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(minutes)# SESSIONS: 

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OUTCOME: 

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INTERVIEW DATE: 

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(month) (day) (year)

## Carolina Lupus Study Questionnaire Follow-Up 2001 -- Controls

*Thank you for agreeing to take part in this follow-up study. Our questions will cover your recent health, jobs and ask about events from around the time you were first interviewed in [INT MO/YR].*

*We understand that some things will be difficult to remember. We would like to have your best possible answer, so please take the time you need to think things over.*

*Everything you tell me in the interview will be kept private and confidential, as required by law. Your name does not go on this questionnaire, only an ID number. But, if for any reason you would rather not answer a question, we can skip it and go on to the next.*

*Also for your information, my supervisor may be monitoring or listening in on some parts of the interview to make sure that I am conducting the interview according to instructions.*

*First I'd like to check the information we already have. You were born (READ BIRTHDATE FROM CONTACT RECORD) and your age now (AS OF DATE LETTER SENT) is (READ AGE FROM CONTACT RECORD). Is that correct? CIRCLE YES or NO.*

*[IF CORRECTIONS ARE NEEDED, SLASH AND CORRECT ON THE CONTACT RECORD.]*

*Do you have any questions before we begin?*

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**A. Medical History Update**

**START TIME:**   :   <sup>AM</sup>   
<sub>PM</sub>

A1. We will begin with some questions about your recent medical history.

In the past 12 months; that is, since  
[CURRENT MONTH] of 2000, have you  
been a patient in a hospital overnight?

YES .....1  
NO ..... [A6] .....2  
DK ..... [A6] .....8

[IF YES:]

A2. How many different times were you a patient  
in the hospital in the past 12 months?

# TIMES

<p style="text-align: center;">A3.</p> <p>What was the most recent month and year you were hospitalized since [CURRENT MONTH] of 2000?</p>	<p style="text-align: center;">A4.</p> <p>How many nights or weeks did you stay?</p>	<p style="text-align: center;">A5.</p> <p style="text-align: center;">Why were you hospitalized this time?</p> <p style="text-align: center;">[CIRCLE ALL THAT APPLY.]</p>
<p style="text-align: center;">[IF DON'T KNOW MO/YR, PROBE FOR SEASON AND YEAR:]</p> <p style="text-align: center;"> <input type="text"/> <input type="text"/>  MONTH </p> <p style="text-align: center;"><b>OR</b></p> <p style="text-align: center;"> <b>01.</b>    <input type="text"/> <input type="text"/>  SEASON </p> <p style="text-align: center;"> <hr style="width: 100px; margin-left: 0;"/> <input type="text"/> <input type="text"/> </p> <p style="text-align: center;"><b>AND</b></p> <p style="text-align: center;"><b>CIRCLE YEAR</b></p> <p style="text-align: center;">2000</p> <p style="text-align: center;">2001</p>	<p style="text-align: center;"> <input type="text"/> <input type="text"/> <input type="text"/>  # OF </p> <p>NIGHTS .....1</p> <p>WEEKS .....2</p>	<p>a. CANCER..... 1  SPECIFY: _____ <input type="text"/> <input type="text"/> <input type="text"/></p> <p>b. HEART ATTACK..... 1</p> <p>c. CONGESTIVE HEART FAILURE ..... 1</p> <p>d. OTHER HEART DISEASES ..... 1  SPECIFY: _____ <input type="text"/> <input type="text"/> <input type="text"/></p> <p>e. STROKE, TIA (TRANSIENT ISCHEMIC ATTACK) ..... 1</p> <p>f. SEIZURE..... 1</p> <p>g. SURGERY..... 1  SPECIFY: _____ <input type="text"/> <input type="text"/> <input type="text"/></p> <p>h. FEVER..... 1</p> <p>i. INFECTION ..... 1</p> <p>j. BLOOD DISORDERS (LOW BLOOD COUNT, ANEMIA) ..... 1</p> <p>k. LUPUS..... 1</p> <p>l. SIDE EFFECT OF MEDICATION ..... 1</p> <p>m. INJURY FROM ACCIDENT..... 1</p> <p>n. OTHER, NON-PREGNANCY RELATED..... 1  SPECIFY: 1. _____ <input type="text"/> <input type="text"/> <input type="text"/>  2. _____ <input type="text"/> <input type="text"/> <input type="text"/>  3. _____ <input type="text"/> <input type="text"/> <input type="text"/></p> <p><b>WOMEN ONLY:</b></p> <p>o. PREGNANCY, DELIVERY WITHOUT COMPLICATIONS .... 1</p> <p><u>PREGNANCY WITH COMPLICATIONS:</u></p> <p>p. PRE-ECLAMPSIA (TOXEMIA) ..... 1</p> <p>q. BLEEDING OR HEMORRHAGE (PLACENTA PREVIA) ..... 1</p> <p>r. THREATENED MISCARRIAGE..... 1</p> <p>s. PREMATURE RUPTURE OF MEMBRANES OR PREMATURE LABOR..... 1</p> <p>t. OTHER, PREGNANCY RELATED..... 1  SPECIFY: _____ <input type="text"/> <input type="text"/> <input type="text"/></p>

A3. And the time before that, what month and year were you hospitalized?	A4. How many nights or weeks did you stay?	A5. Why were you hospitalized this time?  [CIRCLE ALL THAT APPLY.]
<p>[IF DON'T KNOW MO/YR, PROBE FOR SEASON AND YEAR:]</p> <p> <input type="text"/> <input type="text"/>  MONTH </p> <p><b>OR</b></p> <p><b>02.</b> SEASON</p> <p> <input type="text"/> <input type="text"/> <input type="text"/>  # OF </p> <p> NIGHTS .....1  WEEKS .....2 </p> <p><b>AND</b></p> <p><b>CIRCLE YEAR</b></p> <p>2000</p> <p>2001</p>	<p> <input type="text"/> <input type="text"/> <input type="text"/>  # OF </p> <p> NIGHTS .....1  WEEKS .....2 </p>	<p>a. CANCER ..... 1 SPECIFY: _____ <input type="text"/> <input type="text"/> <input type="text"/></p> <p>b. HEART ATTACK ..... 1</p> <p>c. CONGESTIVE HEART FAILURE ..... 1</p> <p>d. OTHER HEART DISEASES ..... 1 SPECIFY: _____ <input type="text"/> <input type="text"/> <input type="text"/></p> <p>e. STROKE, TIA (TRANSIENT ISCHEMIC ATTACK) ..... 1</p> <p>f. SEIZURE ..... 1</p> <p>g. SURGERY ..... 1 SPECIFY: _____ <input type="text"/> <input type="text"/> <input type="text"/></p> <p>h. FEVER ..... 1</p> <p>i. INFECTION ..... 1</p> <p>j. BLOOD DISORDERS (LOW BLOOD COUNT, ANEMIA) ..... 1</p> <p>k. LUPUS ..... 1</p> <p>l. SIDE EFFECT OF MEDICATION ..... 1</p> <p>m. INJURY FROM ACCIDENT ..... 1</p> <p>n. OTHER, NON-PREGNANCY RELATED ..... 1 SPECIFY: 1. _____ <input type="text"/> <input type="text"/> <input type="text"/> 2. _____ <input type="text"/> <input type="text"/> <input type="text"/> 3. _____ <input type="text"/> <input type="text"/> <input type="text"/></p> <p><b>WOMEN ONLY:</b></p> <p>o. PREGNANCY, DELIVERY WITHOUT COMPLICATIONS .... 1</p> <p><u>PREGNANCY WITH COMPLICATIONS:</u></p> <p>p. PRE-ECLAMPSIA (TOXEMIA) ..... 1</p> <p>q. BLEEDING OR HEMORRHAGE (PLACENTA PREVIA) ..... 1</p> <p>r. THREATENED MISCARRIAGE ..... 1</p> <p>s. PREMATURE RUPTURE OF MEMBRANES OR PREMATURE LABOR ..... 1</p> <p>t. OTHER, PREGNANCY RELATED ..... 1 SPECIFY: _____ <input type="text"/> <input type="text"/> <input type="text"/></p>

<p>A3. And the time before that, what month and year were you hospitalized?</p>	<p>A4. How many nights or weeks did you stay?</p>	<p>A5. Why were you hospitalized this time?  [CIRCLE ALL THAT APPLY.]</p>
<p>[IF DON'T KNOW MO/YR, PROBE FOR SEASON AND YEAR:]</p> <p><input type="text"/> <input type="text"/> MONTH</p> <p><b>OR</b></p> <p><b>03.</b> SEASON <input type="text"/> <input type="text"/> <input type="text"/> # OF</p> <p>NIGHTS .....1 WEEKS .....2</p> <p><input type="text"/> <input type="text"/></p> <p><b>AND</b></p> <p><b>CIRCLE YEAR</b></p> <p>2000</p> <p>2001</p>	<p><input type="text"/> <input type="text"/> <input type="text"/> # OF</p> <p>NIGHTS .....1 WEEKS .....2</p>	<p>a. CANCER ..... 1 SPECIFY: _____ <input type="text"/> <input type="text"/> <input type="text"/></p> <p>b. HEART ATTACK ..... 1</p> <p>c. CONGESTIVE HEART FAILURE ..... 1</p> <p>d. OTHER HEART DISEASES ..... 1 SPECIFY: _____ <input type="text"/> <input type="text"/> <input type="text"/></p> <p>e. STROKE, TIA (TRANSIENT ISCHEMIC ATTACK) ..... 1</p> <p>f. SEIZURE ..... 1</p> <p>g. SURGERY ..... 1 SPECIFY: _____ <input type="text"/> <input type="text"/> <input type="text"/></p> <p>h. FEVER ..... 1</p> <p>i. INFECTION ..... 1</p> <p>j. BLOOD DISORDERS (LOW BLOOD COUNT, ANEMIA) ..... 1</p> <p>k. LUPUS ..... 1</p> <p>l. SIDE EFFECT OF MEDICATION ..... 1</p> <p>m. INJURY FROM ACCIDENT ..... 1</p> <p>n. OTHER, NON-PREGNANCY RELATED ..... 1 SPECIFY: 1. _____ <input type="text"/> <input type="text"/> <input type="text"/> 2. _____ <input type="text"/> <input type="text"/> <input type="text"/> 3. _____ <input type="text"/> <input type="text"/> <input type="text"/></p> <p><b>WOMEN ONLY:</b></p> <p>o. PREGNANCY, DELIVERY WITHOUT COMPLICATIONS .... 1</p> <p><u>PREGNANCY WITH COMPLICATIONS:</u></p> <p>p. PRE-ECLAMPSIA (TOXEMIA) ..... 1</p> <p>q. BLEEDING OR HEMORRHAGE (PLACENTA PREVIA) ..... 1</p> <p>r. THREATENED MISCARRIAGE ..... 1</p> <p>s. PREMATURE RUPTURE OF MEMBRANES OR PREMATURE LABOR ..... 1</p> <p>t. OTHER, PREGNANCY RELATED ..... 1 SPECIFY: _____ <input type="text"/> <input type="text"/> <input type="text"/></p>

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A3. And the time before that, what month and year were you hospitalized?	A4. How many nights or weeks did you stay?	A5. Why were you hospitalized this time?  [CIRCLE ALL THAT APPLY.]
<p>[IF DON'T KNOW MO/YR, PROBE FOR SEASON AND YEAR:]</p> <p> <input type="text"/> <input type="text"/>  MONTH </p> <p><b>OR</b></p> <p><b>05.</b> SEASON</p> <p> <input type="text"/> <input type="text"/> <input type="text"/>  # OF </p> <p> NIGHTS .....1  WEEKS .....2 </p> <p><b>AND</b></p> <p><b>CIRCLE YEAR</b></p> <p>2000</p> <p>2001</p>	<p> <input type="text"/> <input type="text"/> <input type="text"/>  # OF </p> <p> NIGHTS .....1  WEEKS .....2 </p>	<p>[CIRCLE ALL THAT APPLY.]</p> <p>a. CANCER ..... 1  SPECIFY: _____ <input type="text"/> <input type="text"/> <input type="text"/></p> <p>b. HEART ATTACK ..... 1</p> <p>c. CONGESTIVE HEART FAILURE ..... 1</p> <p>d. OTHER HEART DISEASES ..... 1  SPECIFY: _____ <input type="text"/> <input type="text"/> <input type="text"/></p> <p>e. STROKE, TIA (TRANSIENT ISCHEMIC ATTACK) ..... 1</p> <p>f. SEIZURE ..... 1</p> <p>g. SURGERY ..... 1  SPECIFY: _____ <input type="text"/> <input type="text"/> <input type="text"/></p> <p>h. FEVER ..... 1</p> <p>i. INFECTION ..... 1</p> <p>j. BLOOD DISORDERS (LOW BLOOD COUNT, ANEMIA) ..... 1</p> <p>k. LUPUS ..... 1</p> <p>l. SIDE EFFECT OF MEDICATION ..... 1</p> <p>m. INJURY FROM ACCIDENT ..... 1</p> <p>n. OTHER, NON-PREGNANCY RELATED ..... 1  SPECIFY: 1. _____ <input type="text"/> <input type="text"/> <input type="text"/>  2. _____ <input type="text"/> <input type="text"/> <input type="text"/>  3. _____ <input type="text"/> <input type="text"/> <input type="text"/></p> <p><b>WOMEN ONLY:</b></p> <p>o. PREGNANCY, DELIVERY WITHOUT COMPLICATIONS .... 1</p> <p><u>PREGNANCY WITH COMPLICATIONS:</u></p> <p>p. PRE-ECLAMPSIA (TOXEMIA) ..... 1</p> <p>q. BLEEDING OR HEMORRHAGE (PLACENTA PREVIA) ..... 1</p> <p>r. THREATENED MISCARRIAGE ..... 1</p> <p>s. PREMATURE RUPTURE OF MEMBRANES OR PREMATURE LABOR ..... 1</p> <p>t. OTHER, PREGNANCY RELATED ..... 1  SPECIFY: _____ <input type="text"/> <input type="text"/> <input type="text"/></p>

[REPEAT UP TO 5 HOSPITALIZATIONS.]



A6. During the past 12 months; that is, since [CURRENT MONTH] of 2000, have you stayed at least one night in a nursing or convalescent home or rehabilitation facility for any reason?

YES .....1  
NO ..... [A8] .....2  
DK ..... [A8] .....8

[IF YES:]

A7. How many days, weeks or months did you stay in one of these facilities in the past 12 months?

# OF  
[DK=998]

DAYS .....1  
WEEKS .....2  
MONTHS .....3

A8. During the past 12 months, have you used paid in home help, nursing or personal care assistance for yourself?

YES .....1  
NO ..... [A10] .....2  
DK ..... [A10] .....8

[IF YES:]

A9. How many days, weeks or months did you use assistance in the past 12 months?

# OF  
[DK=998]

DAYS .....1  
WEEKS .....2  
MONTHS .....3

A10. During the past 12 months, have you been to a hospital emergency room as a patient? (Do not include any hospitalizations you already told us about.)

YES .....1  
NO ..... [A12] .....2  
DK ..... [A12] .....8

[IF YES:]

A11. How many times have you been to an emergency room in the past 12 months?

# TIMES  
[DK=98]

A12. During the past 12 months, have you had outpatient surgery or medical procedures when you did not stay overnight?

YES .....1  
NO ..... [A14] .....2  
DK ..... [A14] .....8

[IF YES:]

A13. How many times have you had outpatient surgery or medical procedures in the past 12 months?

# TIMES  
[DK=98]

A14.	
During the past 12 months, that is since [CURRENT MONTH] of 2000, how many visits have you made to the following kinds of doctors?	
a. Family physician, general internist or primary care provider	<input type="text"/> <input type="text"/> # VISITS
b. Rheumatologist or arthritis doctor	<input type="text"/> <input type="text"/> # VISITS
c. Dermatologist or skin doctor	<input type="text"/> <input type="text"/> # VISITS
d. Kidney or nephrology doctor	<input type="text"/> <input type="text"/> # VISITS
e. Eye doctor, <u>other than</u> to get glasses or contacts	<input type="text"/> <input type="text"/> # VISITS
f. Orthopedic surgeon	<input type="text"/> <input type="text"/> # VISITS
g. Other surgeon SPECIFY: _____	<input type="text"/> <input type="text"/> # VISITS
h. Cardiologist or heart doctor	<input type="text"/> <input type="text"/> # VISITS
i. Hematologist for blood disorders	<input type="text"/> <input type="text"/> # VISITS
j. Neurologist	<input type="text"/> <input type="text"/> # VISITS
k. Psychiatrist, psychologist or counselor	<input type="text"/> <input type="text"/> # VISITS
l. Gastrointestinal or GI doctor (stomach, intestine, liver, colon, gall bladder)	<input type="text"/> <input type="text"/> # VISITS
[FOR WOMEN:] m. Gynecologist or OB/GYN	<input type="text"/> <input type="text"/> # VISITS
[ASK EVERYONE:] n. Urgent care clinic doctors	<input type="text"/> <input type="text"/> # VISITS
o. Other doctor or health care provider SPECIFY: _____ _____ _____	<input type="text"/> <input type="text"/> TOTAL # OTHER VISITS

[FOR ALL WOMEN:]

A15. Have you ever had a mammogram?

YES .....1  
NO ..... [A17] .....2  
DON'T KNOW..... [A17] .....8

[IF YES:]

A16. How old were you when you last had a mammogram?

AGE

[ASK EVERYONE:]

A17. For this question on x-rays, please do not include dental x-rays. In the past 12 months, that is since [CURRENT MONTH] of 2000, how many times have you had x-rays taken? (Not including time you spent in the hospital.)  
[FOR WOMEN:] Do not count mammograms.

# XRAYs  
[DK=98]

A18. In the past 12 months, that is since [CURRENT MONTH] of 2000, how many times have you had blood samples taken for tests (not including time spent in the hospital)?

# BLOOD TESTS  
[DK=98]

A19. During the past 30 days, how many different prescription medicines have you taken?

# MEDS  
[DK=98]

A20. Have you ever been told by a doctor that you had high blood pressure?

YES .....1  
NO ..... [A25] .....2  
DK ..... [A25] .....8

A21. How old were you when you were first told you had high blood pressure?

AGE

A22. Have you ever taken any prescription medication for high blood pressure?

YES .....1  
NO ..... [A25] .....2  
DK ..... [A25] .....8

[IF YES:]

A23. How old were you when you started taking high blood pressure medicine?

AGE

A24. Are you currently taking medication for high blood pressure?

YES .....1  
NO .....2  
DK .....8

				[IF YES:]			
A25. Have you <u>ever</u> been told by a doctor that you had...				A26. How old were you when you were <u>first</u> told? AGE	A27. Are you <u>currently</u> taking any prescription medication for this?		
	Y	N	DK		Y	N	DK
a. high cholesterol?	1	2	8	<input type="text"/> <input type="text"/> <input type="text"/>	1	2	8
b. arteriosclerosis or hardening of the arteries?	1	2	8	<input type="text"/> <input type="text"/> <input type="text"/>			
c. a heart attack?	1	2	8	<input type="text"/> <input type="text"/> <input type="text"/>			

				[IF YES:]	
A28. Since [REF MO/YR], have you been told by a doctor that you had a...				A29. What month and year was the most recent time?	
	Y	N	DK		
a. pulmonary embolism or blood clot in your lungs?	1	2	8	<input type="text"/> <input type="text"/> <input type="text"/> AND <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	MONTH YEAR
b. other blood clot or DVT (deep vein thrombosis)?	1	2	8	<input type="text"/> <input type="text"/> <input type="text"/> AND <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	MONTH YEAR
c. stroke?	1	2	8	<input type="text"/> <input type="text"/> <input type="text"/> AND <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	MONTH YEAR

## B. Occupation

We would like to ask you some questions about your work, health insurance and income and how these things may have changed since our first interview. Any information you give us will be kept confidential and you may choose not to answer any question you are not comfortable answering. These questions will allow us to compare the experience of lupus patients to the experiences of people without lupus. For the questions about work, please include part-time, seasonal work including farm work or work in a home business.

[ASK EVERYONE:]

B1. Were you working for pay for 10 or more hours per week during [REF YR - 1]?  
 YES .....1  
 NO .....[B3] .....2  
 DK .....[B3] .....8

B2. About how many hours per week were you working in [REF YR - 1]? |\_|\_|\_|  
HOURS PER WEEK

B3. Did you work for pay 10 or more hours per week last year?  
 [B1=YES] YES .....[B4] .....1  
 [B1=NO] YES .....[B10] .....1  
 [B1=YES] NO .....[B14] .....2  
 [B1=NO] NO ..... [SECT C].....2  
 REF ..... [SECT C].....7  
 DK..... [SECT C].....8

**GROUP A:** IF B1=YES AND B3=YES WORKED BEFORE REF YR AND WORKED LAST YEAR ..... [B4]

**GROUP B:** IF B1=NO AND B3=YES DID NOT WORK BEFORE REF YR BUT WORKED LAST YEAR ..... [B10]

**GROUP C:** IF B1=YES AND B3=NO WORKED BEFORE REF YR BUT DID NOT WORK LAST YEAR ..... [B14]

**GROUP D:** IF B1=NO AND B3=NO DID NOT WORK BEFORE REF YR DID NOT WORK LAST YEAR .....[SECTION C]

**GROUP A: WORKED BEFORE REF YEAR AND WORKED LAST YEAR**

B4. Was this the same job you had in [REF YR - 1]? YES .....1  
 NO .....2  
 DK ..... [SECT C].....8

B5. How many months were you employed last year, including any time you may have been out sick? |\_|\_|  
MONTHS

B6. About how many hours per week did you work last year? |\_|\_|\_|  
HOURS PER WEEK

B7. Since [REF YR – 1], have you been unable to work for more than 2 months at one time because of your health? YES .....1  
 NO .....2  
 DK .....8

B8. Last year, in 2000, did you miss any time from work because of your health? YES .....1  
 NO ..... [SECT C].....2  
 DK ..... [SECT C].....8

[IF YES:]

B9. How many days, weeks, or months did you miss last year? |\_|\_|  
# OF

DAYS ..... [SECT C] .....1  
 WEEKS ..... [SECT C] .....2  
 MONTHS ..... [SECT C] .....3

**GROUP B: DID NOT WORK BEFORE REF YEAR BUT WORKED LAST YEAR**

B10. How many months were you employed last year, including any time you may have been out sick?

MONTHS

B11. About how many hours per week did you work last year?

HOURS PER WEEK

B12. Last year, in 2000, did you miss any time from work because of your health?

- YES ..... 1
- NO ..... [SECT C] ..... 2
- DK ..... [SECT C] ..... 8

[IF YES:]

B13. How many days, weeks, or months of work did you miss?

# OF

- DAYS ..... [SECT C] ..... 1
- WEEKS ..... [SECT C] ..... 2
- MONTHS ..... [SECT C] ..... 3

**GROUP C: WORKED BEFORE REF YEAR BUT DID NOT WORK LAST YEAR**

B14. What month and year did you stop working?

MONTH  
 [DK=98]

AND

YEAR  
 [DK=9998]

<p style="text-align: center;">B15.</p> <p>I am going to read some reasons why people stop working. Please tell me if any are true for you. Did you stop working because...</p>	<p style="text-align: center;">Y    N    DK</p>	
a. you did not like your job, supervisor or coworkers?	1    2    8	
b. your job ended or you were laid off?	1    2    8	
c. you no longer needed to work?	1    2    8	
d. you retired for reasons other than your health?	1    2    8	[IF YES TO B15e, ASK B16:]
e. of your health?	1    2    8	<p style="text-align: center;">B16.</p> <p>In your last job, did you have a flexible daily schedule, such as what time you came to work and being able to take breaks when you were not feeling well?</p> <p style="text-align: center;"> <u>Y</u>            <u>N</u>            <u>DK</u>            1            2            8         </p>

**GROUP D: DID NOT WORK BEFORE REF YEAR AND DID NOT WORK LAST YEAR.**

[GO TO SECTION C.]



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### C. Work/Health Disability

C1. Have you ever applied for disability benefits from a government program or from an employer?

YES .....[C2] ..... 1  
NO..... [SECT D].....2  
DK..... [SECT D].....8

		[IF YES:]		[IF REJECTED:]
C2. Have you applied for...		C3. How old were you when you first applied?	C4. Was your application initially accepted, rejected, or is it still pending?	C5. Did you appeal this decision?
a. Social Security Disability Insurance, SSDI or SSI? This <u>does not</u> include regular Social Security retirement.	YES ...[C3] .....1 NO .....[C2b] ...2 DK.....[C2b] ...8	<input type="text"/> <input type="text"/> AGE [GO TO C4]	ACCEPTED.. [C8] .....1 REJECTED... [C5] .....2 PENDING..... [C9] .....3 DK..... [C6] .....8	YES .....[C6] .....1 NO .....[C7] .....2 DK.....[C9] .....8
b. Disability benefits through a job, employer, or union?	YES ...[C3] .....1 NO .....[C2c] ...2 DK.....[C2c] ...8	<input type="text"/> <input type="text"/> AGE [GO TO C4]	ACCEPTED.. [C8] .....1 REJECTED... [C5] .....2 PENDING..... [C9] .....3 DK..... [C6] .....8	YES .....[C6] .....1 NO .....[C7] .....2 DK.....[C9] .....8
c. Any other disability program? SPECIFY:  <input type="text"/>	YES ...[C3] .....1 NO .....[D] .....2 DK.....[D] .....8	<input type="text"/> <input type="text"/> AGE [GO TO C4]	ACCEPTED.. [C8] .....1 REJECTED... [C5] .....2 PENDING..... [C9] .....3 DK..... [C6] .....8	YES .....[C6] .....1 NO .....[C7] .....2 DK.....[C9] .....8

[IF DK STATUS OR IF APPEAL:]	[IF NO APPEAL OR REJECTED AFTER APPEAL:]	[IF ACCEPTED:]	[ALL WHO APPLIED:]
<p>C6. Was your application eventually accepted, rejected, or is it still pending?</p>	<p>C7. How many months or years did it take from the time you first applied to the time you got the final decision?</p>	<p>C8. How many months or years did it take from the time you first applied to the time you started getting benefits?</p>	<p>C9. Did you receive advice or help with the application process from...</p> <p style="text-align: right;">Y N DK</p>
<p>ACCEPTED ....[C8]... 1 REJECTED ....[C7]... 2 PENDING .....[C9]... 3 DK .....[C9]... 8</p>	<p style="text-align: center;"> _ _  #OF</p> <p>MONTHS ..... 1 YEARS ..... 2</p> <p style="text-align: center;">[GO TO C9.]</p>	<p style="text-align: center;"> _ _  #OF</p> <p>MONTHS ..... 1 YEARS ..... 2</p>	<p>a. the social security benefits office? ..... 1 2 8</p> <p>b. co-worker or human resources counselor at your job, employer or union? ..... 1 2 8</p> <p>c. a counselor or social worker? ..... 1 2 8</p> <p>d. your doctor or doctor's office? ..... 1 2 8</p> <p>e. your spouse or other relative? ..... 1 2 8</p> <p>f. friends? ..... 1 2 8</p> <p>g. a lawyer? ..... 1 2 8</p> <p>h. anyone else? ..... 1 2 8</p>
<p>ACCEPTED ....[C8]... 1 REJECTED ....[C7]... 2 PENDING .....[C9]... 3 DK .....[C9]... 8</p>	<p style="text-align: center;"> _ _  #OF</p> <p>MONTHS ..... 1 YEARS ..... 2</p> <p style="text-align: center;">[GO TO C9.]</p>	<p style="text-align: center;"> _ _  #OF</p> <p>MONTHS ..... 1 YEARS ..... 2</p>	<p>a. insurance company benefits office? ..... 1 2 8</p> <p>b. co-worker or human resources counselor at your job, employer or union? ..... 1 2 8</p> <p>c. a counselor or social worker? ..... 1 2 8</p> <p>d. your doctor or doctor's office? ..... 1 2 8</p> <p>e. your spouse or other relative? ..... 1 2 8</p> <p>f. friends? ..... 1 2 8</p> <p>g. a lawyer? ..... 1 2 8</p> <p>h. anyone else? ..... 1 2 8</p>
<p>ACCEPTED ....[C8]... 1 REJECTED ....[C7]... 2 PENDING .....[C9]... 3 DK .....[C9]... 8</p>	<p style="text-align: center;"> _ _  #OF</p> <p>MONTHS ..... 1 YEARS ..... 2</p> <p style="text-align: center;">[GO TO C9.]</p>	<p style="text-align: center;"> _ _  #OF</p> <p>MONTHS ..... 1 YEARS ..... 2</p>	<p>a. insurance company benefits office? ..... 1 2 8</p> <p>b. co-worker or human resources counselor at your job, employer or union? ..... 1 2 8</p> <p>c. a counselor or social worker? ..... 1 2 8</p> <p>d. your doctor or doctor's office? ..... 1 2 8</p> <p>e. your spouse or other relative? ..... 1 2 8</p> <p>f. friends? ..... 1 2 8</p> <p>g. a lawyer? ..... 1 2 8</p> <p>h. anyone else? ..... 1 2 8</p>

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**D. Insurance/Income**

D1. Since [REF MO/YR], have you ever been without health insurance for a month or longer? YES .....1  
 NO .....2  
 DK .....8

D2. Do you have health insurance now, including Medicare or Medicaid, or coverage by someone else in your family? YES .....1  
 NO .....[D4] .....2  
 DK .....[D4] .....8

[IF YES:]

D3. Which of the following types of health insurance do you have now? [READ CATEGORIES.]

	<u>Y</u>	<u>N</u>	<u>DK</u>
a. insurance through your job, including HMO and PPO plans? .....	1	2	8
b. insurance through your spouse's job, including HMO and PPO plans? .....	1	2	8
c. Medicare or Medicaid?.....	1	2	8
d. military or veteran's benefits?.....	1	2	8
e. another health insurance plan for which you pay full premiums, including COBRA and supplemental programs for Medicare?.....	1	2	8
f. any other health insurance plan? .....	1	2	8

SPECIFY: \_\_\_\_\_

D4.

The next questions will allow us to determine how lupus can affect people’s income, standard of living and quality of life. We are not interested in finding out exactly how much you earn.

Including Social Security checks and dividends for everyone who contributed to the household income last year, was your total household income per year...

[READ CATEGORIES UNTIL “NO” RESPONSE.]

a. more than \$5,000?	YES ..... [D4-b] .....1 NO ..... [D5] .....2 RF ..... [SECT E] .....7 DK ..... [SECT E] .....8
b. more than \$10,000?	YES ..... [D4-c] .....1 NO ..... [D5] .....2 RF ..... [SECT E] .....7 DK ..... [SECT E] .....8
c. more than \$15,000?	YES ..... [D4-d] .....1 NO ..... [D5] .....2 RF ..... [SECT E] .....7 DK ..... [SECT E] .....8
d. more than \$20,000?	YES ..... [D4-e] .....1 NO ..... [D5] .....2 RF ..... [SECT E] .....7 DK ..... [SECT E] .....8
e. more than \$30,000?	YES ..... [D4-f] .....1 NO ..... [D5] .....2 RF ..... [SECT E] .....7 DK ..... [SECT E] .....8
f. more than \$40,000?	YES ..... [D4g] .....1 NO ..... [D5] .....2 RF ..... [SECT E] .....7 DK ..... [SECT E] .....8
g. more than \$50,000?	YES ..... [D4-h] .....1 NO ..... [D5] .....2 RF ..... [SECT E] .....7 DK ..... [SECT E] .....8
h. more than \$75,000?	YES ..... [D4-i] .....1 NO ..... [D5] .....2 RF ..... [SECT E] .....7 DK ..... [SECT E] .....8
i. more than \$100,000?	YES ..... [D4-j] .....1 NO ..... [D5] .....2 RF ..... [SECT E] .....7 DK ..... [SECT E] .....8
j. more than \$150,000?	YES ..... [D5] .....1 NO ..... [D5] .....2 RF ..... [SECT E] .....7 DK ..... [SECT E] .....8

[OR]

[IF SUBJECT ANSWERS WITH INCOME AMOUNT, RECORD HERE AND GO TO D5] \$ \_\_\_\_\_

D5. How many household members, including yourself, depended on this income last year?

# MEMBERS

D6. How many were under age 18?

# MEMBERS  
UNDER 18



## E. Stress/Racism

The next questions concern stresses in your everyday life, including race-related issues. You may refuse to answer any questions.

- |   |  |
|---|--|
| <p>E1. Many people feel stressed in their day-to-day lives.<br/>How stressful is your day-to-day life? Is it...</p> | <p>Not at all stressful..... [E3] .....1<br/>Mildly stressful.....2<br/>Moderately stressful, or .....3<br/>Very stressful.....4</p>                                     |
| <p>E2. How do you deal with stress in your day-to-day life?<br/>Do you...</p>                                       | <p>View stress as a challenge and<br/>deal well with it .....1<br/>Not like the stress, but manage, or .....2<br/>Feel anxious, overwhelmed, or<br/>exhausted .....3</p> |
| <p>E3. How often do you feel the need to squelch or<br/>swallow strong feelings of anger? Would you say...</p>      | <p>Daily .....1<br/>Weekly, or .....2<br/>Less often or never .....3</p>   |

					[IF YES:]					
E4.					E5.	E6.				
Have you ever been treated unfairly due to your race in any of the following circumstances?					About how many times has this happened?	Has it happened in the past 5 years?				
					#TIMES					
						Y	N	RF	DK	
a.	Job hiring, promotion, or firing	1	2	7	8	□ □ □	1	2	7	8
b.	Home renting, buying, or mortgage	1	2	7	8	□ □ □	1	2	7	8
c.	Being stopped, searched, or threatened by police	1	2	7	8	□ □ □	1	2	7	8

**[IF RACE IS WHITE, ASIAN, NATIVE AMERICAN, OR OTHER, SKIP TO SECTION F.]**

[ASK E7-E8 ONLY IF RACE IS AFRICAN-AMERICAN:]

E7. How often do you think about your race? Would you say... never? .....01  
rarely, such as once a year? .....02  
several times a month? .....03  
once a day? .....04  
several times a day?.....05  
nearly constantly?.....06  
REFUSED .....97

For the next set of questions, we will use a scale. You don't need to wait for me to read the categories every time before you respond unless you need a reminder.

E8. In your day-to-day life, how often have any of the following things happened to you because of your race? Would you say... [READ CATEGORIES.]	Never	A few times a year	Once a month	Once a week	Almost every day	REFUSED
a. You receive poorer service than other people at restaurants or stores?	1	2	3	4	5	7
b. People act as if they think you are not intelligent?	1	2	3	4	5	7
c. People act as if they are afraid of you?	1	2	3	4	5	7
d. People act as if they think you are dishonest?	1	2	3	4	5	7
e. People act as if they are better than you?	1	2	3	4	5	7

**F. Reproductive History**

**[FOR MEN, SKIP TO SECTION G.]**

**[FOR WOMEN AGE 50 AND OLDER, SKIP TO SECTION G.]**

Now I'd like to update any pregnancies since you were first interviewed.

**[FOR WOMEN AGE 49 AND YOUNGER AND NOT PREGNANT OR DON'T KNOW IF PREGNANT AT TIME OF LAST INTERVIEW, SKIP TO F4.]**

[IF PREGNANT AT TIME OF LAST INTERVIEW:]

F1. Our records indicate that you were pregnant when we talked with you in [INT MO/INT YR]. Is that correct? YES ..... 1  
NO.....[F4].....2

[IF YES:]

F2. What was the outcome of the pregnancy? Was it a live birth, miscarriage, stillbirth, abortion, or something else? LIVE BIRTH ..... [F4] ..... 1  
MISCARRIAGE ..... 2  
STILLBIRTH..... [F4] ..... 3  
ABORTION ..... [F4] ..... 4  
SOMETHING ELSE .. [F4] ..... 5

[IF MISCARRIAGE:]

F3. How many weeks or months were you pregnant? | |  
#OF  
WEEKS ..... 1  
MONTHS ..... 2

[FOR AGE 49 OR YOUNGER:]

F4. Are you currently pregnant? YES ..... 1  
NO..... 2  
REFUSED.....[SECT G] ..... 7  
DON'T KNOW .....[SECT G] ..... 8

F5. Have you been pregnant any other time since [INT MO/INT YR] when you were [AGE AT INT MO/INT YR]? YES ..... 1  
NO.....[SECT G] ..... 2  
REFUSED.....[SECT G] ..... 7  
DON'T KNOW .....[SECT G] ..... 8

[IF YES:]

F6. How many times have you been pregnant since [INT MO/INT YR]?

--	--

# PREGS

[IF MULTIPLE BIRTH AND AT LEAST 1 LIVED, CODE 'LIVE BIRTH.' IF MULTIPLE BIRTH OUTCOME IS STILLBIRTH AND MISCARRIAGE, CODE 'STILLBIRTH.']

[SOMETHING ELSE = ECTOPIC, MOLAR, TUBAL PREGNANCY ONLY.]

#SUB 

--	--

		[IF MISCARRIAGE:]				
F7. Please tell me about the (first/next) pregnancy since [INT MO/YR]. How old were you when the pregnancy ended?	F8. Did this pregnancy end in a live birth, miscarriage, stillbirth, abortion, or something else?	F9. How many weeks or months were you pregnant?				
01. <table border="1" style="margin: 0 auto;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table> AGE			LIVE BIRTH.....[NEXT PREG] .... 1 MISCARRIAGE ..... [F9]..... 2 STILLBIRTH.....[NEXT PREG] .... 3 ABORTION .....[NEXT PREG] .... 4 SOMETHING ELSE...[NEXT PREG] .... 5	<table border="1" style="margin: 0 auto;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table> # OF WEEKS ..... 1 MONTHS ..... 2		
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04. <table border="1" style="margin: 0 auto;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table> AGE			LIVE BIRTH.....[NEXT PREG] .... 1 MISCARRIAGE ..... [F9]..... 2 STILLBIRTH.....[NEXT PREG] .... 3 ABORTION .....[NEXT PREG] .... 4 SOMETHING ELSE...[NEXT PREG] .... 5	<table border="1" style="margin: 0 auto;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table> # OF WEEKS ..... 1 MONTHS ..... 2		
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## G. SF-8 Quality of Life

Now we have a few more general questions about your health.

- |  |  |
|--|--|
| <p>G1. Overall, how would you rate your health during the <i>past 4 weeks</i>?<br/>[READ CATEGORIES]</p>   | <p>Excellent..... 01<br/>Very good..... 02<br/>Good..... 03<br/>Fair ..... 04<br/>Poor..... 05<br/>Very poor ..... 06</p>                |
| <p>G2. During the <i>past 4 weeks</i>, how much did physical health problems limit your usual physical activities such as walking or climbing stairs? [READ CATEGORIES]</p>            | <p>Not at all..... 1<br/>Very little ..... 2<br/>Somewhat..... 3<br/>Quite a lot..... 4<br/>Could not do physical activities ..... 5</p> |
| <p>G3. During the <i>past 4 weeks</i>, how much difficulty did you have doing your daily work, both at home and away from home, because of your physical health? [READ CATEGORIES]</p> | <p>None at all ..... 1<br/>A little bit ..... 2<br/>Some ..... 3<br/>Quite a lot..... 4<br/>Could not do daily work..... 5</p>           |
| <p>G4. How much <i>bodily</i> pain have you had during the <i>past 4 weeks</i>? [READ CATEGORIES]</p>  | <p>None..... 01<br/>Very mild ..... 02<br/>Mild..... 03<br/>Moderate ..... 04<br/>Severe..... 05<br/>Very severe ..... 06</p>            |
| <p>G5. During the <i>past 4 weeks</i>, how much energy did you have? [READ CATEGORIES]</p>   | <p>Very much..... 1<br/>Quite a lot..... 2<br/>Some ..... 3<br/>A little ..... 4<br/>None..... 5</p>                                     |
| <p>G6. During the <i>past 4 weeks</i>, how much did your physical health or emotional problems limit your usual social activities with family or friends? [READ CATEGORIES]</p>        | <p>Not at all..... 1<br/>Very little ..... 2<br/>Somewhat..... 3<br/>Quite a lot..... 4<br/>Could not do social activities ..... 5</p>   |
| <p>G7. During the <i>past 4 weeks</i>, how much have you been bothered by <i>emotional problems</i>, such as feeling anxious, depressed or irritable? [READ CATEGORIES]</p>            | <p>Not at all..... 1<br/>Slightly ..... 2<br/>Moderately ..... 3<br/>Quite a lot..... 4<br/>Extremely ..... 5</p>                        |
| <p>G8. During the <i>past 4 weeks</i>, how much did personal or emotional problems keep you from doing your usual work, school or other daily activities? [READ CATEGORIES]</p>        | <p>Not at all..... 1<br/>Very little ..... 2<br/>Somewhat..... 3<br/>Quite a lot..... 4<br/>Could not do daily activities ..... 5</p>    |

## H. Closing and Future Contact Section

END TIME:   :   AM   
PM

*Thank you. These are all the questions I have for you, but we would also like to be able to contact you two or three years from now to follow up on your health and continue to send you the results of the study. In case we are unable to reach you, could you give us the name, address, and telephone number of two relatives or friends who will know your address? It can be someone out of state, if you prefer. [RECORD "FUTURE CONTACT INFORMATION" ON NEXT PAGE.]*

YES

NO

*As we mentioned in the letter, we will mail you a 60-minute AT&T long distance phone card. Thank you very much for your patience and cooperation.*

**Carolina Lupus Study  
Follow-Up 2001**

**FUTURE CONTACT INFORMATION**

*Confidential: To be separated from questionnaire*

**Contact #1:**

Relationship: \_\_\_\_\_ Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_  
City State Zip Code

Phone number: ( \_\_\_\_\_ ) \_\_\_\_\_

**Contact #2:**

Relationship: \_\_\_\_\_ Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_  
City State Zip Code

Phone number: ( \_\_\_\_\_ ) \_\_\_\_\_



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## I. Interviewer Remarks

I-1. The telephone interview was completed... by subject.....1  
 by proxy.....2  
 Both .....3  
 SPECIFY PROXY'S  
 RELATIONSHIP TO SUBJECT:  
 \_\_\_\_\_

I-2. Respondent's cooperation was: Very good.....1  
 Good.....2  
 Fair.....3  
 Poor .....4  
 Other.....5  
 SPECIFY:  
 \_\_\_\_\_

I-3. The overall quality of responses was: High quality ..... [I-7].....1  
 Generally reliable ..... [I-7].....2  
 Questionable ..... [I-4].....3  
 Unsatisfactory..... [I-4].....4  
 Other ..... [I-4].....5  
 SPECIFY:  
 \_\_\_\_\_

[IF I-3 IS ANSWERED 3, 4, OR 5:]

I-4. The main reason for questionable or unsatisfactory quality of information was because the respondent:

[IF MORE THAN 1 MAIN REASON, SPECIFY OTHER.]

Did not know enough information regarding the topic .....01  
 Did not want to be more specific .....02  
 Sounded bored or uninterested.....03  
 Sounded upset, depressed or angry .....04  
 Had poor hearing or speech.....05  
 Was confused or distracted by frequent interruptions.....06  
 Was inhibited by others around him or her .....07  
 Was embarrassed by the subject matter .....08  
 Was emotionally unstable .....09  
 Was physically ill.....10  
 Other (specify): \_\_\_\_\_

\_\_\_\_\_

I-5. The respondent:	<u>Y</u> <u>N</u> <u>DK</u>
Had trouble with amounts or frequencies .....	1      2      8
Had trouble with dates .....	1      2      8
Had trouble recalling overall.....	1      2      8
Other.....	1      2      8

SPECIFY:

---

I-6. The respondent had trouble with the following sections:	<u>Y</u> <u>N</u> <u>N/A</u> <u>DK</u>
A. Medical History Update.....	1      2                      8
B. Occupation.....	1      2                      8
C. Work/Health Disability.....	1      2                      8
D. Insurance/Income.....	1      2                      8
E. Stress/Racism .....	1      2                      8
F. Reproductive History.....	1      2      6              8
G. SF-8 Quality of Life .....	1      2                      8

I-7. Use this space for any other comments you have which may affect the interpretation of this respondent's answers.

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IF MORE THAN ONE SESSION:

DATE	TIME BEGAN	TIME ENDED	TOTAL TIME
_____	_____ AM _____ PM	_____ AM _____ PM	_____
_____	_____ AM _____ PM	_____ AM _____ PM	_____
_____	_____ AM _____ PM	_____ AM _____ PM	_____