

Center or Doctor Name: \_\_\_\_\_ Subject ID: 

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These questions will help us to understand how lupus has affected you. Don't worry if there are some medical words you don't understand. This usually means that you don't have the problem the question is asking about. It should take you less than five minutes to complete the questionnaire.

**Instructions:** These questions are only about problems you developed since the start of your lupus.

**ONLY answer YES if you have had the problem since the START OF YOUR LUPUS. Otherwise answer, NO.**

**Eyes**

- 1) Has a physician or eye doctor told you that you have a cataract?
- 2) Has a physician or eye doctor told you that you had damage in your retina which affects your vision?

YES	NO
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

**Brain and Nerves**

- 3) Have you had serious problems with your memory, concentration, or had difficulty speaking, writing, or doing mathematics that lasted more than 6 months?
- 4) Have you had major mental illness, such as psychosis, schizophrenia, or steroid psychosis that lasted more than 6 months?
- 5) Have you had a problem with seizures or convulsions for which you were treated for six months or more?
- 6) Have you had a stroke that caused symptoms that lasted for more than 6 months?
- 7) Have you had more than one stroke, at least six months apart?
- 8) Have you had brain surgery (not for cancer)?
- 9) Have you had a constant burning pain or numbness in your hands or legs (neuropathy) that lasted more than six months?
- 10) Have you had weakness, numbness, or nerve pain in your face (cranial neuropathy)?
- 11) Have you ever had weakness or numbness of BOTH legs with difficulty in walking that lasted more than 6 months (transverse myelitis)?

YES	NO
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
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<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

**Kidneys**

- 12) Were you told that you had poor renal or kidney function?
- 13) Were you told that you had a lot of protein in your urine for more than 6 months?
- 14) Have you been on dialysis for more than 6 months?
- 15) Have you had a kidney transplant?

YES	NO
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

**Lungs**

- 16) Were you told that you had "pulmonary hypertension"?
- 17) Were you told that you had fibrous tissue (fibrosis or scar tissue) in your lung ("pulmonary fibrosis" or "interstitial lung disease")?
- 18) Were you told that you had scar tissue (fibrosis) in the space surrounding your lungs ("pleural fibrosis")?
- 19) Were you told that your diaphragm didn't move well, causing shortness of breath ("shrinking lung")?
- 20) Were you told that you had a blood clot in your lung (pulmonary embolism)?
- 21) Did you have lung surgery that was not for cancer?

<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>



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	YES	NO
<b>Heart</b>		
22) Did you have cardiac bypass surgery or have a balloon or stent put in to open the arteries of your heart?	<input type="checkbox"/>	<input type="checkbox"/>
23) Has a physician told you that you had angina?	<input type="checkbox"/>	<input type="checkbox"/>
24) Has a physician told you that you had a heart attack (myocardial infarction)?	<input type="checkbox"/>	<input type="checkbox"/>
25) Has a physician told you that you had <u>more than one</u> heart attack (myocardial infarction)?	<input type="checkbox"/>	<input type="checkbox"/>
26) Were you told by a physician that you had decreased heart function called cardiomyopathy or heart failure?	<input type="checkbox"/>	<input type="checkbox"/>
27) Has a physician told you that you had a problem with your heart valves or had a <u>severe</u> heart murmur?	<input type="checkbox"/>	<input type="checkbox"/>
28) Have you had surgery to replace one of your heart valves?	<input type="checkbox"/>	<input type="checkbox"/>
29) Were you told by a physician that you had inflammation surrounding the lining around your heart that lasted more than six months (pericarditis)?	<input type="checkbox"/>	<input type="checkbox"/>
30) Did you have surgery to remove the sack or lining around your heart?	<input type="checkbox"/>	<input type="checkbox"/>
<b>Blood vessels</b>		
31) Have you had to stop walking short distances because of pain in your calves?	<input type="checkbox"/>	<input type="checkbox"/>
32) Were you diagnosed by a physician as having "claudication" or "intermittent claudication"?	<input type="checkbox"/>	<input type="checkbox"/>
33) Have you lost the tip of any finger that was not because of an injury?	<input type="checkbox"/>	<input type="checkbox"/>
34) Have you lost a finger or limb, toe, arm or leg that was not because of injury? If <u>YES</u> , have you lost more than one finger or limb not from injury?	<input type="checkbox"/>	<input type="checkbox"/>
35) Has a physician told you that you had a blood clot in your leg ("thrombosis") that was associated with swelling or ulceration (open sores) on your skin?	<input type="checkbox"/>	<input type="checkbox"/>
36) Have you had persistent swelling in one or both legs that your physician said was caused by problems with your veins? (Not varicose veins)	<input type="checkbox"/>	<input type="checkbox"/>
<b>Stomach and bowels</b>		
37) Have you had surgery on your stomach, or your feeding tube (esophagus)?	<input type="checkbox"/>	<input type="checkbox"/>
38) Has a physician told you that you had a pancreas problem (not diabetes) that required pancreatic enzyme replacement?	<input type="checkbox"/>	<input type="checkbox"/>
39) Has a physician told you that you had any of the following problems: not enough blood flow to your intestine (mesenteric insufficiency), ongoing inflammation around the bowels (chronic peritonitis), or a twist in your intestines?	<input type="checkbox"/>	<input type="checkbox"/>
40) Have you had surgery to remove part or all of your bowel (not stomach), spleen, liver or gallbladder?	<input type="checkbox"/>	<input type="checkbox"/>
41) Has this occurred more than once?	<input type="checkbox"/>	<input type="checkbox"/>
42) Has a physician told you that a part of your bowel, spleen, liver or gallbladder had died (infarction)?	<input type="checkbox"/>	<input type="checkbox"/>
43) Has this occurred more than once?	<input type="checkbox"/>	<input type="checkbox"/>



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**Muscles and Bones**

- 44) Has a physician told you that your muscles had become smaller and weaker (atrophied), a problem that lasted at least 6 months?
- 45) Do you have arthritis in your hands that your physician says the x-ray shows erosions in the bones?
- 46) Do you have arthritis deformities in your finger or knuckle joints, not including the fingertip joints?
- 47) Has a physician told you that you had a broken bone or fracture caused by osteoporosis, including breaks of the spine?
- 48) Has a physician told you that parts of a bone had died (avascular necrosis, aseptic necrosis, osteonecrosis)?  
 If YES, has this problem occurred more than once?
- 49) Has a physician told you that you had an infection on the bones of your arms, legs or back?
- 50) Has a physician told you that you had a torn or ruptured tendon?

YES	NO
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

**Skin**

- 51) Have you developed bald spots (not the result of expected male baldness)?
- 52) Do you have extensive scars of your skin that are not the results of burns or injury?
- 53) Do you have extensive ulcers of your skin that are not the results of trauma or clots?

<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

**Menopause**

- 54) For women, did your menstrual periods stop before you were 40 years of age (not the result of surgery)?

<input type="checkbox"/>	<input type="checkbox"/>
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**Diabetes**

- 55) Have you taken medications for diabetes?

<input type="checkbox"/>	<input type="checkbox"/>
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**Cancer**

- 56) Have you been diagnosed by a physician as having cancer (excluding skin cancers and abnormal Pap smears)?  
 If YES, have you ever been diagnosed with a second, different type of cancer?

<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

Today's date is (mm/dd/yyyy): 

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Please tell us your age: 

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How many years of school have you completed? Please X the box to the left of the number of years of school.

1  2  3  4  5  6  7  8  9  10  11  12  13  14  15  16  17+ \_\_\_\_\_  
 -----Grade School-----      -----High School-----      -----College-----      Post college or Other

And are you:  Male  Female

Please tell us your ethnic background:  White  Asian  American Indian/Alaska Native  African American  
 Hispanic  Puerto Rican  Other

Please tell us your country: \_\_\_\_\_

Approximately when did the above condition begin? We want to know the approximate date your lupus first started. If you don't know for sure, give us your best guess. If all you know is the year, just put that much.

Month: 

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 / Year: 

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