
A Case Control Etiologic Study of Sarcoidosis (ACCESS)

**Summary for Study Participants**

Study Summary

Between November 1996 and June 1999, 10 medical centers (from across the United States) and one coordinating center conducted a study of sarcoidosis called "A Cases Control Etiologic Study of Sarcoidosis ("ACCESS"). ACCESS was funded by the National Heart, Blood and Lung Institute. The centers enrolled 736 patients with sarcoidosis and 706 community volunteers (called "controls") who were similar to the patients with sarcoidosis, except that they did not have this disease. This summary provides an overview of the major results of this study, including new information regarding possible causes, genetic risk factors, clinical severity, associated medical conditions, the clinical characteristics of sarcoidosis, and short term prognosis (or outcome) of this disease.

As of 2005, ACCESS has resulted in fifteen published papers in the peer-reviewed medical literature. Additional research analyses are continuing to occur. The sections below

summarize the results of the published studies and provide citations of the papers in the medical literature, so that interested readers may read for themselves the results in the medical journals.

The ACCESS investigators began the study with the following hypothesis: *Sarcoidosis occurs when a person with a certain genetic (or inherited) make up has an exposure to something that causes him or her to develop the disease.*

Major Conclusions of the Study

ACCESS is the largest study of sarcoidosis ever undertaken in the United States and several new insights were gained: the age at onset of disease for sarcoidosis may be older than previously thought; the genetics of sarcoidosis patients are unique in comparison to those without sarcoidosis; family members of sarcoidosis patients are at an increased risk of also having sarcoidosis; some environmental or occupational exposures are linked to having sarcoidosis and, depending upon the type of exposure, are linked to having certain organs involved with sarcoidosis; the blood specimens from our study sarcoidosis patients did not have evidence of an infection. Further study highlights include:

- Certain genes that help control the body's immune response (called "HLA" genes) are different in sarcoidosis patients, supporting the idea that the risk for developing sarcoidosis can be inherited from our parents. Some of these genetic differences in ACCESS were seen more often in African-American sarcoidosis study participants than in Caucasians.

- Other genes that are involved in controlling the immune system may be important in helping to determine what parts of the body will be affected by sarcoidosis.

- ACCESS did not find one, single cause of sarcoidosis in the environment. However, certain types of work, and certain types of exposures at home and on the job, were linked to an increased risk for getting sarcoidosis.

- People who smoked tobacco products or who breathed other peoples' smoke (called 'second-hand smoke') were less likely to have sarcoidosis.

- People with lung-only sarcoidosis were more likely to have wood burning and agricultural organic dust exposures than people with systemic disease. These findings were especially true for African-Americans with wood burning exposures and Caucasians with agricultural organic dust exposures.

- Work histories were linked to having sarcoidosis in ACCESS. Sarcoidosis participants, especially Caucasians, were more likely to have industrial organic dust exposures than study controls. Sarcoidosis participants were also more likely than controls to have been educators or to have worked in an elementary or secondary school and less likely to have been childcare providers.

- Close relatives of sarcoidosis patients are at an increased risk for being diagnosed with sarcoidosis.

- There are differences in which organs are involved with sarcoidosis based on sex and race of the individual. Women are more likely to have eye and nervous system disease. Men are more likely to have hypercalcemia. African-Americans are more likely to have skin sarcoidosis (other than erythema nodosum) and eye, liver, bone marrow, and lymph node involvement of their sarcoidosis.

- A clinical checklist developed by ACCESS investigators can help determine how likely it is that sarcoidosis is affecting different parts of the body. This checklist produces a "map" of which organs are affected by sarcoidosis.

- The diagnosis of sarcoidosis is often delayed by many months and requires many physician visits, especially when the lungs are involved.

- Sarcoidosis study participants with worse chest x-rays due to sarcoidosis also had poor breathing tests. Sarcoidosis study patients were more likely to report feelings of depression. Worse lung function and greater shortness of breath were associated with study patients reporting to us that they have a poorer quality of life.

- Low income, lack of health insurance, and other financial barriers to medical care are significantly associated with sarcoidosis severity, even after considering other factors such as race, sex, and age.

- Approximately 80% of sarcoidosis patients re-examined after two years showed improvement or stability of lung function tests, chest x-ray, and the sensation of shortness of breath. Although both Caucasians and African-Americans with sarcoidosis showed improvement or stabilization of their breathing tests, African-Americans improved less. African-Americans, people with multiple organs involved at time of first visit, and people of lower income were all more likely to have sarcoidosis show up in one or more new organ after two years.

- A type of bacteria (called “cell wall deficient mycobacteria”) is *not* found in the blood of sarcoidosis patients any more often than in the blood of controls, contrary to previous published reports. This does not completely exclude the possibility that mycobacteria or other bacteria might cause sarcoidosis.