

Appendix A

Sarcoidosis Study Project Pilot Survey

The purpose of this survey is to find out more about the causes and effects of Sarcoidosis. Your responses will be held in strictest confidence and no identifying information will be collected. This survey, designed to identify factors that may have contributed to your diagnosis of Sarcoidosis, will take about 15 to 30 minutes to complete. If you need to take a break, close your browser. When you are ready to begin again click the link in your email and you will be taken to the next question in the survey. You may choose not to answer any question by skipping the question or by selecting the: Choose not to answer option. You may stop participating at any time during the study by closing the browser.

In the future, we may share these study data with other researchers outside of this study team. If we share data or write a report for publication in professional journals about this study, we will do so in such a way that you cannot be identified. Risks from participating in this study are minimal. You will not have any costs for being in this study, nor will you be paid for being in this study. Taking part in this research study is completely voluntary. If you choose to participate in the study your responses will be reported in aggregate form only; no individual will be identified. If you have questions about this study, please contact the Principal Investigator Dr. Louis Caruana at loucaruana@txstate.edu <mailto:loucaruana@txstate.edu>.

This project (IRB application number 2015Z8977) was approved by the Texas State IRB on June 18, 2015. Pertinent questions or concerns about the research, research participants' rights, and/or research-related injuries to participants should be directed to the IRB chair, Dr.

Jon Lasser (512-245-3413 - lasser@txstate.edu) and to Becky Northcut, Director, Research Integrity & Compliance (512-245-2314 - bnorthcut@txstate.edu).

By clicking next, you consent to participate in this survey.

1. What is your current age?
2. What was your age at the onset of symptoms of sarcoidosis?
3. What year were you first diagnosed as having sarcoidosis?
4. What is your sub diagnostic classification?
 - a. Acute sarcoidosis
 - b. Chronic sarcoidosis with limited dissemination
 - c. Chronic sarcoidosis with full dissemination, including cutaneous involvement of the disease
 - d. Chronic sarcoidosis with neurosarcoidosis
 - e. Choose not to Answer
5. Did you seek a second opinion on this diagnosis?

Yes

No

Choose not to Answer
6. Is your Sarcoidosis in remission?

Yes

No

Choose not to Answer
7. What is your blood type?

A Positive

A Negative

B Positive

B Negative

AB Positive

AB Negative

O Positive

O Negative

Not Sure

The next set of questions ask about your health habits.

8. Do you use tobacco?

Yes

No

9. Which of the following best describes your status:

I have never used tobacco.

I used tobacco at one time but I quit.

10. What types of tobacco do you use (check all that apply)?

Cigarettes

Cigars

Pipes

Chew Snuff

Others

11. How many packs do you currently smoke per day?

12. How many years have you smoked?

13. Were you exposed to second hand smoke?

Yes

No

14. How many years were you exposed to second hand smoke?

15. How many cigars do you smoke in a week?

16. How many years have you smoked cigars?

17. How many days a week do you typically smoke your pipe?

18. How many years have you smoked a pipe?

19. How many days a week do you typically use chew?

20. How many years have you used chew?

21. How many days a week do you typically use snuff?

22. How many years have you used snuff?

23. Do you drink alcohol?

Yes

No

24. How many 8 oz. drinks do you typically consume daily?

25. Do you use medical marijuana to elevate pain or symptoms associated with your sarcoidosis?

Yes

No

26. I use medical marijuana for pain/symptoms:

Less than once a month

Monthly

Weekly Daily

27. During a typical week, how often do you eat the following meals?

	Never	1-2 days a week	3-5 days a week	6-7 days a week
Breakfast				
Lunch				
Dinner				

28. During a typical week, how often do you eat the following types of foods?

	Never	1-2 days a week	3-5 days a week	6-7 days a week	Every meal
Meat, Poultry, Fish, Dry beans, Eggs & Nuts					
Milk, Yogurt & Cheese					
Fruit					
Vegetables					
Bread, Cereal, Rice, & Pasta					

29. How often do you eat meals that contain at least one food that contains antioxidants (e.g., bananas, tomatoes, sweet peppers, broccoli, carrots, cabbage, cauliflower, leeks, onions, apricots, berries, carrots, spinach, apples, pumpkin, mangoes, pink grapefruit, watermelons, whole grains, nuts, and green tea)?

Never

1-2 days a week

3-5 days a week

6-7 days a week

Every meal

Choose not to Answer

30. How often do you eat meals that contain at least one food that contain magnesium (e.g., avocados, potatoes, corn, oats, soy, brown rice, dark leafy greens, nuts, seeds, fish, beans, whole grains, avocados, yogurt, bananas, dried fruit, and dark chocolate)?

Never

1-2 days a week

3-5 days a week

6-7 days a week

Every meal

Choose not to Answer

31. Approximately how much water do you drink daily? Enter the approximate number of cups you drink per day (e.g., 0, 2, 4.5).

32. How often do you consume foods or drinks that contain the following?

	Monthly	Weekly	Daily
MSG (Monosodium glutamate, also known as sodium glutamate)			
Artificial sweeteners, Aspartame know as Equal and NutraSweet			
High fructose corn syrup			
Trans fats			

33. Do you take vitamins, herbals or dietary supplements?

Yes

No

34. How often do you take vitamins, herbals, or dietary supplements?

Never

1-2 days a week

3-5 days a week

6-7 days a week

35. Specifically do you take vitamin D supplements?

Yes

No

36. How many milligrams do you take daily?

37. How much sunlight exposure do you typically get daily?

Less than or at least 15 minutes

More than 15 minutes but less than 30 minutes

30 minutes or more

38. Do you use protein powders, creatine or other supplements that claim to increase muscles?

Yes

No

39. Do you drink coffee?

Yes

No

40. Approximately how many 8 ounce cups of coffee do you typically consume daily?

List any other food/drink that contains caffeine that you consume on a daily basis.

41. Do you use any pills or teas to lose weight?

Yes

No

42. How often do you use pills or teas to lose weight?

Monthly Weekly Daily

43. Do you have a diagnosis of sleep apnea?

Yes

No

44. When were you diagnosed with sleep apnea?

Before sarcoidosis diagnosis

After sarcoidosis diagnosis

45. During a typical week, how many times on average do you do the following kinds of exercise?

Strenuous (Hard) exercise (heart beats rapidly). Examples: running, jogging, football, soccer, basketball, martial arts, aerobics.

--Click Here--

0

1

2

3

4

5.

6

7

Choose not to Answer

46. Average time spent at each session

--Click Here--

0 min

15 min

30 min

45 min

1 hr

1 hr 15 min

1 hr 30 min

1 hr 45 min

2 hr

2+ hr

Choose not to Answer

47. Moderate exercise (not exhausting). Examples: fast walking, tennis, easy bicycling, easy swimming.

--Click Here--

0

1

2

3

4

5

6

7

Choose not to Answer

48. Average time spent at each session

--Click Here--

0 min

15 min

30 min

45 min

1 hr

1 hr 15 min

1 hr 30 min

1 hr 45 min

2 hr

2+ hr

Choose not to Answer

49. Mild exercise (easy effort). Examples, fishing, bowling, easy walking.

--Click Here--

0

1

2

3

4

5

6

7

Choose not to Answer

50. Average time spent at each session

--Click Here--

0 min

15 min

30 min

45 min

1 hr

1 hr 15 min

1 hr 30 min

1 hr 45 min

2 hr

2+ hr

Choose not to Answer

51. What types of exercise you engage in (check all that apply)?

Endurance or Aerobic (e.g., cycling, walking, hiking, running, playing tennis) Strength or

Anaerobic (e.g., weight training, resistance training)

Balance exercises (e.g., stand on one foot, Tai Chi)

Flexibility (e.g., yoga)

The next set of questions ask about antibiotics, infectious agents, fungus infections, bacterial

infections, viruses, or metals you may have ingested or been exposed to during your lifetime.

52. Have you ever taken the following types of antibiotics (check all that apply)?

Ciprofloxacin

Chloramphenicol

Sulfonamides (sometimes called sulfa drugs or sulpha drugs)

53. List the major clinical symptoms you had as a result of taking Ciprofloxacin.

54. List the major clinical symptoms you had as a result of taking Chloramphenicol.

55. List the major clinical symptoms you had as a result of taking Sulfonamides.

56. Have you ever been diagnosed with any of the following infectious agents (check all that apply)?

57. Primary pulmonary tuberculosis (e.g., *Mycobacterium tuberculosis*) *Chlamydomphila pneumonia*

58. *Mycoplasma pneumonia* (also known as walking pneumonia) *Chlamydomphila psittaci*

59. Did the TB disease process spread to the following (check all that apply)?

Liver

Gastrointestinal tract

Kidney(s)

Bones

60. List the major clinical symptoms you experienced with tuberculosis

61. List the major clinical symptoms you experienced with *Chlamydomphila pneumonia*.

62. List the major clinical symptoms you experienced with *Mycoplasma pneumonia*.

63. List the major clinical symptoms you experienced with *Chlamydomphila psittaci*.

64. Have you ever been diagnosed as having any of the following systemic or deep seated fungus infections (check all that apply)?

Coccidioides immitis (the cause of Coccidioidomycosis or Valley Fever) Cryptococcus neoformans

Histoplasma capsulatum (Histoplasmosis)

Blastomyces dermatitidis or B. resiliencies (Blastomycosis), Candida albicans (Candidiasis),

Aspergillus fumigatus or A. flavus (Aspergillosis),

Sporothrix schenckii (Sporotrichosis (often referred to as "rose handler's disease"))

65. List the major clinical symptoms you experienced with Coccidioides immitis

66. List the major clinical symptoms you experienced with Cryptococcus neoformans

67. List the major clinical symptoms you experienced with Histoplasma capsulatum

68. List the major clinical symptoms you experienced with Blastomyces dermatitidis

69. List the major clinical symptoms you experienced with Candida albicans

70. List the major clinical symptoms you experienced with Aspergillus fumigatus

71. List the major clinical symptoms you experienced with Sporothrix schenckii

72. Have you ever been infected by the following bacterial organisms (check all that apply)?

Propionibacterium acnes (linked to the skin condition of acne) Lyme Disease

Helicobacter pylori (major cause of gastric (stomach) cancer) Methicillin-resistant

Staphylococcus aureus (MRSA) Legionella pneumophila (the cause of Legionnaires disease)

Toxoplasma gondii (the cause of toxoplasmosis)

73. List the major clinical symptoms you experienced with Propionibacterium acnes

74. List the major clinical symptoms you experienced with Lyme Disease

75. List the major clinical symptoms you experienced with Helicobacter pylori

76. List the major clinical symptoms you experienced with MRSA

77. List the major clinical symptoms you experienced with Legionella pneumophila

78. List the major clinical symptoms you experienced with Toxoplasma gondii

79. Have you ever been diagnosed with the following viruses (check all that apply)?

Hepatitis B Hepatitis C

Human herpesvirus 8

Herpes simplex virus 1

Human papillomavirus

Epstein-Barr virus

Kaposi's sarcoma herpes virus

Human T-cell leukemia virus-1

Human respiratory syncytial virus

Rubella virus Cytomegalovirus Parvovirus B19

80. List the major clinical symptoms you experienced with hepatitis B.

81. List the major clinical symptoms you experienced with hepatitis C.

82. List the major clinical symptoms you experienced with human herpesvirus 8.

83. List the major clinical symptoms you experienced with herpes simplex virus 1.

84. List the major clinical symptoms you experienced with Legionella human papillomavirus.

85. List the major clinical symptoms you experienced with Epstein-Barr virus.

86. List the major clinical symptoms you experienced with Kaposi's sarcoma herpes virus.

87. List the major clinical symptoms you experienced with human T-cell leukemia virus-1.

88. List the major clinical symptoms you experienced with human respiratory syncytial virus.

89. List the major clinical symptoms you experienced with rubella virus.

90. List the major clinical symptoms you experienced with cytomegalovirus.

91. List the major clinical symptoms you experienced with parvovirus B19.

92. To your knowledge have you ever been exposed to the following metals? Exposure

means that you work or have worked in an industry where this metal was used, in an

environmental contamination exposure situation, or that you had any contact inhalation or skin contact with the metal.

(Check all that apply)?

Lead Mercury Arsenic Beryllium Cadmium Chromium Nickel Barium Cobalt Copper Iron
Platinum Selenium Thallium Tungsten Uranium Zinc

93. Do you still have symptoms related to Lead exposure?

Yes

No

94. Do you still have symptoms related to Mercury exposure?

Yes

No

95. Do you still have symptoms related to Arsenic exposure?

Yes

No

96. Do you still have symptoms related to Beryllium exposure?

Yes

No

97. Do you still have symptoms related to Cadmium exposure?

Yes

No

98. Do you still have symptoms related to Chromium exposure?

Yes

No

99. Do you still have symptoms related to Nickel exposure?

Yes

No

100. Do you still have symptoms related to Barium exposure?
Yes
No
101. Do you still have symptoms related to Cobalt exposure?
Yes
No
102. Do you still have symptoms related to Copper exposure?
Yes
No
103. Do you still have symptoms related to Iron exposure?
Yes
No
104. Do you still have symptoms related to Platinum exposure?
Yes
No
105. Do you still have symptoms related to Selenium exposure?
Yes
No
106. Do you still have symptoms related to Thallium exposure?
Yes
No
107. Do you still have symptoms related to Tungsten exposure?
Yes
No
108. Do you still have symptoms related to Uranium exposure?
Yes
No

109. Do you still have symptoms related to Zinc exposure?

Yes

No

110. Have you been exposed to silica or coal?

Yes

No

111. Did you develop symptoms of upper respiratory illness?

Yes

No

112. Have you ever been diagnosed with lung cancer or mesothelioma?

Yes

No

113. Have you been exposed to asbestos?

Yes

No

114. How many years was the exposure?

115. Have you been exposed to other organic dust?

Yes

No

116. How many years was the exposure?

117. Did you develop symptoms of upper respiratory illness?

Yes

No

118. Are you allergic to latex?

Yes

No

119. Have you worked in an industrial or other setting where lactic acid was used?

Yes

No

Demographic Information

120. Are you Latino or Hispanic?

Yes

No

121. What is your race?

--Click Here--

White

Black/African American

American Indian/Eskimo/Aleut Alaskan Native

Asian/Pacific Islander

Two or more

Other

122. What is your gender?

Male

Female

Self-Identified

123. Are you on birth control pills?

Yes

No

124. What is your current zip code?

Please add any additional information or comments below