



Participant Profile

1. **Full name**
2. **Gender**
3. **Birthdate**
4. **Ethnicity**
 - Hispanic or Latino or Spanish
 - Not Hispanic/Latino/Spanish origin
 - Prefer not to answer
 - Unavailable
5. **Race**
 - American Indian/Alaska Native
 - Asian
 - Black/African American
 - Native Hawaiian/Other Pacific Islander
 - White
 - Some other race
 - Prefer not to answer
 - Unavailable
6. **City of birth**
7. **Country of birth**
8. **State of birth (USA only)/Province of birth (Outside USA)**
9. **Is the participant living?**
 - Yes
 - No
 - Don't Know
 - Refused
10. **If deceased, date of death**
11. **Full address**
12. **Participant's primary telephone number**
13. **Participant's cellphone number**
14. **Participant's email addresses**

Section 1: Diagnosis

1. **Were you diagnosed with sarcoidosis as an adult or a child?**
 - Adult sarcoidosis (diagnosed age 18 or older)
 - Juvenile sarcoidosis (diagnosed before the age of 18)
2. **What was your age in years when the formal diagnosis was made? This was your age when first told you were extremely likely to have or definitely had sarcoidosis.**
 - Age of diagnosis unknown
 - 0 to 4
 - *Separate choices for 5-89*
 - 90+ years
3. **What was your age in years when you first began experiencing symptoms of sarcoidosis?**
 - Age of symptom onset unknown
 - Participant never experienced symptoms
 - 0 to 4
 - *Separate choices for 5-89*
 - 90+ years



4. How many doctor visits for symptoms of sarcoidosis did you have *BEFORE* being diagnosed with sarcoidosis?
- *Separate choices for 1-10*
 - More than 10
 - Unsure
5. What kind of health care provider(s) did you see for the symptoms *BEFORE* a diagnosis was made? (Select all that apply.)
- Cardiologist
 - Dermatologist
 - Endocrinologist
 - Gastroenterologist
 - Family Medicine Doctor
 - Internal Medicine Doctor
 - Neurologist
 - Ophthalmologist
 - Pediatrician
 - Psychologist/Psychiatrist
 - Pulmonologist
 - Rheumatologist
 - Other: _____
6. How long did it take for a doctor to diagnose sarcoidosis once the symptoms were first noticed?
- Diagnosis not yet confirmed
 - Unsure
 - Less than 1 month
 - 1-3 months
 - 3-6 months
 - 6-12 months
 - 1-2 years
 - 2-4 years
 - 4-5 years
 - Greater than 5 years
7. What organs have been diagnosed with sarcoidosis by a medical provider?
To answer the first item, if you know what type of sarcoidosis you have select Not Involved. If you have sarcoid, but unsure of what organs select Diagnosed or Suspected.
- I have sarcoid, but unsure of what organs
 - Bone and/or vertebrae
 - Brain or Cranial Nerves (includes nerves of the face, ears, or eyes such as the optic nerve or facial nerve)
 - Central Lymph Nodes (lymph nodes in the chest or abdomen)
 - Eyes
 - Heart
 - Joints (Arthritis)
 - Kidney (not including Kidney Stones)
 - Parotid glands (salivary gland type) or Lacrimal gland (tear glands)
 - Liver
 - Lungs (*choices continued page 3*)

Status (Question 7):

- Not Involved
- Suspected
- Diagnosed



- Muscle
- Peripheral Lymph Nodes (lymph nodes in the neck, armpit, groin)
- Peripheral Nerves (nerves of the arms, legs, or torso that cause pain, pins and needles, numbness or burning)
- Sinuses
- Skin
- Spleen
- Stomach/Intestine
- Other

8. What test(s) did physicians or other health professionals do to make the sarcoidosis diagnosis? (Select all that apply. Please refer to the glossary for unfamiliar terms.)

Choose the tests used to make the initial diagnosis of sarcoidosis

- Biopsy - Conjunctiva or Lacrimal Gland Eye
- Biopsy - Lung
- Biopsy - Skin
- Biopsy - Other
- Blood Test - Angiotensin Converting Enzyme (ACE)
- Blood Test - Calcium
- Blood Test - Lysozyme
- Bronchoscopy with Bronchoalveolar lavage
- Colonoscopy
- CT Scan - Abdomen
- CT Scan - Chest
- CT Scan - Brain
- CT Scan - Other
- Echocardiogram of the heart (ECHO)
- Eye Exam
- Gallium-67 Nuclear Scan
- Holter Monitor
- Lumbar Puncture (spinal tap) with Cerebrospinal Fluid Analysis
- MRI - Chest
- MRI - Brain
- MRI - Heart
- PET Scan (FDG or FDG/CT) Body
- PET Scan Heart
- Physical Exam
- Pulmonary Function Testing (PFT)
- Quantitative Sensory Testing (neuropathy)
- Skin Test (Kveim)
- Skin Test by punch biopsy to assess the number of nerves in your skin (Quantitative Nerve Density Analysis)
- Slit Lamp Exam (eye)
- Tilt Table Test
- Ultrasound Abdomen
- Urine - 24 hour collection calcium
- X-Ray
- Other



9. Which family members also are known to have sarcoidosis?
- Daughter
 - Son
 - Mother
 - Father
 - Sister
 - Brother
 - Maternal Aunt
 - Maternal Uncle
 - Maternal Grandmother
 - Maternal Grandfather
 - Maternal Cousin
 - Paternal Aunt
 - Paternal Uncle
 - Paternal Grandmother
 - Paternal Grandfather
 - Paternal Cousin
 - Niece
 - Nephew
 - Granddaughter
 - Grandson
 - Half-brother
 - Half-sister
 - I have no family members or family history of sarcoidosis
 - I am unsure if any family members have sarcoidosis
 - Other
10. Have you ever been admitted to the hospital for your sarcoidosis (Not for diagnostic procedures)?
- Yes
 - No
 - Prefer not to answer
 - Unsure
11. If you have ever been admitted for sarcoidosis, how many times have you been admitted to a hospital due to your condition?
- I have not been admitted to the hospital for sarcoidosis
 - *Separate choices for 1-12*
 - 13 or more
 - Unsure

Section 2: Pulmonary (Lung)

12. Have you been diagnosed with pulmonary (lung) sarcoidosis by a medical provider?
- Yes
 - No
 - Unsure
13. Have you had a biopsy of your lung tissue or lymph nodes in your chest?
- Yes
 - No
 - Unsure



14. Have you ever used oxygen or a breathing device? (Select all that apply.)

- BiPAP
- CPAP
- Inhalers
- Oxygen
- Ventilator
- None

15. Multi-part question

a. Please choose the best description of how breathing can be for you currently:

- Grade 0: I only get breathless with strenuous exercise.
- Grade 1: I get short of breath when hurrying on level ground or walking up a slight hill.
- Grade 2: On level ground, I walk slower than people of the same age because of breathlessness, or have to stop for breath when walking at my own pace.
- Grade 3: I stop for breath after walking about 100 yards or after a few minutes on level ground.
- Grade 4: I am too breathless to leave the house or I am breathless when dressing.

b. Please choose the best description of how breathing can be for you in the past 2 weeks:

- Grade 0: I only get breathless with strenuous exercise.
- Grade 1: I get short of breath when hurrying on level ground or walking up a slight hill.
- Grade 2: On level ground, I walk slower than people of the same age because of breathlessness, or have to stop for breath when walking at my own pace.
- Grade 3: I stop for breath after walking about 100 yards or after a few minutes on level ground.
- Grade 4: I am too breathless to leave the house or I am breathless when dressing.

16. Have you ever been given the diagnosis of asthma or chronic obstructive pulmonary disease by a medical provider?

- Yes
- No
- Unsure

17. Have you ever been diagnosed with Pulmonary Arterial Hypertension by a medical provider? (Pulmonary Arterial Hypertension is high blood pressure in the lungs.)

- Yes
- No
- Unsure

18. Multi-part question

a. Have you ever been prescribed medications for Pulmonary Arterial Hypertension?

- Yes
- No
- Unsure

b. If yes, indicate the Status of each of the following medications

- Tadalafil (Cialis)
- epoprostenol (Flolan, Veletri)
- ambrisentan (Letairis)
- intravenous or subcutaneous treprostinil (Remodulin)
- bosentan (Tracleer) *(choices continued page 6)*

Status (Question 18b):

- Never used
- Currently use
- Used in the past but no longer
- Unsure



- iloprost (Ventavis)
- sildenafil (Revatio)
- macitentan (Opsumit)
- selexipag (Uptravi)
- riociguat (Adempas)
- inhaled treprostinil (Tyvaso)
- oral treprostinil (Orenitram)

Section 3: Skin

19. Have you ever had any of the following skin conditions that are associated with your sarcoidosis? (Select all that apply. Please refer to the glossary for unfamiliar terms.) If you have not been diagnosed with sarcoidosis of the skin, then check "No skin involvement."

- No skin involvement
- Abnormal skin pigmentation (darker or lighter skin)
- Erythema nodosum (tender, red bumps on legs)
- Lofgren's syndrome (constellation of erythema nodosum, lymph nodes in the chest and joint pain/arthritis)
- Lupus pernio (purplish patches or lesions)
- Nodules under the skin in the area around scars or tattoos
- Papules (small nodules anywhere on the skin that are granulomas)
- Plaques (large, flat, scaly lesions)
- I have been told I have skin sarcoidosis, but I am unsure of what type
- Unsure

20. Have you been examined by a dermatologist (skin specialist)?

- Yes
- No
- Unsure

21. Have you ever had a skin biopsy?

- Yes - one time
- Yes - more than once
- No
- Unsure

22. Have you ever used topical creams or injections?

- Yes
- No
- Unsure

23. Have you ever been treated with any of the following medications for sarcoidosis of the skin? (Select all that apply.)

- cyclosporine (Neoral, Sandimmune, Gengraf)
- infliximab (Remicade)
- Injection of corticosteroids directly into skin lesion
- etanercept (Enbrel), adalimumab (Humira), ustekinumab (Stelara)
- Laser Pulse Therapy
- Laser Surgery Using Carbon Dioxide
- leflunomide (Arava)
- Pentoxifylline
- hydroxychloroquine (Plaquenil)
- minocycline or doxycycline (*choices continued page 7*)



- thalidomide
- topical tacrolimus
- Radiation
- Unsure
- corticosteroids (taken in pill form)
- methotrexate
- azathioprine (Imuran, Azasan)
- mycophenolate mofetil (Cellcept, Myfortic)
- adrenocorticotrophic hormone (Acthar gel)

Section 4: Eyes and Vision

24. Have you been examined by an ophthalmologist or optometrist (eye specialist)?

- Yes
- No
- Unsure

25. Have you had any of the following eye symptoms? (Select all that apply.)

- Blurry vision
- Double vision
- Dry eyes
- Eye discomfort
- Floaters
- Loss of half the vision in one or both eyes
- Pain in the eyes
- Red Eyes
- Trouble focusing eyes
- Trouble looking in any direction
- Trouble seeing in the sunlight (photophobia)
- None
- Unsure

26. Have you ever been given the diagnosis of any of the following eye disorders associated with sarcoidosis by a medical provider? (Select all that apply. Please refer to the glossary for unfamiliar terms.)

- No diagnosis of ocular (eye) sarcoidosis
- I have been told that I have eye sarcoidosis, but I am unsure what type
- Anterior uveitis
- Posterior uveitis
- Nodules
- Keratoconjunctivitis
- Optic Neuritis
- Vasculitis of the Retina
- Unsure if I have eye sarcoidosis
- Other

27. Since the diagnosis of ocular (eye) sarcoidosis, have you experienced any of the following? (Select all that apply.)

- Not Applicable: have not been diagnosed with eye disease
- No change in vision
- Needed glasses to read or drive
- Unable to perform activities of daily living
- Unable to drive because of some eye problems (*choices continued page 8*)



- Legally blind
- Other: _____

Section 5: Cardiac (Heart)

28. Have you been diagnosed with cardiac sarcoidosis (sarcoidosis of the heart)?
- Yes
 - No
 - Unsure
29. Have you been examined by a cardiologist (heart specialist)?
- Yes
 - No
 - Unsure
30. Have you been examined by an electrophysiologist? (An electrophysiologist is a cardiologist who specializes in diagnosing and treating heart rhythm abnormalities.)
- Yes
 - No
 - Unsure
31. Have you had any of the following cardiac tests or procedures? (Select all that apply. Please refer to the glossary for unfamiliar terms.)
- Cardiac (heart) biopsy
 - Cardiac bypass grafting (i.e Bypass surgery)
 - Left heart cardiac catheterization in arteries to look at blood vessels of heart
 - Right heart cardiac catheterization in veins to measure pressures in the heart
 - Cardiac defibrillator placement (ICD or AICD) and/or Pacemaker of the heart
 - Cardiac MRI
 - Cardiac Stent
 - Cardiac Transplant (heart transplant)
 - Echocardiogram
 - Ablation of the heart for treatment of arrhythmias
 - Electrocardiogram (EKG)
 - Electrophysiology diagnostic study
 - Exercise tolerance test
 - Gallium Scan
 - Holter Monitor/Event monitor
 - Nuclear stress test
 - Cardiac PET Scan (i.e. PET of the heart)
 - Valve Replacement
 - None
 - Unsure
 - Other: _____
32. Has a cardiologist ever diagnosed any of the following heart conditions related to your sarcoidosis? (Select all that apply and refer to the glossary for further descriptions.)
- Atrial Arrhythmias
 - Ventricular Arrhythmias
 - I have been told that I have cardiac sarcoidosis, but I am unsure of what type
 - Cardiomyopathy
 - Congestive heart failure
 - Heart rhythm block (*choices continued page 9*)



- Heart valve abnormality (mitral, tricuspid, pulmonic or aortic valve) – heart valve leaks
 - Pericarditis
 - Pulmonary hypertension
 - Syncope (i.e. passing out or loss of consciousness)
 - None
 - Unsure if I have cardiac sarcoidosis
33. When was your cardiac sarcoidosis diagnosed in relation to any other sarcoidosis you may have?
- Not applicable
 - More than 5 years before
 - 1 - 5 years before
 - Less than 1 year before
 - Same time
 - Less than 1 year after
 - 1 - 5 years after
 - More than 5 years after
34. Which cardiac devices are you currently using? (Select all that apply.)
- Defibrillator alone (automatic implantable cardioverter defibrillator, AICD, ICD)
 - Pacemaker alone
 - Pacemaker/defibrillator combination
 - None
 - Unsure
 - Other: _____
35. If you have a defibrillator (ICD or AICD), has it ever been used to deliver therapy (deliver a shock)? (Select all that apply.)
- Participant does not have a defibrillator
 - The defibrillator has delivered appropriate therapy/shock due to a life-threatening heart rhythm to return participant to a stable rhythm
 - Participant has received an inappropriate therapy/shock from the defibrillator (shocked when NOT in a dangerous rhythm)
 - The defibrillator has not delivered therapy/shock (therapy never required)

Section 6: Neurologic (Nervous System)

36. Have you ever been diagnosed with neurosarcoidosis by a medical provider? This can include any of the following diagnoses. (Select all that apply.)
- Brain or lining of the brain - (meninges or brain tissue)
 - Peripheral Neuropathy (e.g. nerves of the arms or legs)
 - Small fiber neuropathy (e.g. small nerves of the skin that cause pain or burning)
 - Spinal cord involvement
 - I have not been diagnosed with neurosarcoidosis
 - Unsure
 - Other: _____
37. Have you ever had a consultation with a neurologist (specialist of the brain, spinal cord, and nerves)?
- Yes
 - No
 - Unsure



38. Multi-part question

- a. **Have you ever had any neurological tests performed?**
- Yes
 - No
 - Unsure
- b. **If Yes, indicate the status of each of the following neurological tests.**
- Computed Tomography (CT) of the brain or spinal cord
 - Electroencephalography (EEG)
 - Electromyogram (EMG)
 - Magnetic Resonance Imaging (MRI) of the brain or spinal cord
 - Muscle Biopsy
 - Nerve Conduction Study/Test
 - Positron Emission Tomography (PET scan)
 - Spinal tap (lumbar puncture)

Test Result (Question 38b):

- Tested, normal response
- Tested, abnormal response
- Tested, results unknown
- Did not test
- Unsure

Section 7: Endocrine (Hormone System)

39. Have any of the following endocrine conditions been diagnosed by a physician? (Select all that apply. Please refer to the glossary for unfamiliar terms.)

- Cushing's disease or syndrome
- Diabetes or Hyperglycemia (high blood sugar)
- Difficulty regulating body temperature
- Hypercalcemia (high blood calcium level)
- Hypercalciuria (high urine calcium level)
- Hypoglycemia (low blood sugar)
- Hypoparathyroidism (low blood parathyroid level)
- Hyperparathyroidism (high blood parathyroid level)
- Hypothyroid
- Hyperthyroid
- Insomnia
- Low testosterone
- Obesity
- Osteopenia/osteoporosis (low bone density)
- Parotid gland enlargement or other salivary gland issues
- Vitamin D deficiency (low vitamin D levels)
- Vitamin D excess (high vitamin D levels)
- None
- Unsure
- Other: _____

40. Have you developed any of the following disorders AFTER you were given the diagnosis of sarcoidosis? (Select all that apply.)

- Cancer
- Cataracts
- Chronic Fatigue Syndrome
- Chronic Pain Syndrome (requiring medications)
- Congestive Heart Failure
- Diabetes
- Depression
- Fibromyalgia
- Glaucoma (*choices continued page 11*)



- Hypertension
- Lymphoma
- Obesity
- Osteoporosis/osteopenia
- Sleep Apnea
- Sleep Disorders
- None
- Unsure

Section 8: Medications

41. Multi-part question

a. **Have you EVER taken medications for sarcoidosis?**

- Yes
- No
- Unsure

b. **If Yes, indicate the status of each of the following medications.**

- Prednisone
- methylprednisolone (Medrol, Solumedrol)
- inhaled corticosteroids or combination inhalers (Advair, Aerobid, Aerospan, Alvesco, Asmanex, Flovent, Pulmicort, Dulera, Breo, Qvar, Symbicort)
- hydroxychloroquine (Plaquenil, Quinoprex)
- chloroquine (Aralen)
- methotrexate (Rheumatrex, Trexall)
- azathioprine (Azasan, Imuran)
- leflunomide (Arava)
- mycophenolate mofetil (Cellcept, Myfortic)
- infliximab (Remicade)
- adalimumab (Humira)
- certolizumab (Cimzia)
- golimumab (Simponi)
- etanercept (Enbrel)
- rituximab (MabThera, Rituxan)
- cyclophosphamide (Cytoxan, Neosar)
- pentoxifylline (Pentoxil, Trental)
- IVIG: intravenous immunoglobulin (Carimune, Flebogamma, Gamunex, Gammagard, Octagam, Privigen)
- thalidomide (Thalomid)
- adrenocorticotrophic hormone (Acthar Gel)
- dexamethasone (Decadron)

Status (Question 41b):

- Have not taken medication
- Still using this treatment
- Completed treatment
- Have not had this treatment
- Side effects/complications
- Stopped working
- Never worked
- Unsure

42. What are the medications you are CURRENTLY taking? (Select all that apply.) The following is a list of medications that have been used to treat sarcoidosis. There may be several different brand names used for the same generic medication that is listed at the beginning of each row. Please check the box next to the row of any/all medication(s) you are currently taking.

- NO MEDICATIONS TAKEN CURRENTLY FOR SARCOIDOSIS
- Prednisone
- methylprednisolone (Medrol, Solumedrol) *(choices continued page 12)*



FSR-SARC: Sarcoidosis Patient Registry Baseline Clinical Questionnaire

- inhaled corticosteroids or combination inhalers (Advair, Aerobid, Aerospan, Alvesco, Asmanex, Flovent, Pulmicort, Dulera, Breo, Qvar, Symbicort)
- hydroxychloroquine (Plaquenil, Quinoprex)
- chloroquine (Aralen)
- methotrexate (Rheumatrex, Trexall)
- azathioprine (Azasan, Imuran)
- leflunomide (Arava)
- mycophenolate mofetil (Cellcept, Myfortic)
- infliximab (Remicade)
- adalimumab (Humira)
- certolizumab (Cimzia)
- golimumab (Simponi)
- etanercept (Enbrel)
- rituximab (MabThera, Rituxan)
- cyclophosphamide (Cytoxan, Neosar)
- pentoxifylline (Pentoxil, Trental)
- IVIG: intravenous immunoglobulin (Carimune, Flebogamma, Gamunex, Gammagard, Octagam, Privigen)
- thalidomide (Thalomid)
- adrenocorticotrop hormone (Acthar Gel)
- Unsure
- dexamethasone (Decadron)
- Other medication not listed above: _____

43. What other medications have you been prescribed for the effects of sarcoidosis and the treatment of side effects (such as anxiety, sleep difficulties, osteoporosis and fatigue)? (Select all that apply.)

- Anti-anxiety medications such as lorazepam (Ativan), alprazolam (Xanax), clonazepam (Klonopin), diazepam (Valium), oxazepam (Serax)
- Antidepressant or antidepressant/anti-anxiety medications such as citalopram (Celexa), fluoxetine (Prozac), escitalopram (Lexapro), fluvoxamine (Luvox), duloxetine (Cymbalta), venlafaxine (Effexor), paroxetine (Paxil), sertraline (Zoloft)
- Other Antidepressant or antidepressant/anti-anxiety medications such as nortriptyline (Pamelor), amitriptyline (Elavil), mirtazapine (Remeron), quetiapine (Seroquel), bupropion (Wellbutrin), milnacipran (Savella), trazadone (Desyrel)
- Bone strengthening meds or bisphosphonates, zoledronic acid (Reclast, Zometa, Aclasta), pamidronate (Aredia), ibandronate (Boniva), etidronate (Didronel), risedronate (Atelvia, Actonel), alendronate (Fosamax, Binosto), tiludronate (Skelid)
- NON-Steroid inhalers: albuterol (ProAir, Ventolin, Proventil), levalbuterol (Xopenex), pirbuterol (MaxAir), salmeterol (Serovent), formoterol (Foradil), ipratropium (Atrovent), tiotropium (Spiriva), umeclidinium (Incruse), acclidinium (Tudorza)
- NON-Steroid combination inhalers such as albuterol/ipratropium (Combivent) or umeclidinium/vilanterol (Anoro)
- Asthma or Allergy medications such as montelukast (Singulair), zafirlukast (Accolate), zileuton (Zyflo)
- Sleep Disorder medications such as zolpidem (Ambien), eszopiclone (Lunesta), ramelteon (Rozerem), zaleplon (Sonata), doxepin (Silenor)
- Vitamin D such as ergocalciferol (Vitamin D2), cholecalciferol (Vitamin D3), or combination calcium/vitamin D supplements (e.g. Os-Cal) *(choices cont'd page 13)*



- No medications
 - Unsure
 - Other, please specify: _____
44. Do you take any medical foods, supplements, or follow a special diet for treatment of your sarcoidosis?
- No
 - Unsure
 - Other, please specify: _____
45. Have you had any of the following surgeries to treat sarcoidosis? (Select all that apply.)
- Heart transplant
 - Liver transplant
 - Lung transplant
 - Shunt for hydrocephalus (high pressure in the brain)
 - Splenectomy (removal of the spleen)
 - None
 - Unsure
 - Other: _____
46. Do you use any type of medical or assistive device(s) to help you move around, communicate, or do things? (Select all that apply.)
- Cane
 - Scooter
 - Walker
 - Wheelchair
 - None
 - Unsure
 - Other: _____

Section 9: Disease Effects of Sarcoidosis

47. What is your employment status? (Select all that apply.)
- Employed - full-time
 - Employed - part-time
 - Disabled - working
 - Disabled - not working
 - Unemployed
 - Student
 - Unsure
 - Prefer not to answer
48. How many days of work did you miss due to the diagnosis in the last 12 months?
- Not applicable - does not work
 - 0 days
 - 1 - 7 days
 - 8 - 14 days
 - 15 - 30 days
 - More than 31
 - Unsure
 - Prefer not to answer
49. Have you needed to end your job due to health effects from sarcoidosis?
- Not applicable - not employed currently
 - Yes (*choices continued page 14*)



- No
- Unsure
- Prefer not to answer

50. How has your diagnosis affected your family's finances?

- No financial impact
- Slightly affected
- Greatly affected
- Severely affected
- Unsure
- Prefer not to answer

51. What is the annual gross income for the household in which you live (in U.S. dollars)?

- Less than \$10,000 (USD)
- \$10,000 - \$14,999
- \$15,000 - \$19,999
- \$20,000 - \$24,999
- \$25,000 - \$29,999
- \$30,000 - \$34,999
- \$35,000 - \$39,999
- \$40,000 - \$44,999
- \$45,000 - \$49,999
- \$50,000 - \$54,999
- \$55,000 - \$59,999
- \$60,000 - \$74,999
- \$75,000 - \$84,999
- \$85,000 - \$99,999
- \$100,000 - \$149,999
- \$150,000 - \$199,999
- \$200,000 - \$249,999
- \$250,000 and above
- Unsure
- Prefer not to answer

52. In general, would you say your health is...

- Excellent
- Very good
- Good
- Fair
- Poor
- Unsure

53. Do you feel depressed...

- Never
- Rarely
- Sometimes
- Often
- Always
- Unsure

54. How often do you feel tired?

- Never
- Rarely (*choices continued page 14*)



- Sometimes
- Often
- Always
- Unsure

55. Do you take any of the following approaches or medications for fatigue?

- Exercise
- methylphenidate (Ritalin, Concerta)
- dexamethylphenidate (Focalin)
- modafinil (Provigil)
- armodafinil (Nuvigil)
- lisdexamfetamine (Vyvanse)
- dextroamphetamine/amphetamine (Adderall)

Was Treatment Used? (Q55):

- Yes
- No

Was Treatment Effective? (Q55):

- Yes
- Temporary - helped for awhile
- No
- Don't know

56. How does sarcoidosis affect your daily life? This question should only be answered by the participant. Please read each question carefully and answer each item, thinking back about how you have felt over the past 2 weeks. Choose what you feel is the best single answer for each question.

- Been bothered by headaches?
- Felt that you needed medications to function day to day?
- Felt that you were full of energy?
- Experienced mood swings?
- Been bothered by skin or hair problems related to sarcoidosis?
- Felt your breathing was completely comfortable during your normal daily activities?
- Worried about the amount of pain or discomfort you might have experienced?
- Felt that everything you did took a lot of effort or made you tire easily?
- Felt satisfied with the support you get from your family and friends?
- Had joint pains?
- Felt shortness of breath walking up stairs, the length of a city block, or up a small hill?
- Felt that you expect your health to be good in the future?
- Had a cough?
- Felt that your physical problems interfered in your social activities with family and friends?
- Felt that you accomplished all that you wanted?
- Been discouraged by recent weight gain?
- Felt bodily pain?
- Felt that you could concentrate easily?
- Felt that your emotional problems affected your relationships with family, friends, or co-workers?
- Felt that sarcoidosis controls your life?
- Had a good night's sleep?
- Felt depressed?
- Been bothered by problems with your eyes or eyesight?
- Felt satisfied with the appearance of your body?
- Experienced wheezing? *(choices continued page 16)*

Status (Q56):

- All of the time
- Most of the time
- A good bit of the time
- Some of the time
- A little bit of the time
- Very little bit of the time
- None of the time



- Worried that your sarcoidosis might flare up or get worse?
- Felt confidence in yourself and your abilities?
- Felt that you were as healthy as others your age?
- Been discouraged by physical limitations in performing your normal daily activities or your job?

57. Does your health now limit you in doing vigorous activities?

- Not at all
- Very little
- Somewhat
- Quite a lot
- Cannot participate in vigorous activities
- Unsure

58. What is your ability to participate in social roles and activities? Please respond to each question by marking one box per row.

- I have trouble doing all of my regular leisure activities with others...
- I have trouble doing all of the family activities that I want to do...
- I have trouble doing all of my usual work (include work at home)....
- I have trouble doing all of the activities with friends that I want to do...
- I have to limit the things I do for fun with others...
- I have to limit my regular activities with friends
- I have to limit my regular family activities
- I have trouble doing all of the work that is really important to me (include work at home)...

<p>Status (Q58):</p> <ul style="list-style-type: none"> • Never • Rarely • Sometimes • Often • Always

59. How much does pain interfere with your enjoyment of life?

- Not at all
- A little bit
- Somewhat
- Quite a bit
- Very much

60. In the past 7 days how much did pain from your disease interfere with your daily life?

This question should only be answered by the participant.

- How much did pain interfere with your day to day activities?
- How much did pain interfere with work around the home?
- How much did pain interfere with your ability to participate in social activities?
- How much did pain interfere with your household chores?
- How much did pain interfere with the things you usually do for fun?
- How much did pain interfere with your enjoyment of social activities?
- How much did pain interfere with your enjoyment of life?
- How much did pain interfere with your family life?

<p>Status (Q60):</p> <ul style="list-style-type: none"> • Not at all • A little bit • Somewhat • Quite a bit • Very much
--

61. How has your pain been treated? (Select all that apply.)

- Non-prescription medications such as acetaminophen (Tylenol), ibuprofen (Advil), naproxen (Aleve, Naprosyn), aspirin
- Prescription narcotic medications such as hydrocodone (Lortab, Vicodin, Norco), oxycodone (Percocet, Oxycontin), codeine (Tylenol #3), hydromorphone (Dilaudid), morphine (*choices continued page 17*)



- Prescription non-narcotic medications such as celecoxib (Celebrex), meloxicam (Mobic), gabapentin (Neurontin), tramadol (Toradol), pregabalin (Lyrica)
- Acupuncture
- Biofeedback
- Chiropractic
- Physical therapy
- Transcutaneous electrical nerve stimulation (TENS)
- Pain present but no treatment required
- Have never had any pain due to sarcoidosis
- Unsure
- Other: _____

Section 10: Research Participation

62. Do you CURRENTLY participate in any clinical trials related to your sarcoidosis?

- Yes
- No
- Unsure
- Prefer not to answer

63. Have you PREVIOUSLY participated in any clinical trials related to your sarcoidosis?

- Yes
- No
- Unsure
- Prefer not to answer

64. Are you willing to be contacted in the future about RESEARCH RELATED TO YOUR SARCOIDOSIS?

- Yes
- No
- Unsure
- Prefer not to answer

65. Are you currently participating in any other registry?

- Yes
- No
- Unsure

Section 11: Demographics

66. If you have health insurance or a health care plan, what type of health insurance do you currently have? (Select all that apply.) For health insurance coverage outside the USA, please select the categories that most closely describe the source of the participant's health insurance. If you do NOT have health insurance or a health care plan, please answer "No health care coverage".

- Private health insurance
- Medicare
- Medi-gap
- Medicaid
- SCHIP (Children's Health Insurance Program)
- Military health care (Tricare/VA, Champ-VA)
- Indian health service
- State-sponsored health plan
- Other government program (*choices continued page 18*)



- Single service plan (e.g. dental, vision, prescription)
 - No health care coverage
 - Unsure
 - Prefer not to answer
67. **What is your current marital status?**
- Married or living as married
 - Single/never married
 - Widowed
 - Separated/divorced
 - Unsure
 - Prefer not to answer
68. **Has there been a change in marital status since you were diagnosed with sarcoidosis?**
- Yes
 - No
 - Unsure
 - Prefer not to answer
69. **If you are less than 18 years old, what is the highest grade you have started? For participants receiving special educational services, please select the grade level assigned by their education provider.**
- Not applicable - participant is older than 18 years
 - No schooling
 - Preschool or nursery school
 - Kindergarten
 - *Separate Choices 1st grade to 12th grade*
 - GED
 - College
 - Prefer not to answer
70. **If you are 18 years or older, what is the highest grade or level of school you completed?**
- Not applicable - participant is younger than 18 years
 - 8th grade or less
 - More than 8th grade, but did not graduate from high school
 - Went to a business, trade, or vocational school instead of high school
 - High school graduate
 - Completed a GED
 - Went to a business, trade, or vocational school after high school
 - Went to college, but did not graduate
 - Graduated from a college or university
 - Professional training beyond a four-year college or university
 - He/she never went to school
 - He/she went to school, but respondent doesn't know what level
 - Prefer not to answer
 - Unsure if he/she went to school
71. **How do you prefer to be contacted?**
- Email
 - Mail
 - Phone



72. Name of the country(s) from which you or your biological family had previous residence or past ancestors. (Select all that apply in the previous three generations.) Please be as specific as possible. If you are unsure, please select the appropriate continent.

- Africa - Region Unknown
- Africa - Central Africa
- Africa - East Africa
- Africa - North Africa
- Africa - Southern Africa
- Africa - West Africa
- Americas - Region Unknown
- Americas - Caribbean Islands
- Americas - Central America
- Americas - North America
- Americas - South America
- Antarctic
- Asia - Region Unknown
- Asia - Central Asia
- Asia - Eastern Asia
- Asia - Northern Asia
- Asia - South-East Asia
- Asia - Southern Asia
- Asia - Western Asia
- Europe - Region Unknown
- Europe - Eastern Europe
- Europe - Scandinavia
- Europe - Western Europe
- Oceania - Region Unknown
- Oceania - Australia
- Oceania - Melanesia
- Oceania - Micronesia
- Oceania - Polynesia
- Unsure
- Prefer not to answer



SARCOIDOSIS
ADVANCED
REGISTRY for
CURES

FSR-SARC: Sarcoidosis Patient Registry Baseline Clinical Questionnaire

FSR-SARC was established in collaboration with the Office of Rare Diseases Research (ORDR), National Center National Center for Advancing Translational Sciences (NCATS), National Institutes of Health as part of the Global Rare Diseases Patient Registry and Data Repository (GRDR) pilot project.

Sponsor: Foundation for Sarcoidosis Research
Investigator: Leslie K. Serchuck, MD, MA, MBe
Site(s): Foundation for Sarcoidosis Research
1820 West Webster Avenue, Suite #304, Chicago, IL 60614
Phone: (312) 341-0500
Website: www.fsr-sarc.org
Study Coordinator: Ginger Spitzer ginger@stopsarcoidosis.org

Reference study number: Pro00008556

If you are an investigator interested in reviewing and/or utilizing data contained within FSR-SARC, please complete application at www.stopsarcoidosis.org or email ginger@stopsarcoidosis.org for additional information. Applications will be reviewed and a response sent within 30 days. Please note that no researcher will have access to the identity of registry participants and they will not be able to contact any participant directly.

Any potential new studies they derive from this data will require review and approval by an Institutional Review Board and must include reference to FSR-SARC Registry.

Hosted by:

PatientCrossroads™
Rights Reserved - All