

20

JAHRE / ANS
SSARV - AScS
sarkoidose.ch

Sarcoidosis: a rare disease with many facets

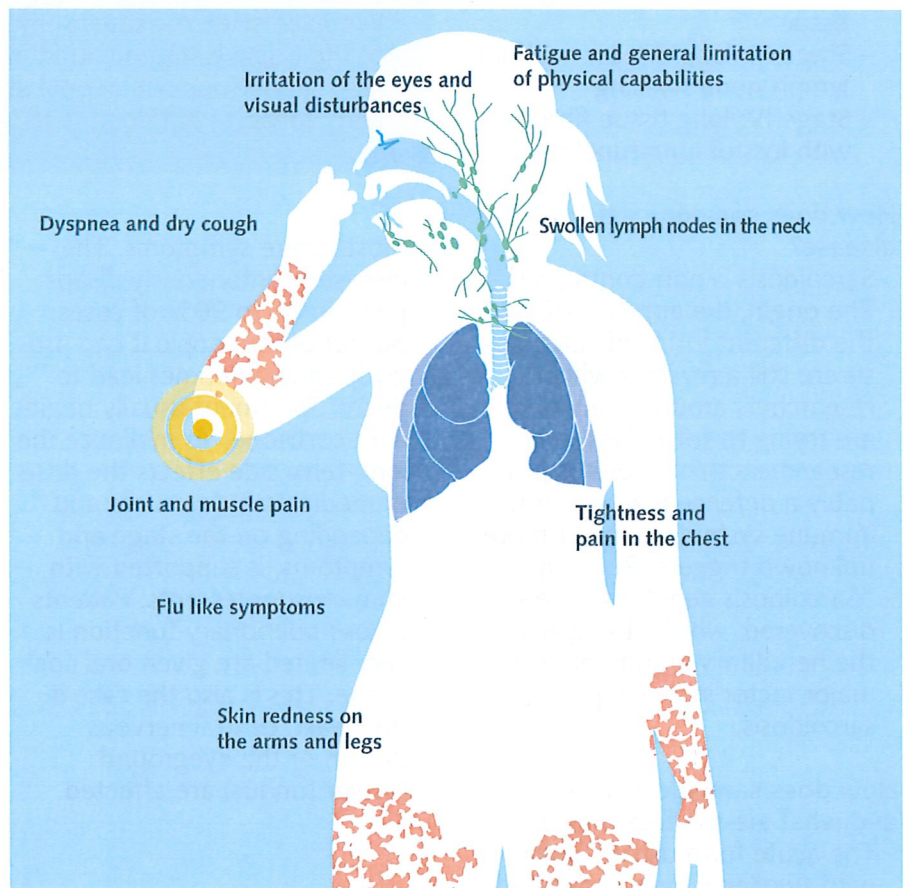
In Switzerland, nearly 3500 people suffer from sarcoidosis. In this rare disease, inflammatory nodules of varying size develop in various organs. The lungs are the most commonly affected. The symptoms are varied, making diagnosis difficult. The exact causes of the disease are still uncertain.

What is sarcoidosis?

It is a rare disease characterised by the development of small nodules of connective tissue called inflammatory granulomas. Lungs, skin, muscles, joints, bones, eyes, liver, kidneys, heart and nervous system - often several at once - can be affected. Granulomas may leave scars, hinder the functioning of damaged organs and can cause pain. In over 90% of cases the lungs are affected and progressive fibrosis of lung tissue often causes dyspnea (breathlessness) and cough.

How is it diagnosed?

Because sarcoidosis is rare and has very diverse symptoms, which can make it look like other diseases, it can take months or years before a diagnosis is made. An x-ray of the lungs (conventional radiography and/or CT-scan) can show the small nodules in the lung tissue. The lung specialist can detect these typical small nodules and determine the stage of the disease. Sometimes there are also swollen lymph nodes or thickened (fibrotic) lung tissue. A spirometry test



The most common symptoms

can indicate the effect on lungs function. Using a bronchoscopy, samples of the lung tissue or neighbouring lymph glands can be taken. Further



investigation can be done on granulomas using endobronchial ultrasonography (EBUS). As the disease can affect a wide variety of organs, an ophthalmic (eye) examination, an electrocardiograph (ECG) and blood and urine tests are also often taken. Thus, diagnosis requires the participation of different specialists.

Stages of pulmonary sarcoidosis:

- Stage I: symmetrical swollen lymph nodes with no visible damage to the lung tissue
- Stage II: bilateral lymph node swelling with diffuse granuloma formation in the lung tissue
- Stage III: lung disease without lymph node swelling
- Stage IV: lung tissue fibrosis with loss of lung function

How does someone get this disease?

Sarcoidosis is non-contagious. The origin, the appearance and the different forms of sarcoidosis are still a mystery which researchers around the world are trying to solve. However, researchers think that it is probably a defence reaction of the immune system to one or more unknown triggers. Recently a "Sarcoidosis gene" has been discovered, which strengthens the hereditary argument as a major factor in developing sarcoidosis.

How does sarcoidosis develop and what are the treatments?

The acute form usually begins with swollen lymph nodes and flu-like symptoms. Sometimes anti-inflammatory pain killers are used and a cortisone medication may be used for the

Three questions to Dorrit Irène Novel, President of the Swiss Sarcoidosis Association (SSARV-ASCS)

What makes the diagnosis of sarcoidosis so difficult?

The clinical picture is confusing, difficult to grasp and not consistent. The risk of confusion with other diseases is high; hence the importance of close cooperation between the family doctor/general practitioner together with pulmonary and sarcoidosis specialists.

What sort of discomfort is there?

Sarcoidosis can severely restrict quality of life. The cortisone drug treatment can cause significant side effects such as weight gain or promote the occurrence of osteoporosis and diabetes. In severe cases of pulmonary sarcoidosis, an extra supply of oxygen is needed. The development of the chronic sarcoidosis is not predictable. There are transitional phases of recovery, but uncertainty remains.

What are the new developments in therapy?

We need scientific advancements to better understand the onset of the disease, improve treatment and avoid complications. Our association supports people affected by sarcoidosis and maintains contact with doctors to learn more about this rare disease.

most severe symptoms. The disease spontaneously disappears in 80 to 90% of cases, but for other people it can progress and sometimes lead to death. Treatment usually begins with cortisone. To minimize the long-term side effects the dose of medication decreases and depending on the stage and symptoms, is supported with immunosuppressants. Patients whose pulmonary function is very limited are given oral cortisone. This is also the case if the heart, central nervous system or the eyeground (ocular fundus) are affected.

The choice of individual treatment requires a lung specialist. A comprehensive treatment involving breathing and mobility, relaxation exercises and stress reduction improves quality of life. The development of the disease should be closely monitored for at least three years after the end of treatment because relapse is possible.

→ For more information:
www.sarcoidose.ch

