

## **MANAGING YOUR SARCOIDOSIS**

### **What Is Sarcoidosis?**

Sarcoidosis is an illness that causes inflammation of many organs. It most often starts in the lungs or lymph nodes (glands). The illness affects both sexes and all ages but is more common in females between the ages of 20 and 40 years old.

### **What Causes Sarcoidosis?**

The cause isn't known. It is a granulomatous disease. Granuloma means a special kind of tissue inflammation seen with a microscope, and granulomatous means related to granuloma.

Sarcoidosis isn't contagious or hereditary, although the risk is increased if a close family member carries the diagnosis.

### **What Are the Symptoms of Sarcoidosis?**

Some people have only one or two symptoms, but others have many. These may include shortness of breath, dry cough, joint aches and pain, chest pain, dry eyes, dry mouth, fever, large lymph glands, loss of appetite and weight, palpitations, chronic runny or stuffy nose, rash, and stiff or swollen joints. Other signs and symptoms are tiredness, vision changes, and tender red areas over the legs known as "erythema nodosum." In complicated cases, eye inflammation, high blood calcium levels, liver and kidney problems, heart rhythm problems, and skin lesions may occur.

### **How Is Sarcoidosis Diagnosed?**

The diagnosis is difficult, because people may not have symptoms, and other disorders can cause similar problems. The health care provider will do a physical examination and order a chest x-

ray. The x-ray is often abnormal and the physical examination may be normal. The health care provider may want blood tests, breathing tests, computed tomography (CT), tissue biopsy, tuberculosis (TB) tests, and electrocardiography (ECG). If the health care provider needs a lung sample for diagnosis, a procedure called bronchoscopy will be done by a lung specialist (pulmonologist). The doctor puts a flexible tube through the nose into the lungs. If results are unclear, surgery to open the lungs and get a more extensive piece of tissue (open lung biopsy) may be done.

### **How Is Sarcoidosis Treated?**

Many people get better without treatment, especially in earlier stages and people without symptoms. However, in people with severe symptoms, treatment may be needed for several weeks to years. Oral corticosteroids (anti-inflammatory steroids such as prednisone) usually help in 1 to 3 months, but close follow-up and dose changes are necessary. Prednisone is usually given for at least 6 to 12 months. Usually, the lowest dose to control sarcoidosis is used. Response to treatment is checked by watching for changes in symptoms, chest x-rays, breathing tests, and other abnormalities. Relapses may occur. For severe progressive disease not responding to prednisone, more powerful medications, such as methotrexate, azathioprine, or hydroxychloroquine, may be used.

### **DOs and DON'Ts in Managing Sarcoidosis**

- ✓ **DO** tell your health care provider about your medicines (prescription and over-the-counter).
- ✓ **DO** tell your health care provider if you're pregnant.
- ✓ **DO** eat a low-salt diet if you take corticosteroids, to prevent fluid gain.

- ✓ **DO** have your blood pressure checked and blood tested for diabetes while taking corticosteroids.
- ✓ **DO** get a flu shot each fall.
- ✓ **DO** get vaccinated for pneumococcal pneumonia.
- ✓ **DO** call your health care provider if you're very thirsty, urinate a lot, or have weight changes. It could indicate a very high sugar level from prednisone.
- ✓ **DO** call your health care provider if you cough discolored sputum or blood.
- ✓ **DO** call your health care provider if you have fever, chills, vision changes, chest pain, or palpitations.
- ✓ **DO** call your health care provider if your symptoms don't get better or get worse.
- ⊗ **DON'T** stop taking your medicine or change your dosage because you feel better, unless your health care provider tells you to.
- ⊗ **DON'T** smoke. Smoking makes symptoms worse.
- ⊗ **DON'T** get too much direct sun exposure. It will make any skin rash from sarcoidosis worse.

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## FOR MORE INFORMATION

Contact the following sources:

- National Sarcoidosis Resources Center: Tel: (732) 699-0733; Website: <http://www.nsrc-global.net>
- American Lung Association: Tel: (800) LUNG-USA (586-4872); Website: <http://www.lungusa.org>

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