**Clinical Questionnaire**

**Section 1: Diagnosis**

1. **What is your diagnosis?**
   * Sarcoidosis
   * Juvenile sarcoidosis (diagnosed before the age of 18)
2. **What was your age in years when you first began experiencing symptoms of sarcoidosis?**IF ANSWER TO QUESTION #1 IS "SARCOIDOSIS", THEN THE ANSWER TO #2 MUST BE >18.  
   IF THE ANSWER TO #1 IS "JUVENILE SARCOIDOSIS" - ANSWER TO #2 MUST BE <18.
   * Age of onset unknown
   * Participant never experienced symptoms
   * Prenatal
   * At birth
   * Less than one year
   * \*Separate choices for “1 – 89”
   * 90+years
3. **How many doctors did you see before being diagnosed?**
   * \*Separate choices for “1-10”
   * More than 10
   * Unsure
4. **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
5. **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 week
   * 1 - 2 weeks
   * 2 - 4 weeks
   * 1 - 6 months
   * 6 - 12 months
   * 1 - 2 years
   * 2 - 4 years
   * 4 - 5 years
   * Greater than 5 years
6. **What was your age in years when the formal diagnosis was made? This is the first time the participant was told they had sarcoidosis in general or of a specific organ.**
   * Age of diagnosis unknown
   * Prenatal
   * At birth
   * Less than one year
   * \*Separate choices for “1 – 89”
   * 90+years
7. **What organs have been diagnosed with sarcoidosis by a medical provider?** **Please choose one answer for each row (Not involved; Suspected; Diagnosed)** 
   * Generalized Sarcoidosis or NOT-Specified
   * Bone and/or vertebrae
   * Brain or Cranial Nerves, including the inflammation of the optic neuritis
   * Central Lymph Nodes (Chest)
   * Eyes (Uveitis, Red or Dry Eyes)
   * Heart
   * Joints (Arthritis)
   * Kidney (not including Kidney Stones)
   * Lacrimal or Parotid glands
   * Liver
   * Lungs
   * Muscle
   * Peripheral Lymph Nodes (Neck, Armpit, Groin)
   * Peripheral Nerves (Pain, Pins and Needles, Numbness or Burning)
   * Sinuses
   * Skin
   * Spleen
   * Stomach/Intestines
   * 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 (ECHO)
   * Eye Exam
   * Gallium-67 Nuclear Scan
   * Holter Monitor
   * Lumbar Puncture with Cerebrospinal Fluid Analysis
   * MRI – Chest
   * MRI - Brain
   * MRI – Heart
   * PET Scan (FDG or FDG/CT)
   * PET Scan Heart
   * Physical Exam
   * Pulmonary Function Testing (PFT)
   * Quantitative Sensory Testing (neuropathy)
   * Skin Test (Kveim)
   * Skin Test (Quantitative Nerve Density Analysis)
   * Slit Lamp Exam (eye)
   * Tilt Table Test
   * Ultrasound Abdomen
   * Urine - 24 hour collection calcium
   * X-Ray
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
   * None
   * Unsure
10. **Have you ever been admitted to the hospital for your sarcoidosis (Not for diagnostic procedures)?** IF THE ANSWER IS "NO' - PLEASE MARK THAT AND MOVE TO SECTION 2
    * Yes
    * No
    * Refused
    * Unsure
11. **In the past 12 months, how many times have you been admitted to a hospital due to your condition?**
    * Options 1-12
    * 13 or more
    * Unsure

**Section 2: Pulmonary (Lung)**

1. **Have you been diagnosed with pulmonary (lung) sarcoidosis by a medical provider?**  IF THE ANSWER IS "YES" PLEASE MARK THAT AND THEN MAKE CERTAIN THAT YOUR ANSWER FOR QUESTION #7 INDICATES THAT "LUNGS" ARE MARKED "DIAGNOSED".
   * Yes
   * No
   * Unsure
2. **Have you ever been diagnosed with Pulmonary Arterial Hypertension by a medical provider?** **(Pulmonary Arterial Hypertension is high blood pressure in the lungs.)** IF THE ANSWER IS "NO" - PLEASE MARK THAT AND THEN SKIP TO QUESTION #15
   * Yes
   * No
   * Unsure
3. **Have you ever been prescribed any of the following medications for Pulmonary Arterial Hypertension?**

*Answers:*

* + Cialis (Tadalafil)
  + Folan, Veletr (Epoprostenol)
  + Letairis (Ambrisentan)
  + Remodulin (Tadalafil)
  + Tracleer (Bosentan)
  + Ventavis (Iloprost)
  + Viagra (Sildenafil)

*Status:*

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

1. **Have you ever used oxygen or a breathing device? (Select all that apply.)**
   * BiPAP
   * BiPAP with Sip ventilation during the day
   * CPAP
   * Inhalers
   * Oxygen
   * Ventilator
   * None
2. **If you have breathlessness, describe how and when it affects you by selecting one for** **each area.** **Choose the ONE best answer for each column.** 
   * I only get breathless with strenuous exercise.
   * I get short of breath when hurrying on level ground or walking up a slight hill.
   * 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.
   * I stop for breath after walking about 100 yards or after a few minutes on level ground.
   * I am too breathless to leave the house or I am breathless when dressing.
3. **Have you ever been given the diagnosis of asthma or chronic obstructive pulmonary disease by a medical provider?**
   * Yes
   * No
   * Unsure

**Section 3: Skin**

1. **Have you been examined by a dermatologist (skin specialist)?**
   * Yes
   * No
   * Unsure
2. **Have you ever had any of the following skin conditions or diagnoses? (Select all that apply. Please refer to the glossary for unfamiliar terms.)** IF THE ANSWER IS "SARCOIDOSIS OF THE SKIN" - PLEASE MARK THAT ND THEN CONFIRM THAT IN QUESTION #7 YOU HAVE SKIN MARKED AS "DIAGNOSED". IF THE ANSWER IS "NO SKIN INVOLVEMENT" - PLEASE MARK THAT AND SKIP TO SECTION 4.
   * No skin involvement
   * Sarcoidosis of the skin
   * Abnormal skin pigmentation
   * Erythema nodosum
   * Lofgren’s syndrome
   * Lupus pernio
   * Nodules under the skin, especially around scars or tattoos
   * Papules
   * Plaques
   * Other skin lesions that have been diagnosed as caused by sarcoidosis
   * Unsure
3. **Have you ever used topical creams or injections?**
   * Yes
   * No
   * Unsure
4. **Have you ever been treated with any of the following medications for sarcoidosis of the skin?** **(Select all that apply.)**
   * Cyclosporine (Neoral, Sandimmune, Gengrap)
   * Influximab (Remicade)
   * Injection of steroids directly into skin lesion
   * Etanercept, Adalimumab, Ustekinumab
   * Laser Pulse Therapy
   * Laser Surgery Using Carbon Dixode
   * Leflunomie
   * Pentoxifylline
   * Hydroxichloroquine
   * Minocycline or Doxycycline
   * Thalomide
   * Topical Tacrolimus
   * Radiation
   * Unsure
5. **Have you ever had a skin biopsy?**
   * Yes – one time
   * Yes – more than once
   * No
   * Unsure

**Section 4: Eyes and Vision**

1. **Have you been examined by an ophthalmologist or optometrist (eye specialist)?** IF THE ANSWER IS "NO" - PLEASE MARK THAT AND ANSWER QUESTION #24. THEN SKIP TO SECTION 5.
   * Yes
   * No
   * Unsure
2. **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
3. **Have you ever been given the diagnosis of any of the following eye disorders by a medical provider? (Select all that apply. Please refer to the glossary for unfamiliar terms.)** 
   * No diagnosis of ocular sarcoidosis
   * Anterior uveitis
   * Posterior uveitis
   * Nodules
   * Keratoconjunctivitis
   * Optic Neuritis
   * Vasculitis of the Retina
   * Unsure
4. **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
   * Legally blind

**Section 5: Cardiac**

1. **Have you been examined by a cardiologist (heart specialist)?** IF THE ANSWER IS "NO" - PLEASE MARK THAT AND SKIP TO SECTION 6
   * Yes
   * No
   * Unsure
2. **Have you been examined by an electrophysiologist?** **(An electrophysiologist is a cardiologist who specializes in diagnosing and treating heart rhythm abnormalities.)**
   * Yes
   * No
   * Unsure
3. **Have you had any of the following cardiac tests or procedures?** **(Select all that apply. Please refer to the glossary for unfamiliar terms.)** 
   * Cardiac biopsy
   * Cardiac bypass graft
   * Cardiac catheterization in arteries to look at blood vessels of heart
   * Cardiac catheterization in veins to measure pressure
   * Cardiac defibrillator placement
   * Cardiac MRI
   * Cardiac Stent
   * Cardiac Transplant
   * Echocardiogram
   * Electrical ablation
   * Electrocardiogram (EKG)
   * Electrophysiology study
   * Exercise tolerance test
   * Gallium Scan
   * Holter Monitor/Event monitor
   * Nuclear stress test
   * Pet Scan-Cardiac
   * Valve Replacement
   * None
   * Unsure
4. **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.)** IF THE ANSWER IS "CARDIAC SARCOIDOSIS" - PLEASE MARK THAT AND MAKE CERTAIN THAT IN YOUR ANSWER TO QUESTION #7 YOU MARKED HEART AS "DIAGNOSED". IF THE ANSWER IS "NONE" - PLEASE MARK THAT AND THEN SKIP TO SECTION 6.
   * Atrial Arrhythmias
   * Ventricular Arrhythmias
   * Cardiac sarcoidosis
   * Cardiomyopathy
   * Congestive heart failure
   * Heart block
   * Heart valve abnormality (mitral regurgitation, tricuspid or aortic valve) – heart valve leaks
   * Pericarditis
   * Pulmonary hypertension
   * Syncope
   * None
   * Unsure
5. **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
6. **Which cardiac devices are you currently using? (Select all that apply.)**
   * Defibrillator alone
   * Pacemaker alone
   * Pacemaker/Defibrillator
   * None
   * Unsure
7. **Has an Automatic Implantable Cardiac Defibrillator (AICD) ever been used to deliver therapy? (Select all that apply.)**
   * Participant does not have an AICD
   * The AICD has delivered appropriate therapy/shock to return participant to a stable rhythm
   * Participant has received an appropriate therapy/shock from the AICD (shocked when NOT in a dangerous rhythm)
   * The AICD has not delivered therapy/shock (therapy never required)

**Section 6: Neurological**

1. **Have you ever had a consultation with a neurologist (specialist of the brain, spinal cord, and nerves)?** IF THE ANSWER IS "NO", PLEASE MARK THAT, ANSWER QUESTION 35, AND THEN SKIP TO SECTION 7
   * Yes
   * No
   * Unsure
2. **Have you ever had any of the following neurological tests performed?**

*Answers:*

* + 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 Test
  + Positron Emission Tomography (PET scan)
  + Spinal tap
  + No tests performed

*Test Result:*

* Tested, normal response
* Tested, abnormal response
* Tested, results unknown
* Did not test
* unsure

1. **Have you ever been diagnosed with neurosarcoidosis by a medical provider? This can include any of the following diagnoses. (Select all that apply.) IF YOUR ANSWER IS "YES" - PLEASE MAKE CERTAIN YOUR ANSWER TO #7 INDICATE THE SAME INFORMATION.**
   * Brain or lining of the brain - (meninges)
   * Peripheral Neuropathy
   * Small fiber neuropathy
   * Spinal cord involvement
   * None
   * Unsure

**Section 7: Endocrine (Hormone System)**

1. **Have any of the following endocrine conditions been diagnosed by a physician?** **(Select all that apply. Please refer to the glossary for unfamiliar terms.)**
   * Yes, but I don't know what it is called
   * Cushing's disease or syndrome
   * Diabetes (high blood sugar)
   * Difficulty regulating body temperature
   * Hypercalcemia
   * Hyperglycemia
   * Hypoglycemia
   * Hypoparathryroid
   * Hyperthyroid
   * Hypothyroid
   * Insomnia
   * Low testosterone
   * Obesity
   * Osteopenia/osteoporosis (low bone density)
   * Parotid gland enlargement
   * Vitamin D deficiency (low vitamin 25D)
   * Vitamin D (1,25D) excess (high vitamin 1,25D)
   * None
   * Unsure
2. **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
   * Hypertension
   * Lymphoma
   * Obesity
   * Osteoporosis/osteopenia
   * Sleep apnea
   * Sleep disorders
   * None
   * Unsure

**Section 8: Medications**

1. **What are the medications you have EVER taken for sarcoidosis? Please select each type of medication you have EVER been prescribed for your disease. If you are not currently taking the medication please select the reason it was stopped.**

*Answers:*

* + Prednisone, Dexamethasone (Deltasone, Prednicot, Rayos, Sterapred)
  + Methylprednisolone (Medrol, Solumedrol)
  + Inhaled Steroids (Advair, Aerobid, Aerospan, Alvesco, Asmanex, Flovent, Pulmicort, Qvar, Symbicort)
  + Hydroxychloroquine (Plaquenil, Quinoprex)
  + Chloroquine (Aralen)
  + Methotrexate (Rheumatrex, Trexall)
  + Azathioprine (Azasan, Imuran)
  + Lefunomide (Arava)
  + Mycophenoloate Mofetil (Cellcept)
  + Infliximab (Remicade)
  + Adalimumab (Humira)
  + Certolizumab (Cimzia)
  + Golimumab (Simponi)
  + Etanercept (Enbrel)
  + Rituximab (MabThera, Rituxan)
  + Cyclophosphamide (Cytoxan, Neosar)
  + Pentoxifyline (Pentoxil, Trental)
  + IVIG (Carimune, Flebogamma, Gamunex, Gammagard, Octagam, Privegen)
  + Thalidomide (Thalomid)
  + Adrenocorticotropic (Acthar Gel)

*Reason treatment stopped:*

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

1. **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 end of each row. Please check the box next to the row of any/all medication(s) you are currently taking.**
   * NO MEDICATIONS TAKEN CURRENTLY
   * Prednisone, Dexamethasone (Deltasone, Prednicot, Rayos, Sterapred)
   * Methylprednisolone (Medrol, Solumedrol)
   * Inhaled Steroids (Advair, Aerobid, Aerospan, Alvesco, Asmanex, Flovent, Pulmicort, Qvar, Symbicort)
   * Hydroxychloroquine (Plaquenil, Quinoprex)
   * Chloroquine (Aralen)
   * Methotrexate (Rheumatrex, Trexall)
   * Azathioprine (Azasan, Imuran)
   * Lefunomide (Arava)
   * Mycophenoloate Mofetil (Cellcept)
   * Infliximab (Remicade)
   * Adalimumab (Humira)
   * Certolizumab (Cimzia)
   * Golimumab (Simponi)
   * Etanercept (Enbrel)
   * Rituximab (MabThera, Rituxan)
   * Cyclophosphamide (Cytoxan, Neosar)
   * Pentoxifyline (Pentoxil, Trental)
   * IVIG (Carimune, Flebogamma, Gamunex, Gammagard, Octagam, Privegen)
   * Thalidomide (Thalomid)
   * Adrenocorticotropic (Acthar Gel)
   * Unsure
2. **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 (Ativan, Celexa, Klonopin, Lexapro, Luvox, Serax, Xanax, Valium)
   * Anti-depressant medications (Cymbalta, Desyrel, Effexor, Pamelor, Paxil, Remeron, Seroquel, Wellbutrin, Zoloft)
   * Bisphosphonates (Aredia, Boniva, Didronel, Fosamax, Zometa)
   * NON-Steroid Inhalers (Accolate, Foradil, MaxAir Singulair, Serovent, Xopenex, Zyflo)
   * Sleep Disorder medications (Ambien, Lunesta, Rozerem, Sonata, Silenor)
   * Vitamin D (Calcidol, Calciferol, Delta D3, Drisdol, Hectorol, Rocaltrol)
   * Fatigue medications (Focalin, Nuvigil, Provigil, Vyvanse, Ritalin, Adderall)
   * No other medications
   * Unsure
3. **Do you take any medical foods or follow a special diet for treatment of your rare disease?**
   * Yes
   * No
   * Unsure
4. **Have you had any of the following surgeries to treat sarcoidosis?**
   * Cardiac ablation for arrhythmia
   * Heart transplant
   * Liver transplant
   * Lung transplant
   * Pacemaker/defibrillator placement
   * Shunt for hydrocephalus
   * Splenectomy (removal of the spleen)
   * None
   * Unsure
5. **Do you use any type of medical or assistive device(s) to help you move around, communicate, or do things?**
   * Cane
   * Oxygen
   * Walker
   * Wheelchair
   * None
   * Unsure

**Section 9: Disease Effects of Sarcoidosis**

1. **What is your employment status?** 
   * Employed – full-time
   * Employed – part-time
   * Disabled working
   * Disabled – not working
   * Unemployed
   * Student
   * Unsure
   * Refused
2. **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
3. **Have you needed to quit your job due to health effects from sarcoidosis?**
   * Not applicable – did not work
   * Yes
   * No
   * Unsure
4. **How has your diagnosis affected your family’s finances?**
   * No financial impact
   * Slightly affected
   * Greatly affected
   * Severely affected
   * Unsure
   * Refused
5. **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
   * Refused
6. **In general, would you say your health is…**
   * Excellent
   * Very good
   * Good
   * Fair
   * Poor
   * Unsure
7. **Do you feel depressed…**
   * Never
   * Rarely
   * Sometimes
   * Often
   * Always
   * Unsure
8. **How often do you feel tired?** 
   * Never
   * Rarely
   * Sometimes
   * Often
   * Always
   * Unsure
9. **Do you take any of the following approaches for fatigue?**

*Answers:*

* Exercise
* Concerta, Ritalin, Adderall
* Focalin
* Provigil
* Nuvigil
* Vyvance

*Was treatment used?*

* Yes
* No

*Was treatment effective?*

* Yes
* Temporary - helped for awhile
* No
* Don’t know

1. **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 upstairs, 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?
* 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?

1. **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
2. **What is your ability of the participant 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)…
3. **How much does pain interfere with your enjoyment of life?**
   * Not at all
   * A little bit
   * Somewhat
   * Quite a bit
   * Very much
4. **In the past 7 days how much did pain from your disease interfere with your daily life? Please respond to each question or statement by marking one box per row.** 
   * 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 enjoyment of life?
   * 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 household chores?
   * How much did pain interfere with your family life?
5. **How has your pain been treated? (Select all that apply.)**
   * Non-prescription medications such as Tylenol, Advil, Aleve, Aspirin
   * Prescription narcotic medications such as Hydrocodone, Lortab, Vicodin
   * Prescription non-narcotic medications such as Celebrex, Lyrica, Meloxicam, Neurontin, Toradol
   * 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

**Section 10: Research Participation**

1. **Do you CURRENTLY participate in any clinical trials related to your sarcoidosis?**
   * Yes
   * No
   * Unsure
   * Refused
2. **Have you PREVIOUSLY participated in any clinical trials related to your sarcoidosis?**
   * Yes
   * No
   * Unsure
   * Refused
3. **Have you donated a sample of blood, tissue, or other bio specimen for research in the past?**
   * Yes
   * No
   * Unsure
   * Refused
4. **If a bio specimen was donated in the past, what type was it?**
   * Blood
   * Saliva/cheek swab
   * Tissue
   * Urine
   * Not applicable – no bio specimen donated
   * Unsure
5. **What is the name of the hospital/clinic where the bio specimen was donated? If the name of the hospital/clinic is not known, please write "unsure" in the text box.**
6. **Are you willing to be contacted about donating a sample of blood, tissue, or other bio specimen for research in the future?**
   * Yes
   * No
   * Unsure
   * Refused
7. **Are you currently participating in any other registry?**
   * Yes
   * No
   * Unsure
8. **Are you willing to be contacted in the future about research related to your sarcoidosis?**
   * Yes
   * No
   * Unsure
   * Refused

**Section 11: Demographics**

1. **Are you covered by any kind of health insurance or some other kind of health care plan?**
   * Yes
   * No
   * Unsure
   * Refused
2. **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.** 
   * 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
   * Single service plan (e.g. dental, vision, prescription)
   * No coverage
   * Unsure
3. **What is your current marital status?** 
   * Married or living as married
   * Single/never married
   * Widowed
   * Separated/divorced
   * Unsure
   * Refused
4. **Has there been a change in marital status since you were was diagnosed with sarcoidosis?** 
   * Yes
   * No
   * Unsure
   * Refused
5. **How many people (including yourself) currently live in your house, apartment, or mobile home?**
   * \*Separate choices for “1-20”
6. **If you live in a group house, how many people live in the group house including yourself? A group home is a private residence designed to serve children or adults with chronic disabilities.** 
   * \*Separate choices for “1-20”
7. **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
   * 1st Grade
   * 2nd Grade
   * 3rd Grade
   * 4th grade
   * 5th grade
   * 6th grade
   * 7th grade
   * 8th grade
   * 9th grade
   * 10th grade
   * 11th grade
   * 12th grade
   * GED
   * College
   * Unsure
8. **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 schoo
   * 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
   * Respondent doesn’t know if he/she went to school
   * Refused
   * Unsure
9. **What is the highest level of education your mother finished?**
   * Not applicable - participant is younger than 18 years
   * 8th grade or less
   * More than 8th grade, but did not graduate from high schoo
   * 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
   * Respondent doesn’t know if he/she went to school
   * Refused
   * Unsure
10. **What is the highest level of education your father finished?**
    * Not applicable - participant is younger than 18 years
    * 8th grade or less
    * More than 8th grade, but did not graduate from high schoo
    * 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
    * Respondent doesn’t know if he/she went to school
    * Refused
    * Unsure
11. **For adult female participants, what is the total number of pregnancies, including living children, deceased children, and abortions (spontaneous and therapeutic)?**
    * Not applicable
    * \*Separate choices for “1-20”
    * Refused
12. **For adult female participants, what is the number of live births?** 
    * Not applicable
    * \*Separate choices for “1-20”
    * Refused
13. **What is the number of living children of the participant?**
    * Not applicable
    * \*Separate choices for “1-20”
    * Refused
14. **Were you (the participant) born at or close to your due date?**
    * Yes
    * No
    * Unsure
    * Refused
15. **When were you born in relation to your due date?**
    * Unsure
    * 2 weeks late
    * 1 week late
    * On time
    * \*Separate answer choices for “1-20 week(s) premature”
16. **How much did you weigh when you were born? (If birth weight is unknown, please select "Don't know" from the pull down list.) Please convert kilograms to pounds**

*Pounds*

* Don't know birth weight
* \*Separate answer choices for “1-20”

*Ounces*

* Don't know birth weight
* \*Separate answer choices for “1-15”

1. **How do you prefer to communicate?**
   * Sign language
   * Spoken language
   * Written language
2. **How do you prefer to be contacted?**
   * Email
   * Mail
   * Phone
3. **Did the individual with sarcoidosis provide the information for this registry update?**
   * Yes
   * No
   * Unsure
   * Refused
4. **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
   * Refused

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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.

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If you are an investigator interested in reviewing and/or utilizing data contained within FSR-SARC, please complete application at [www.stopsarcoidosis.org](http://www.stopsarcoidosis.org) or email [ginger@stopsarcoidosis.org](mailto: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.

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