens
(818) 850-0223
Asongfoundation@gmail.com