



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.

Study Design Summaries

1. Article Title: “ACCESS Research Group. Design of a Case Control Etiologic Study of Sarcoidosis (ACCESS)”

Lead Author: The ACCESS Research Group

Article Journal: Journal of Clinical Epidemiology 1999; Vol. 52: pp. 1173-86.

This paper, which was published in the Journal of Clinical Epidemiology, describes in detail the way in which the study was performed. The study is what scientists call a “case control study design.” This means that patients in ACCESS are compared to people who are the same sex, race, and within 5 years of age, but who do not have sarcoidosis. In this kind of study, researchers in many different ways ask one main question: “How are patients with sarcoidosis different from people who do not have sarcoidosis?”. This type of study does not usually prove what causes a particular disease, but the findings help point scientists in the right direction for future studies.

The 10 study centers enrolled patients who had recently been diagnosed with sarcoidosis. They then enrolled controls from the same community, by making telephone calls to home phones of people who had the same first three numbers in their telephone exchange as the sarcoidosis patients. ACCESS tried to find volunteers who otherwise were generally similar to the patients with sarcoidosis, matching them for their age, sex, race, and neighborhood. The diagnosis of sarcoidosis was double-checked in study patients by ACCESS doctors reviewing chest x-rays and medical records, and by performing physical examination, laboratory and breathing testing. Sarcoidosis patients and controls were asked many questions about their work and home environments, where they have lived, their families, their habits, and, in the case of

patients with sarcoidosis, about their diagnosis and treatment. Blood was collected from all participants for laboratory testing and for special studies. These special blood studies included looking for signs of infectious causes of sarcoidosis, signs of an immune system not working properly, and differences in the genes (or inherited information) in patients with sarcoidosis as compared to their matched controls.

2. Article Title: “Defining Organ Involvement in Sarcoidosis: The ACCESS Proposed Instrument”

Lead Author: Marc Judson, MD

Article Journal: Sarcoidosis, Vasculitis, and Diffuse Lung Diseases 1999; Vol. 16: pp. 75-86.

Sarcoidosis often affects the lungs, eyes, and skin but can affect any organ in the body. Sometimes doctors biopsy an organ that is involved with sarcoidosis. In this case, if the organ biopsy shows clusters of cells called “granulomas,” and if they do not find some other cause of these granulomas, the diagnosis of sarcoidosis is made. Sometimes a doctor determines that an organ is involved with sarcoidosis without doing a biopsy. In these cases, the doctor makes the determination that an organ is involved with sarcoidosis based on x-ray, CT scans, laboratory tests, and clinical examinations. However, not all doctors agree on the laboratory tests required to state that an organ is involved with sarcoidosis. A biopsy is the surest method of making the diagnosis of sarcoidosis.

For this reason, the ACCESS investigators developed a list of clinical tests that help determine how likely it is that sarcoidosis is affecting different parts of the body. This produces

something like a “map” of where sarcoidosis is affecting the body. It is hoped that this list will be used whenever doctors do studies of patients with sarcoidosis, so that there can be agreement as to when an organ is involved with sarcoidosis.

Summaries of Specific ACCESS Findings

Environmental or Occupational Risk Studies

3. Article Title: “A Case Control Etiologic Study of Sarcoidosis: Environmental and Occupational Risk Factors”

Lead Author: Lee S. Newman, MD

Article Journal: American Journal of Respiratory and Critical Care Medicine. 2004, Vol 170, pp. 1324-1330

The cause of sarcoidosis is unknown. Past research suggests that a number of exposures in a person’s home or work environment may be linked to sarcoidosis. Interviewers asked questions of people who had been diagnosed with sarcoidosis and of their matched controls. We asked both groups questions about their jobs, homes, and hobbies. We studied all the answers and a combination of answers to determine if patients with sarcoidosis and their controls shared the same type of exposure.

We found sarcoidosis was more likely to occur in people with certain types of jobs and certain types of exposures in their jobs or homes. More so than in the home, people’s workplace exposures more often were linked to having sarcoidosis. The *jobs* we found associated with sarcoidosis were farming, raising birds, and being a middle school or high school teacher. The *exposures* in people’s work places linked to sarcoidosis were insecticides or pesticides, mold or mildew, and musty odors.

People in the study who smoked tobacco products or who breathed other peoples’ smoke (called ‘second-hand smoke’) tended to be the study controls, not those with sarcoidosis.

In ACCESS, several environmental exposures that past authorities had thought to be linked to sarcoidosis were found *not* to be associated with sarcoidosis. For instance, ACCESS did not find that being exposed to pine trees, wood dust, metals, silica, talc at work, or eating clay to be associated with having sarcoidosis.

In conclusion, ACCESS did not find the cause of sarcoidosis. Importantly, the study suggests that there may be more than one exposure that can cause this disease. We found several job, home, and hobby exposures linked to having sarcoidosis. Future studies will be needed to look harder at certain environmental factors, such as insecticide use on the job, working in musty, moldy environments, or being a school teacher. Although ACCESS showed that these kinds of environments were associated with an increased risk for having sarcoidosis, this study does not *prove* that these environmental factors are the *cause* of sarcoidosis.

4. Article Title: “Job and Industry Classifications Associated with Sarcoidosis in A Case Control Etiologic Study of Sarcoidosis (ACCESS)”

Lead Author: Juliana Barnard, MA

Article Journal: Journal of Occupational and Environmental Medicine. 2005;Vol. 47: pp. 226-234.

One of the goals of the ACCESS study was to investigate whether jobs that people have held in the past contribute to their risk for sarcoidosis. We asked the study participants (706 people with sarcoidosis and 706 people without sarcoidosis) to give us a summary of all of the jobs they had held for at least 6 months during their working life. For each job, we recorded job title, company name, type of business, specific job duties, year started, and total time they

worked at that job with those duties. We analyzed these jobs to see if certain jobs or businesses had been held more often by the people with sarcoidosis or by the people who did not have sarcoidosis.

We found that certain jobs may be associated with an increased risk of sarcoidosis. Workers who reported jobs in an industry with industrial organic dust exposures (such as cabinet makers, paper mill workers, or those with agricultural exposures) were more likely to have sarcoidosis. Workers at suppliers of building materials, hardware, and gardening materials were also more likely to be a sarcoidosis case than a control (someone not diagnosed with sarcoidosis). Educators and people who work at elementary or secondary schools were more likely to have been diagnosed with sarcoidosis as well.

Some job histories were given more often by those study participants without sarcoidosis. These jobs included childcare providers or workers in the childcare industry as well as workers with metal dust or metal fume exposures.

In summary, we did not find that only one type of job or business was linked to sarcoidosis. Some of the jobs and industries we found associated with sarcoidosis were reported by only a small number of people with sarcoidosis. We did find that work at certain jobs or businesses may be related to the development of sarcoidosis. Further study of these findings is necessary to truly understand the occupational and environmental contributions to sarcoidosis risk.

5. Article Title: “Relationship of Environmental Exposures to the Clinical Phenotype of Sarcoidosis”

Lead Author: Mary Elizabeth Kreider, MD

Article Journal: Chest. July 2005; Vol. 128 (Issue 1): pp. 207-215.

As noted above, certain exposures in a person’s home or work environment have been linked to sarcoidosis in previous research. In addition to asking whether sarcoidosis subjects were more likely to have been exposed to certain substances than their matched controls, we also asked whether people with different symptoms or manifestations of sarcoidosis were more likely to have been exposed to certain exposures than people with other kinds of sarcoidosis. In particular, were study participants whose sarcoidosis only affected their lungs more likely to have had an inhalational (breathed in) exposure than study participants with other organs involved with sarcoidosis (for instance, the liver, skin, or eyes)?

We found that people with lung only involvement of their sarcoidosis were more likely to have been exposed to wood smoke and agricultural organic dusts (for instance, farming, working with animals, exposure to vegetable dusts, or raising birds). Race was also important. African-American participants with lung only sarcoidosis reported more wood smoke exposure and Caucasian participants with lung only sarcoidosis reported more agricultural organic dust exposure in comparison to the participants with systemic sarcoidosis. This suggests that how one is exposed to environmental agents may affect the type of sarcoidosis they develop. This study does not prove that these agents are the cause of sarcoidosis but merely may affect what form of sarcoidosis a patient may develop.

Infection Risk Study

6. Article Title: “Recovery of cell wall-deficient organisms from blood does not distinguish between patients with sarcoidosis and control subjects”

Lead Author: Sheldon Brown, MD

Article Journal: Chest. February 2003; Vol. 123 (Issue 2): pp. 413-417.

In an ACCESS substudy, blood obtained from 197 patients with sarcoidosis and 150 control participants without sarcoidosis were studied. Because past research has suggested that the cause of sarcoidosis might possibly be a form of bacteria (called mycobacteria), the investigators looked in the blood for a kind of bacteria called “cell-wall deficient (CWD) mycobacteria”. Previous studies of small numbers of sarcoidosis patients have reported growth of this type of bacteria in sarcoidosis patients.

In this ACCESS substudy, mycobacteria could not be found in the blood of sarcoidosis participants. It is still possible that bacteria are involved in the cause of sarcoidosis. Future studies may need to look for bacteria in the organs of people with sarcoidosis instead of in their blood.

Genetic Risk Studies

7. Article Title: “HLA-DRB1*1101: A Significant Risk Factor for Sarcoidosis in Blacks and Whites”

Lead Author: Milton D. Rossman, MD

Article Journal: American Journal of Human Genetics. October 2003; Vol. 73 (Issue 4): pp. 720-735.

Sarcoidosis is a disease in which the immune system “overreacts.” ACCESS used modern technology to look at how genes that control the immune system might be different in sarcoidosis patients compared to controls. The study found differences between sarcoidosis patients and the matched controls in one important set of genes (which researchers call the “HLA”). These genes tell the immune system when (or when not) to respond to things that are foreign to the body. Some of these genetic differences in the immune system that were seen in sarcoidosis patients were present more frequently in African-American than in Caucasian patients. This discovery may explain why African-Americans with sarcoidosis are more likely than Caucasians to have family members diagnosed with sarcoidosis. The key conclusion is that ACCESS found support for the idea that part of the reason why some people get sarcoidosis is because of an inherited (genetic) risk.

8. Article Title: “Familial Aggregation of Sarcoidosis”

Lead Author: Benjamin Rybicki, Ph.D.

Article Journal: American Journal of Respiratory and Critical Care Medicine. December 1, 2001; Vol. 164 (Issue 11): pp. 2085-2091.

Sarcoidosis is known to occur in families. In ACCESS, we asked sarcoidosis patients and controls if they had family members with sarcoidosis. From this, we estimated the risk of sarcoidosis in family members. We found that brothers and sisters of sarcoidosis patients have the largest increased risk. They were almost six times more likely to be diagnosed with sarcoidosis than were people who did not have a sibling with sarcoidosis. Other groups of relatives, including parents, grandparents and uncles and aunts were also at an increased risk for sarcoidosis. When the analysis took into account some other factors that might influence sarcoidosis risk, such as age, sex, and shared home or work environments, we found that the most important of these is: you are the parent or sibling of a sarcoidosis patient. In fact, you are more than 4 times more likely to be diagnosed with sarcoidosis if you are the parent or sibling of a sarcoidosis patient than are people who do not have a child or sibling with sarcoidosis. In summary, the ACCESS study has shown that close relatives of sarcoidosis patients are at an increased risk for being diagnosed with sarcoidosis.

9. Article Title: “TNF-alpha, IL1-beta, and Immunoglobulin (GM and KM) Gene Polymorphisms in Sarcoidosis”

Lead Author: Janardan P. Pandey, Ph.D.

Article Journal: Human Immunology. June 2002; Vol. 63: pp. 485-491.

Parts of the human immune system are controlled by the non-HLA genes. ACCESS investigated some of these other genes. In this study, we studied the genes other than HLA which control how well the immune system cells manufacture proteins that are involved in inflammation. Overall, ACCESS found no differences in these sets of genes between patients with sarcoidosis and controls without sarcoidosis. Since not all sarcoidosis patients have the same organ involvement by sarcoidosis, additional analyses were done to see if patients with and without erythema nodosum (painful bumps on the lower legs) were genetically different from each other. In African-American patients without erythema nodosum, we found a greater distribution of a certain gene (called a “KM genotype”) in comparison to controls. More specifically, sarcoidosis patients in ACCESS who were African-American and without erythema nodosum were two times more likely to have a certain distribution of KM1 genes in comparison to controls. These KM genes have been shown in other studies to be an important part of the body’s ability to fight disease.

Clinical Studies

10. Article Title: “Clinical characteristics of patients in a case control study of sarcoidosis”

Lead Author: Robert Baughman, MD

Article Journal: American Journal of Respiratory and Critical Care Medicine. 2001; Vol. 164: pp. 1885-1889.

The ACCESS patient population was diverse in terms of race (53% Caucasian, 44% African-American), sex (64% female, 36% male), and age (46% of the study patients were less than 40 years of age, 54% were equal to or more than 40 years of age). Women were more likely

to have eye and nervous system involvement, have erythema nodosum (painful bumps on the lower legs), and be older. Men were more likely to have hypercalcemia (high calcium levels in the blood). African-American study participants were more likely to have skin involvement other than erythema nodosum, and were more likely to have eye, liver, bone marrow, and lymph node involvement outside of the chest area.

The ACCESS investigators conclude that the initial presentation of sarcoidosis is related to sex, race, and age of the patient. This study was not designed to determine how often these different organs are involved in the general U.S. population, but to relate these different patterns of disease to some of the other questions addressed in the study—such as genetics and exposures.

11. Article Title: “Pulmonary and Psychosocial Findings at Enrollment in ACCESS”

Lead Author: Henry Yeager, MD

Article Journal: *Sarcoidosis, Vasculitis, and Diffuse Lung Diseases*. June 2005; Vol. 22 (Issue 2): pp. 147-153.

To understand if lung involvement for ACCESS sarcoidosis participants was affected by their age, race, gender, or mental health, we looked at medical histories and physical examinations, chest x-rays, breathing tests, and questionnaire answers about shortness of breath. Mental health was studied using standard tests, called the Short Form-36 Health Survey, and the Center for Epidemiologic Studies Depression (CES-D) questionnaire.

Nearly all study patients with sarcoidosis in ACCESS (95%) had lung involvement. About three-fourths had mild to moderate sarcoidosis based on the chest x-ray; only 5% had advanced stage disease (stage IV). About half of the sarcoidosis study subjects reported

significant shortness of breath. In general, as one would expect, sarcoidosis participants with worse chest x-rays due to sarcoidosis were also the people with poor breathing tests. But there were exceptions: 8% of patients with no lung involvement by chest x-ray had poor breathing tests, and 35% of patients with chest x-rays showing a lot of disease said they had no exercise limitation on the shortness of breath questionnaire.

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.

Current smokers had poorer lung function than did non-smokers. Lower lung function was more common in people with sarcoidosis who were at least 40 years old, were African-American, or who were overweight.

Conclusion: understanding sarcoidosis patient's disease requires careful evaluation of not only lung function, but also chest x-ray changes, symptoms such as shortness of breath, and how the disease impacts their quality of life.

12. Article Title: "The Spectrum of Biopsy Sites for the Diagnosis of Sarcoidosis"

Lead Author: Alvin Teirstein, MD

Article Journal: Sarcoidosis, Vasculitis, and Other Granulomatous Disorders. June, 2005; Vol. 22 (Issue 2): pp. 139-146.

The 736 sarcoidosis patients who participated in ACCESS were required to have biopsy proof of sarcoidosis within 6 months of entering the study. This large group of patients gives the

ACCESS investigators the chance to understand the variety of organs with sarcoidosis involvement at the time of diagnosis, and those most often biopsied by doctors.

There were 776 diagnostic biopsies performed in the 736 patients (some had more than one). The ACCESS sarcoidosis patients had a total of 23 different organs biopsied to diagnose their sarcoidosis. Since most patients with sarcoidosis have abnormal chest x-rays, it is not surprising that the most common biopsies were of the lungs, followed by lymph nodes (inside and outside the chest), and skin (see table). Skin and swollen lymph nodes outside of the chest are easier to biopsy than other sites for both the patient and doctor and are often the favored biopsy, even if the chest x-ray is abnormal. The diagnosis of sarcoidosis is most definite when proven by a biopsy.

| Biopsy Site | Number of Biopsies |
|--|---------------------------|
| INTRATHORACIC (within the chest) | |
| Lung | 329 |
| Lymph Node | 181 |
| Trachea/Bronchi | 57 |
| EXTRATHORACIC (outside of the chest) | |
| Skin | 74 |
| Lymph Node | 61 |
| Liver | 19 |
| Kveim Site | 11 |
| Other | 44 |
| Total (including multiple biopsies) | 776 |

13. Article Title: “Diagnostic Pathway to Sarcoidosis”

Lead Author: Marc Judson, MD

Article Journal: Chest. February 2003; Vol. 123 (Issue 2): pp. 406-412.

Patients with sarcoidosis often have symptoms of the disease for months to years before the correct diagnosis is made. On many occasions, sarcoidosis is misdiagnosed as another condition for a long period of time. The ACCESS investigators tried to determine how long it took doctors to diagnose sarcoidosis after the patient’s symptoms began. The investigators also determined how long it took to make the diagnosis of sarcoidosis after the patient made the first visit to a doctor for a problem related to sarcoidosis. It was found that almost half the time, it took more than six months after the first doctor visit (or 4 or more doctor visits) for the diagnosis of sarcoidosis to be made. In almost 20% of patients, it took more than a year for the diagnosis to be correctly made. Patients who had sarcoidosis of the skin were diagnosed more quickly than patients who did not have sarcoidosis of the skin. When the lungs were involved, it took longer for the diagnosis to be made than it did for the average patient. The likely reason that skin sarcoidosis was diagnosed quickly is because a skin biopsy is often done early if there is an abnormal skin lesion. In addition, lung sarcoidosis is often misdiagnosed as another lung condition such as asthma, bronchitis, or pneumonia.

14. Article Title: “Sarcoidosis: Social Predictors of Severity at Presentation”

Lead Author: David Rabin, MD

Article Journal: European Respiratory Journal. 2004; Vol. 24: pp. 601-608

In many chronic illnesses, how much the disease affects a person may be related to social factors, such as a person’s income, health insurance, age, race, or sex. ACCESS examined the impact of these social factors in sarcoidosis. ACCESS found that lower income, the lack of private or Medicare health insurance, and other barriers to care were associated with the amount of sarcoidosis involvement in study participants, as were race, sex, and age. ACCESS also found that sarcoidosis patients with lower incomes improved less over 2 years in comparison to those study patients with greater incomes.

African-Americans were more likely to have severe disease. Women were more likely than men to report more severe symptoms. Older individuals were more likely to have severe disease based on lab testing and symptoms that they reported. In conclusion, lack of insurance, low income and other financial barriers to medical care are related to sarcoidosis severity, even after considering other factors such as race, sex, and age.

Follow-up Study

15. Article Title: “Two Year Prognosis of Sarcoidosis: the ACCESS Experience”

Lead Author: Marc Judson, MD

Article Journal: Sarcoidosis, Vasculitis, and Diffuse Lung Diseases. October 2003; Vol. 20 (Issue 3): pp. 204-211.

Patients with sarcoidosis often wonder about their prognosis (future course of their disease). They wonder if additional parts of the body will become involved with sarcoidosis. They wonder if their condition will improve, remain stable, or worsen. In ACCESS, 215 sarcoidosis patients were examined twice: once when they were initially enrolled in the study, and again two years later.

Approximately 80% of these sarcoidosis patients showed improved or stable pulmonary function, 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. Patients with lower annual family income had less improvement in their symptoms of shortness of breath over the 2-year period and were more likely to have a new organ become involved with sarcoidosis. The likelihood of a new organ becoming involved with sarcoidosis over 2 years was more common in African-Americans compared to Caucasians, and also occurred more often in those who already had several organs involved when diagnosed. The overall conclusion was that the general prognosis of sarcoidosis is good over a 2-year period, although a subgroup of patients requires closer monitoring for the development of new organ involvement.

Post Script

ACCESS investigators and some participants have been a part of a subsequent and more detailed genetic study of sarcoidosis, called SAGA (Sarcoidosis Genetic Analysis Study). It is a study of African-American families affected by sarcoidosis. The information we are able to collect during SAGA will hopefully help us to better understand the inherited (genetic) basis of sarcoidosis in African-Americans. Two papers have been published to date based on the information gathered during SAGA:

1. Article Title: “Genome-wide Search for Sarcoidosis Susceptibility Genes in African Americans”

Article Lead Author: Michael Iannuzzi, MD

Journal: Genes and Immunity. June 9, 2005

2. Article Title: “A Sarcoidosis Genetic Linkage Consortium: the Sarcoidosis Genetic Analysis (SAGA) Study”

Lead Author: Benjamin Rybicki, Ph.D.

Journal: Sarcoidosis, Vasculitis, and Diffuse Lung Diseases. June, 2005; Vol. 22 (Issue 2): pp. 115-122.