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INTERVIEWER INITIALS: _____

ID#:

INTERVIEW LENGTH:

(minutes)

SESSIONS:

OUTCOME:

INTERVIEW DATE:

(month)

(day)

(year)

Carolina Lupus Study Questionnaire Follow-Up 2001-CASES

Thank you for agreeing to take part in this follow-up study. Our questions will cover your recent health, jobs and personal habits. (FOR WOMAN) We will also update the questions about women's health.

The questions will ask you about events from around the time you were diagnosed with lupus up until now.

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. Also, if you are currently taking any prescription or other medications, would you get them now? [HOLD]

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 does. 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 assure that I am conducting the interview according to instructions.

First I'd like to check the information we already have. You were born (READ BIRTH DATE 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 CALL RECORD.]

Do you have any questions before we begin?

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A. Medical History Update

START TIME: : ^{AM}
PM

A1. We will begin by updating your medical history.
 You were diagnosed with lupus in [DIAGNOSIS
 MONTH] of [DIAGNOSIS YEAR].

YES1
 NO2
 DON'T KNOW8

Were you hospitalized at that time?

A2. Since your diagnosis in [DIAG MO/YR]
 have you been a patient in a hospital overnight?

YES1
 NO [A8].....2
 DON'T KNOW [A8].....8

[IF YES:]

A3. Since [DIAG MO/YR] how many different
 times were you a patient in a hospital overnight?
 (Do not count hospitalization at diagnosis.)

TIMES

A4. In the past 12 months; that is, since
 [CURRENT MONTH] of 2000, how many
 different times were you a patient in a hospital
 overnight?

TIMES
 [IF 00, SKIP TO A8.]

<p>A5. What was the most recent month and year you were hospitalized since [CURRENT MONTH] of 2000?</p>	<p>A6. How many nights or weeks did you stay?</p>	<p>A7. 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>OR</p> <p>01. SEASON <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> # OF</p> <p>NIGHTS1 WEEKS2</p> <p>AND</p> <p>CIRCLE YEAR</p> <p>2000 <input type="text"/> <input type="text"/> <input type="text"/></p> <p>2001 <input type="text"/> <input type="text"/> <input type="text"/></p>	<p><input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> # OF</p> <p>NIGHTS1 WEEKS2</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>WOMEN ONLY:</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>

A5. And the time before that, what month and year were you hospitalized?	A6. How many nights or weeks did you stay?	A7. 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"/> <input type="text"/> MONTH</p> <p>OR</p> <p>02. SEASON <input type="text"/> <input type="text"/> <input type="text"/> # OF</p> <p>NIGHTS1 WEEKS2</p> <p>AND</p> <p>CIRCLE YEAR</p> <p>2000 <input type="checkbox"/></p> <p>2001 <input type="checkbox"/></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>WOMEN ONLY:</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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[REPEAT UP TO 5 HOSPITALIZATIONS.]

A8. 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?

YES1
NO [A10]2
DK [A10]8

[IF YES]

A9. 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

A10. During the past 12 months, have you used paid in-home help, nursing or personal care assistance for yourself?

YES1
NO [A12]2
DK [A12]8

[IF YES]

A11. How many days, weeks or months did you use assistance in the past 12 months?

OF
[DK=998]

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

A12. 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.)

YES1
NO [A14]2
DK [A14]8

[IF YES:]

A13. How many times have you been to an emergency room in the past 12 months?

TIMES
[DK = 98]

A14. During the past 12 months, have you had outpatient surgery or medical procedures when you did not stay overnight?

YES1
NO [A16]2
DK [A16]8

[IF YES:]

A15. How many times have you had outpatient surgery or medical procedures in the past 12 months?

TIMES
[DK = 98]

A16.
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:]

A17. Have you ever had a mammogram?

YES1

NO..... [A19]2

DON'T KNOW..... [A19]8

[IF YES:]

A18. How old were you when you last had a mammogram?

AGE

[ASK EVERYONE:]

A19. 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]

A20. 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 you spent in the hospital)?

BLOOD TESTS
[DK=98]

A21. During the past 30 days, how many different prescription medicines have you taken?

MEDS
[DK = 98]
[IF NONE, SKIP TO A25]

A22. We would like to list all of the prescription medicines you are currently taking for any reason. Do you have all of your prescription bottles handy?

YES 1
 NO [A24] 2
 REF BOTTLES BUT KNOWS
 MED NAMES [A23] 7

[IF YES:]
 Please read the name on each label. [GO TO A23.]

[IF NO:]
 I will read you a list of drugs that are commonly taken for lupus. [GO TO A24.]

[REPEAT SPELLING. CLARIFY LETTERS THAT MAY BE UNCLEAR.]

#SUB

A23.	
What is the name on the (first/next) bottle (medication)?	
NAME OF MEDICATION	
01.	<input type="text"/>
02.	<input type="text"/>
03.	<input type="text"/>
04.	<input type="text"/>
05.	<input type="text"/>
06.	<input type="text"/>
07.	<input type="text"/>
08.	<input type="text"/>
09.	<input type="text"/>
10.	<input type="text"/>
11.	<input type="text"/>
12.	<input type="text"/>
13.	<input type="text"/>
14.	<input type="text"/>
15.	<input type="text"/>

[GO TO A25.]

[ASK A24 ONLY IF NO PRESCRIPTION BOTTLES HANDY:]

A24.			
Are you currently taking any of the following prescription medicines for lupus? [READ LIST]			
MEDICATION	Y	N	DK
a. Prednisone, which is a steroid drug	1	2	8
b. Plaquenil or hydroxychloroquine	1	2	8
c. Aralen or chloroquine	1	2	8
d. Atabrine or quinacrine	1	2	8
e. Imuran or Azothioprine	1	2	8
f. Methotrexate or Rheumatrex	1	2	8
g. Cellcept	1	2	8
h. Cyclosporin	1	2	8
i. Arava	1	2	8
j. OTHER SPECIFY:	1	2	8
_____			<input type="text"/> <input type="text"/> <input type="text"/>
_____			<input type="text"/> <input type="text"/> <input type="text"/>
_____			<input type="text"/> <input type="text"/> <input type="text"/>

A25. Have you ever had Cytoxan or Cyclophosphamide, a medicine that is often administered intravenously by an IV tube?

YES 1
 NO [A28]..... 2
 DON'T KNOW [A28]..... 8

[IF YES:]

A26. How old were you when you were first given Cytoxan?

AGE

A27. How many times did you have Cytoxan as an IV?

TIMES IV
 [DK = 98]

A28. Have you ever been told by a doctor that you had high blood pressure?

YES 1
 NO [A32] 2
 DON'T KNOW [A32] 8

A29. How old were you when you were first told you had high blood pressure?

AGE

A30. Have you ever taken prescription medication for high blood pressure?

YES 1
 NO [A32] 2
 DON'T KNOW [A32] 8

[IF YES:]

A31. How old were you when you started taking high blood pressure medicine?

AGE

A32. Have you <u>ever</u> been told by a doctor that you had...	[IF YES:]			A33. How old were you when you were <u>first</u> told? AGE	A34. Are you <u>currently</u> taking any prescription medication for this?
	Y	N	DK		
a. diabetes?	1	2	8	<input type="text"/> <input type="text"/>	1 2 8
b. high cholesterol?	1	2	8	<input type="text"/> <input type="text"/>	1 2 8
c. arteriosclerosis or hardening of the arteries?	1	2	8	<input type="text"/> <input type="text"/>	

				[IF YES:]
A35.				A36.
Since your diagnosis in [DIAG MO/YR], has a physician told you that you had a...	Y	N	DK	What month and year was the most recent time?
a. pulmonary embolism or blood clot in your lungs?	1	2	8	MONTH: <input type="text"/> <input type="text"/> AND YEAR: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
b. any other blood clot or DVT? (deep vein thrombosis)	1	2	8	MONTH: <input type="text"/> <input type="text"/> AND YEAR: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
c. stroke?	1	2	8	MONTH: <input type="text"/> <input type="text"/> AND YEAR: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
d. heart attack?	1	2	8	MONTH: <input type="text"/> <input type="text"/> AND YEAR: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>

A37. Since [DIAG MO/YR], have you had any seizures?

YES 1
 NO [A39] 2
 DK [A39] 8

A38. What was the month and year of the most recent seizure?

 MONTH YEAR

A39. What is your current height?

 FT IN
 [DK=98]

A47. To the best of your knowledge, has your mother, father, sisters, brothers or children ever had kidney disease, dialysis, high blood pressure or diabetes?

YES1
 NO [A49].....2
 DK..... [A49].....8

[IF YES:]

A48. Which relatives, if any, had:

[CIRCLE "1" IF YES.]	NONE	MOTHER	FATHER	SISTER	BROTHER	CHILD
a. Kidney Disease	0	1	1	1	1	1
b. Dialysis	0	1	1	1	1	1
c. High Blood Pressure	0	1	1	1	1	1
d. Diabetes	0	1	1	1	1	1

				[IF YES:]
A49. Have you taken any of the following over-the-counter drugs in the last 12 months?				A50. How many days total in the last 12 months did you take it?
	Y	N	DK	
a. aspirin, Anacin, Bufferin, Bayer, Excedrin or Ecotrin	1	2	8	<input type="text"/> <input type="text"/> <input type="text"/> # DAYS
b. acetaminophen or Tylenol	1	2	8	<input type="text"/> <input type="text"/> <input type="text"/> # DAYS
c. ibuprofen, Motrin, Advil, Nuprin or Medipren	1	2	8	<input type="text"/> <input type="text"/> <input type="text"/> # DAYS
d. naproxen or Aleve	1	2	8	<input type="text"/> <input type="text"/> <input type="text"/> # DAYS
e. ketoprofen, Orudis or Actron	1	2	8	<input type="text"/> <input type="text"/> <input type="text"/> # DAYS
f. Goody's powder or BC powder	1	2	8	<input type="text"/> <input type="text"/> <input type="text"/> # DAYS

[USE SPACE BELOW TO CALCULATE TOTAL DAYS, IF NEEDED.]

	[IF YES:]			[IF YES TO A52:]			[IF YES TO A53:]			[IF YES TO A54:]					
A51. Now I will read a list of herbal, natural, or “alternative” therapies you may have used for lupus or for any other reason. In the past 12 months, have you used any of the following for a total of 14 or more days?	A52. Did you use it for 45 days or more during the past 12 months?			A53. How helpful was it? [READ CATEGORIES.]			A54. Did you also take your prescription medicines when you were using [ALTERNATIVE THERAPY]								
Y N DK	Y N DK	Y N DK	Y N DK	Y N DK	Y N DK	Y N DK	Y N DK	Y N DK	Y N DK	Y N DK	Y N DK				
a. DHEA (dehydro- epiandrosterone)?	1	2	8	1	2	8	not helpful1 somewhat helpful2 very helpful3	1	2	8	1	2	8		
b. echinacea?	1	2	8	1	2	8	not helpful1 somewhat helpful2 very helpful3	1	2	8	1	2	8		
c. fish oil or omega- 3 fatty acids?	1	2	8	1	2	8	not helpful1 somewhat helpful2 very helpful3	1	2	8	1	2	8		
d. ginkgo biloba?	1	2	8	1	2	8	not helpful1 somewhat helpful2 very helpful3	1	2	8	1	2	8		
e. ginseng?	1	2	8	1	2	8	not helpful1 somewhat helpful2 very helpful3	1	2	8	1	2	8		
f. melatonin?	1	2	8	1	2	8	not helpful1 somewhat helpful2 very helpful3	1	2	8	1	2	8		
g. St. John’s Wort?	1	2	8	1	2	8	not helpful1 somewhat helpful2 very helpful3	1	2	8	1	2	8		
h. multivitamins?	1	2	8	1	2	8									
i. Vitamin E supplements?	1	2	8	1	2	8									
j. other supplements?	1	2	8				not helpful1 somewhat helpful2 very helpful3				1	2	8		
SPECIFY:															
1. _____	1.	1	2	8	1.	1	2	8	not helpful1 somewhat helpful2 very helpful3	1	2	8	1	2	8
2. _____	2.	1	2	8	2.	1	2	8	not helpful1 somewhat helpful2 very helpful3	1	2	8	1	2	8

A55. In the past year, have you used prayer or meditation on 14 days or more for health or other reasons?	YES 1 NO..... [SECT B] 2 REF [SECT B] 7 DK..... [SECT B] 8
---	---

[IF YES:]

A56. Did you generally pray or meditate... [READ CATEGORIES.]	every day? 1 once a week? 2 once a month or less? 3
--	---

A57. How helpful was it? Was it...	Not helpful? 1 Somewhat helpful?..... 2 Very helpful? 3 DK..... 8
------------------------------------	--

[IF A56 IS "EVERY DAY," ASK:]

A58. Did you also take your prescription medicine when you were using prayer or meditation?	YES 1 NO..... 2 REF 7
---	---

B. Depression (CES-D Scale)

Next, I will read a list of the ways you might have felt or behaved. Please tell me if you have felt this way for at least 3 of the past 7 days.

	YES	NO
B1. I felt depressed.	1	2
B2. I felt that everything I did was an effort.	1	2
B3. My sleep was restless for at least 3 of the past 7 days.	1	2
B4. I was happy.	1	2
B5. I felt lonely.	1	2
B6. People were unfriendly for at least 3 of the past 7 days.	1	2
B7. I enjoyed life.	1	2
B8. I felt sad for at least 3 of the past 7 days.	1	2
B9. I felt that people dislike me.	1	2
B10. I could not get "going" for at least 3 of the past 7 days.	1	2

C. Occupation

C1. In the next few sections, we would like to ask you some questions about your schooling, work, health insurance, income, and how these may have changed since you were diagnosed with lupus. Any information you give us will be kept confidential and you may choose not to answer any question you are not comfortable answering.

Around the time you were diagnosed with lupus, were you in school?	YES..... 1
	NO [C3] 2
	DON'T KNOW [C3] 8

[IF YES:]

C2. What type of school?	HIGH SCHOOL 1
	VOCATIONAL/ JUNIOR COLLEGE 2
	4-YEAR COLLEGE 3
	GRADUATE SCHOOL 4
	OTHER 5
	SPECIFY:

C3. Have you completed any additional schooling (high school, vocational, or college) since that time?	YES..... 1
	NO [C5] 2

[IF YES:]

C4. What is the highest level you completed?	HIGH SCHOOL/GED 1
	VOCATIONAL/ JUNIOR COLLEGE 2
	4-YEAR COLLEGE 3
	GRADUATE SCHOOL 4
	OTHER 5
	SPECIFY:

For the questions about work, please include part-time, seasonal work including farm work, or work in a home business.

C5. Were you working for pay for 10 or more hours per week during [DIAG YR - 1]?
 YES..... 1
 NO [C10] 2
 DON'T KNOW [C10] 8

[IF YES:]

C6. What was your job title?

 JOB TITLE

C7. What were your main activities or duties as a [JOB TITLE]?

 OCCUPATION

C8. About how many hours per week did you work in [DIAG YR - 1]? | | |
#HOURS

C9. Thinking back to the job you had in [DIAG YR-1], how much time per day did you spend doing the following activities at work? [READ CATEGORIES]	None/Less than 2 hours	2 - 6 hours	More than 6 hours
a. Sitting	1	2	3
b. Standing/walking	1	2	3
c. Lifting 25 pounds or more	1	2	3

C10. Did you work for pay for 10 or more hours per week last year?
 [C5 = YES] YES[C11] 1
 [C5=NO] YES[C29] 1
 [C5=YES] NO[C37] 2
 [C5=NO] NO[SECT D] 2
 REF[SECT D] 7
 DK[SECT D] 8

GROUP A: IF C5=YES AND C10=YES WORKED BEFORE DIAGNOSED AND WORKED LAST YEAR..... [C11]

GROUP B: IF C5=NO AND C10=YES **DID NOT** WORK BEFORE DIAGNOSED AND WORKED LAST YEAR [C29]

GROUP C: IF C5=YES AND C10=NO WORKED BEFORE DIAGNOSED AND **DID NOT** WORK LAST YEAR [C37]

GROUP D: IF C5=NO AND C10=NO **DID NOT** WORK BEFORE DIAGNOSED AND **DID NOT** WORK LAST YEAR [SECTION D]

GROUP A: WORKED BEFORE DIAGNOSED AND WORKED LAST YEAR

C11. Was this the same job you had in [DIAG YR - 1]? YES..... 1
 NO [C19] 2
 DON'T KNOW [SECT D] 8

[IF YES TO C11:]

C12. How many months were you employed last year, including any time you may have been out sick? #MONTHS

C13. About how many hours per week did you work last year? #HOURS

C14. Compared to your work in [DIAG YR - 1], were the physical demands of your work last year lighter, heavier, or about the same? LIGHTER 1
 HEAVIER..... 2
 ABOUT THE SAME..... 3
 DON'T KNOW 8

C15. 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? YES..... 1
 NO 2
 DON'T KNOW 8

C16. Since [DIAG YR - 1] have you been unable to work for more than 2 months at one time because of your health? YES..... 1
 NO 2
 DON'T KNOW 8

C17. Last year, in 2000, did you miss any time from work because of your health? YES..... 1
 NO [SECT D]..... 2
 DON'T KNOW [SECT D]..... 8

[IF YES:]

C18. How many days, weeks, or months did you miss last year? #OF

DAYS [SECT D] 1
 WEEKS [SECT D] 2
 MONTHS [SECT D] 3

IF DIFFERENT JOB NOW, BUT WORKED BEFORE DIAGNOSED AND WORKED LAST YEAR

C19. What was the job title of the job you had last year? _____
JOB TITLE

C20. What were your main activities or duties as a [JOB TITLE]?

OCCUPATION

C21. Did you change jobs because of your health? YES..... 1
NO 2
DON'T KNOW 8

C22. How many months were you employed at this or any other job last year, including any time you may have been out sick?
#MONTHS

C23. About how many hours per week did you work last year?
#HOURS

C24. 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? YES..... 1
NO 2
DON'T KNOW 8

C25. Compared to the job you had in [DIAG YR – 1], were the physical demands of your work last year lighter, heavier, or about the same? LIGHTER 1
HEAVIER..... 2
ABOUT THE SAME..... 3
DON'T KNOW 8

C26. Since [DIAG YR – 1] have you been unable to work for more than 2 months at one time because of your health? YES..... 1
NO 2
DON'T KNOW 8

C27. Last year, in 2000, did you miss any time from work because of your health? YES..... 1
NO [SECT D]..... 2
DON'T KNOW [SECT D]..... 8

[IF YES:]

C28. How many days, weeks, or months did you miss?
OF

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

GROUP B: DID NOT WORK BEFORE DIAGNOSED BUT WORKED LAST YEAR

C29. What was your job title? _____
JOB TITLE

C30. What were your main activities or duties as a [JOB TITLE]? _____

OCCUPATION

C31. How many months were you employed last year, including any time you may have been out sick? #MONTHS

C32. About how many hours per week did you work last year? #HOURS

C33. 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?
YES..... 1
NO 2
DON'T KNOW 8

C34. Last year, how much time per day did you spend doing the following activities at work? [READ CATEGORIES.]	None/Less than 2 hours	2 - 6 hours	More than 6 hours
a. Sitting	1	2	3
b. Standing/walking	1	2	3
c. Lifting 25 pounds or more	1	2	3

C35. Last year, in 2000, did you miss any time from work because of your health?
YES..... 1
NO [SECT D]..... 2
DON'T KNOW [SECT D]..... 8

[IF YES:]
C36. How many days, weeks, or months did you miss? # OF

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

GROUP C: WORKED BEFORE DIAGNOSIS BUT DID NOT WORK LAST YEAR

C37. What month and year did you stop working?

--	--	--

MONTH
[DK=98]

AND

--	--	--	--	--

YEAR
[DK=9998]

<p>C38. 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>	Y	N	DK							
a. you did not like your job, supervisor or co-workers?	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 C38e, ASK C39:]						
e. of your health?	1	2	8	<p>C39. 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> <table border="0"> <tr> <td><u>Y</u></td> <td><u>N</u></td> <td><u>DK</u></td> </tr> <tr> <td>1</td> <td>2</td> <td>8</td> </tr> </table>	<u>Y</u>	<u>N</u>	<u>DK</u>	1	2	8
<u>Y</u>	<u>N</u>	<u>DK</u>								
1	2	8								

Section D. Disability

D1. Have you ever applied for disability benefits from a government program or from an employer?

YES [D2] 1
NO [SECT E] 2
DK [SECT E] 8

		[IF YES:]	[IF REJECTED:]
D2. Have you applied for...		D3. How old were you when you first applied?	D4. Was your application initially accepted, rejected or is it still pending?
		D5. Did you appeal this decision?	
a. Social Security Disability Insurance, SSDI or SSI? This <u>does not</u> include regular Social Security retirement.	YES...[D3].....1 NO.....[D2b]...2 DK.....[D2b]...8	<input type="text"/> <input type="text"/> AGE [GO TO D4]	ACCEPTED. [D8].... 1 REJECTED.. [D5].... 2 PENDING.... [D9]... 3 DK.....[D6]... 8
b. Disability benefits through a job, employer, or union?	YES...[D3].....1 NO.....[D2c]...2 DK.....[D2c]...8	<input type="text"/> <input type="text"/> AGE [GO TO D4]	ACCEPTED. [D8].... 1 REJECTED.. [D5].... 2 PENDING.... [D9].... 3 DK..... [D6].... 8
c. Any other disability program? SPECIFY: <input type="text"/>	YES...[D3].....1 NO.....[E]2 DK.....[E]8	<input type="text"/> <input type="text"/> AGE [GO TO D4]	ACCEPTED. [D8].... 1 REJECTED.. [D5].... 2 PENDING.... [D9].... 3 DK..... [D6].... 8

[IF DK STATUS OR IF APPEAL:]	[IF NO APPEAL OR REJECTED AFTER APPEAL:]	[IF ACCEPTED:]	[ALL WHO APPLIED:]
<p>D6. Was your application eventually accepted, rejected, or is it still pending?</p>	<p>D7. How many months or years did it take from the time you first applied to the time you got the final decision?</p>	<p>D8. How many months or years did it take from the time you first applied to the time you started getting benefits?</p>	<p>D9. Did you receive advice or help with the application process from...</p> <p style="text-align: right;">Y N DK</p>
<p>ACCEPTED ..[D8]... 1 REJECTED ...[D7]... 2 PENDING[D9]... 3 DK[D9]... 8</p>	<p style="text-align: center;"> <input type="text"/> <input type="text"/> #OF MONTHS1 YEARS2 [GO TO D9.] </p>	<p style="text-align: center;"> <input type="text"/> <input type="text"/> #OF MONTHS1 YEARS2 </p>	<p>a. the social security benefits office?1 2 8 b. co-worker or human resources counselor at your job, employer or union?1 2 8 c. a counselor or social worker?.....1 2 8 d. your doctor or doctor’s office?1 2 8 e. your spouse or other relative?1 2 8 f. friends?.....1 2 8 g. a lawyer?1 2 8 h. anyone else?1 2 8</p>
<p>ACCEPTED ..[D8]... 1 REJECTED ...[D7]... 2 PENDING[D9]... 3 DK[D9]... 8</p>	<p style="text-align: center;"> <input type="text"/> <input type="text"/> #OF MONTHS1 YEARS2 [GO TO D9.] </p>	<p style="text-align: center;"> <input type="text"/> <input type="text"/> #OF MONTHS1 YEARS2 </p>	<p>a. insurance company benefits office?1 2 8 b. co-worker or human resources counselor at your job, employer or union?1 2 8 c. a counselor or social worker?.....1 2 8 d. your doctor or doctor’s office?1 2 8 e. your spouse or other relative?1 2 8 f. friends?.....1 2 8 g. a lawyer?1 2 8 h. anyone else?1 2 8</p>
<p>ACCEPTED ..[D8]... 1 REJECTED ...[D7]... 2 PENDING[D9]... 3 DK[D9]... 8</p>	<p style="text-align: center;"> <input type="text"/> <input type="text"/> #OF MONTHS1 YEARS2 [GO TO D9.] </p>	<p style="text-align: center;"> <input type="text"/> <input type="text"/> #OF MONTHS1 YEARS2 </p>	<p>a. insurance company benefits office?1 2 8 b. co-worker or human resources counselor at your job, employer or union?1 2 8 c. a counselor or social worker?.....1 2 8 d. your doctor or doctor’s office?1 2 8 e. your spouse or other relative?1 2 8 f. friends?.....1 2 8 g. a lawyer?1 2 8 h. anyone else?1 2 8</p>

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E. Demographics/Insurance/Income

E1.	Are you currently...	single, never married [E3]..... 1 married, or living as married..... 2 widowed..... 3 separated 4 divorced 5
E2.	And at [DIAG AGE], when you were diagnosed with lupus, what was your marital status?	single, never married 1 married, or living as married..... 2 widowed..... 3 separated 4 divorced 5
E3.	Do you own your home?	YES..... 1 NO 2
E4.	Since [DIAG MO/YR], have you ever been without health insurance for a month or longer?	YES..... 1 NO 2 DON'T KNOW 8
E5.	Do you have health insurance now, including Medicare or Medicaid, or coverage by someone else in your family?	YES..... 1 NO [E7]..... 2 DON'T KNOW [E7]..... 8

[IF YES:]

E6. 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: _____

E7.

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[E7-b] 1 NO [E8]..... 2 RF [SECT F]..... 7 DK [SECT F]..... 8
b. more than \$10,000?	YES[E7-c] 1 NO [E8]..... 2 RF [SECT F]..... 7 DK [SECT F]..... 8
c. more than \$15,000?	YES[E7-d] 1 NO [E8]..... 2 RF [SECT F]..... 7 DK [SECT F]..... 8
d. more than \$20,000?	YES[E7-e] 1 NO [E8]..... 2 RF [SECT F]..... 7 DK [SECT F]..... 8
e. more than \$30,000?	YES[E7-f] 1 NO [E8]..... 2 RF [SECT F]..... 7 DK [SECT F]..... 8
f. more than \$40,000?	YES[E7-g] 1 NO [E8]..... 2 RF [SECT F]..... 7 DK [SECT F]..... 8
g. more than \$50,000?	YES[E7-h] 1 NO [E8]..... 2 RF [SECT F]..... 7 DK [SECT F]..... 8
h. more than \$75,000?	YES[E7-i]..... 1 NO [E8]..... 2 RF [SECT F]..... 7 DK [SECT F]..... 8
i. more than \$100,000?	YES [E7-j]..... 1 NO [E8]..... 2 RF [SECT F]..... 7 DK [SECT F]..... 8
j. more than \$150,000?	YES [E8]..... 1 NO [E8]..... 2 RF [SECT F]..... 7 DK [SECT F]..... 8

[OR]

[IF SUBJECT ANSWERS WITH INCOME AMOUNT, RECORD HERE AND GO TO E8] \$ _____

E8. How many household members, including yourself, depended on this income last year?

MEMBERS

E9. How many were under age 18?

MEMBERS
UNDER 18

F. Stress/Racism

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

- F1. How hard is it for your family to pay for basic expenses like food, clothing, shelter, medical care, and transportation? Is it...
 No problem 1
 Slight or occasionally difficult..... 2
 Moderately difficult, or..... 3
 Very difficult to pay expenses 4
- F2. Many people feel stressed in their day-to-day lives. How stressful is your day-to-day life? Is it...
 Not at all stressful[F4]..... 1
 Mildly stressful 2
 Moderately stressful, or 3
 Very stressful..... 4
- F3. How do you deal with stress in your day-to-day life? Do you...
 View stress as a challenge and deal well with it 1
 Not like the stress, but manage, or..... 2
 Feel anxious, overwhelmed, or exhausted 3
- F4. How often do you feel the need to squelch or swallow strong feelings of anger? Would you say...
 Daily 1
 Weekly, or 2
 Less often or never..... 3

					[IF YES:]				
F5. Have you ever been treated unfairly due to your race in any of the following circumstances?					F6. About how many times has this happened? #TIMES	F7. Has it happened in the past 5 years?			
	Y	N	RF	DK		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 G.]

[ASK F8-F9 ONLY IF RACE IS AFRICAN-AMERICAN:]

F8. 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

F9. 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. In your day-to-day life, how often have any of the following things happened to you because of your race? Would you say...	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? [READ CATEGORIES]	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

G. Reproductive History

[FOR MEN, SKIP TO SECTION H]

[FOR WOMEN AGE 50 AND OLDER, SKIP TO G10 INSTRUCTION:]

Now I'd like to update any pregnancies since you were interviewed and other events related to women's health.

[FOR WOMEN AGE 49 AND YOUNGER AND NOT PREGNANT OR DON'T KNOW IF PREGNANT AT TIME OF LAST INTERVIEW, SKIP TO G4]

[IF PREGNANT AT TIME OF FIRST INTERVIEW:]

G1. Our records indicate that you were pregnant when we talked with you in [INT MO/INT YR]. Is that correct?	YES..... 1
	NO [G4] 2

[IF YES:]

G2. What was the outcome of the pregnancy? Was it live birth, miscarriage, stillbirth, abortion, or something else?	LIVEBIRTH [G4] 1
	MISCARRIAGE..... 2
	STILLBIRTH [G4] 3
	ABORTION..... [G4] 4
	SOMETHING ELSE .. [G4] 5

[IF MISCARRIAGE:]

G3. How many weeks or months were your pregnant?	<table border="1" style="display: inline-table; border-collapse: collapse;"> <tr> <td style="width: 20px; height: 20px;"></td> <td style="width: 20px; height: 20px;"></td> </tr> </table>			WEEKS..... 1
	# OF	MONTHS..... 2		

[FOR AGE 49 AND UNDER:]

G4. Are you currently pregnant?	YES..... 1
	NO 2
	REFUSED [G10] 7
	DON'T KNOW [G10] 8

G5. Have you been pregnant any other time since [INT MO/INT YR] when you were age [AGE AT INT MO/INT YR]?	YES..... 1
	NO [G10] 2
	REFUSED [G10] 7
	DON'T KNOW [G10] 8

[IF YES:]

G6. 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:]				
<p>G7.</p> <p>Please tell me about the (first/next) pregnancy since [INT MO/INT YR]. How old were you when the pregnancy ended?</p>	<p>G8.</p> <p>Did this pregnancy end in a live birth, miscarriage, stillbirth, abortion, or something else?</p>	<p>G9.</p> <p>How many weeks or months were you pregnant?</p>				
<p>01.</p> <p style="text-align: center;"><table border="1" style="display: inline-table; vertical-align: middle;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table> AGE</p>			<p>LIVE BIRTH [NEXT PREG].... 1</p> <p>MISCARRIAGE..... [G9]..... 2</p> <p>STILLBIRTH..... [NEXT PREG].... 3</p> <p>ABORTION..... [NEXT PREG].... 4</p> <p>SOMETHING ELSE .. [NEXT PREG].... 5</p>	<p style="text-align: center;"><table border="1" style="display: inline-table; vertical-align: middle;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table> # OF</p> <p>WEEKS 1</p> <p>MONTHS 2</p>		
<p>02.</p> <p style="text-align: center;"><table border="1" style="display: inline-table; vertical-align: middle;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table> AGE</p>			<p>LIVE BIRTH [NEXT PREG].... 1</p> <p>MISCARRIAGE..... [G9]..... 2</p> <p>STILLBIRTH..... [NEXT PREG].... 3</p> <p>ABORTION..... [NEXT PREG].... 4</p> <p>SOMETHING ELSE .. [NEXT PREG].... 5</p>	<p style="text-align: center;"><table border="1" style="display: inline-table; vertical-align: middle;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table> # OF</p> <p>WEEKS 1</p> <p>MONTHS 2</p>		
<p>03.</p> <p style="text-align: center;"><table border="1" style="display: inline-table; vertical-align: middle;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table> AGE</p>			<p>LIVE BIRTH [NEXT PREG].... 1</p> <p>MISCARRIAGE..... [G9]..... 2</p> <p>STILLBIRTH..... [NEXT PREG].... 3</p> <p>ABORTION..... [NEXT PREG].... 4</p> <p>SOMETHING ELSE .. [NEXT PREG].... 5</p>	<p style="text-align: center;"><table border="1" style="display: inline-table; vertical-align: middle;"><tr><td style="width: 20px; height: 20px;"></td><td style="width: 20px; height: 20px;"></td></tr></table> # OF</p> <p>WEEKS 1</p> <p>MONTHS 2</p>		
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**[ASK G10-G16 ONLY IF STILL HAVING PERIODS AT PREVIOUS INTERVIEW = YES:]
 [IF NO PERIODS REPORTED ON DATA SHEET, SKIP TO SECTION H]**

G10. Are you using birth control pills, Depo-Provera® shots or hormonal contraception? YES.....[SECT H] 1
 NO[G11] 2

[IF NO:]

G11. Are you using hormone replacement therapy or medications for menopausal symptoms? YES.....[G12] 1
 NO[G14] 2
 DK[G14] 8

G12. About how often were you getting periods when you started taking this medication? Would you say it was... [READ CATEGORIES.]
 fairly regular 1
 infrequent or irregular, that is, sometimes more than 2 months between periods 2
 or had your periods stopped for at least 12 months[G15] 3

G13. How old were you when you started taking this medication?
 AGE
 [SKIP TO SECTION H]

G14. Have you had a menstrual period in the past 12 months? YES.....[SECT H] 1
 NO[G15] 2
 DK 8

[IF NO:]

G15. How old were you when your periods stopped?
 AGE

G16. Did your menstrual periods stop because of surgery, hysterectomy or removal of ovaries, because of some kind of medication or medical treatments, or did your periods stop naturally? SURGERY..... 1
 MEDICATION/
 MEDICAL TREATMENTS..... 2
 NATURALLY 3
 OTHER..... 4
 SPECIFY:

 DON'T KNOW 8

H. Helplessness Scale

The following statements concern your personal beliefs and general health beliefs. Please tell me how strongly you disagree or agree with each statement. There are no right or wrong answers.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
H1. My condition is controlling my life. Would you say... [READ CATEGORIES.]	1	2	3	4	5
H2. I would feel helpless if I couldn't rely on other people for help with my condition.	1	2	3	4	5
H3. No matter what I do or how hard I try, I just can't seem to get relief from my pain.	1	2	3	4	5
H4. I am coping effectively with my condition.	1	2	3	4	5
H5. It seems as though fate and other factors beyond my control affect my condition.	1	2	3	4	5

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I. Quality of Social Support Scale (QSSS)

For each statement, please indicate whether the statement is true.

	Never true	Sometimes true	Mostly true	Always true
I-1. There is someone who will take over my tasks or chores when I feel sick. [READ CATEGORIES]	1	2	3	4
I-2. The important people in my life accept me as I am, including both my worst and best points.	1	2	3	4
I-3. I can count on someone to listen to my innermost feelings, even when I'm angry at someone or depressed about something.	1	2	3	4
I-4. The people I'm close to are willing to use their skills and abilities to help me out in my everyday life.	1	2	3	4
I-5. The people I'm close to treat me like a worthwhile person and make me feel I have something positive to contribute.	1	2	3	4
I-6. I find it hard to be the sort of person I'd like to be when I'm around relatives and friends.	1	2	3	4
I-7. Someone would loan me money or loan me something else of value if I needed it.	1	2	3	4
I-8. No one will really listen when I need to talk about personal problems.	1	2	3	4
I-9. I can find someone to take me somewhere or run an errand for me if I need to.	1	2	3	4
I-10. It is easy to talk to my friends and relatives about things going on in my life.	1	2	3	4

J. Smoking and Alcohol Section

Now we will ask some questions about smoking and alcohol.

J1. In the past month, have you smoked at least one cigarette?

YES..... 1
 NO[J4] 2
 REFUSED[J4] 7

[IF YES:]

J2. Do you generally smoke every day?

YES..... 1
 NO[J4] 2
 REFUSED[J4] 7

J3. How many cigarettes do you usually smoke per day?

--	--	--

 #CIGS/DAY
 [1 PACK=20 CIGS]

J4. Now I have some questions about beer, wine, wine coolers, hard liquor, such as gin, bourbon, or scotch, or any other type of drink with alcohol in it. [1 DRINK = 12 OZ. GLASS BEER, 4 OZ. WINE, SHOT OF LIQUOR.]

Over your entire life, have you had at least 10 drinks of any kind of alcoholic beverage?

YES..... 1
 NO[J8] 2

[IF YES:]

J5. Thinking back to [DIAG YR-1], the year before you were diagnosed, how many drinks did you have per day, week or month?

--	--	--

 # OF DRINKS

PER DAY.....	1
PER WEEK.....	2
PER MONTH.....	3
TOTAL.....	4

J6. In the past month, have you had one or more drinks of wine, beer, or liquor?

YES..... 1
 NO[J8] 2
 REFUSED[J9] 7

[IF YES:]

J7. About how many drinks per day, week, or month did you drink in the past month?

OF DRINKS

- PER DAY 1
- PER WEEK 2
- PER MONTH 3

[IF R DOES NOT DRINK, J4 = NO OR J6 = NO:]

J8. What are the reasons you did not drink?

[CIRCLE ALL THAT APPLY.]

- DON'T LIKE EFFECTS OR FEELINGS 1
- RELIGIOUS/MORAL 1
- LUPUS RELATED HEALTH/ MEDICAL REASONS 1
- NOT LUPUS RELATED HEALTH/ MEDICAL REASONS 1
- TASTE 1
- COST 1
- NURSING 1
- RECOVERING ALCOHOLIC 1
- FAMILY MEMBER WITH ALCOHOL PROBLEM 1
- OTHER 1

SPECIFY: _____

[ASK EVERYONE:]

J9. Have you ever had moonshine?

- YES 1
- NO [SECT K] 2

[IF YES:]

J10. About how many drinks of moonshine have you had in your lifetime? Would you say...

[READ CATEGORIES.]

- 5 or less 1
- 6 to 10 2
- 11 to 25 3
- more than 25 4

K. Cognitive Symptoms

The next questions concern possible problems in everyday activities.

K1. <u>Over the last 4 weeks</u> , how much of a problem has it been to...	<u>Never</u> a problem	A problem <u>some</u> of the time	A problem <u>most</u> of the time	A problem <u>all</u> of the time	N/A
a. Dial a telephone? Would you say... [READ CATEGORIES.]	1	2	3	4	6
b. Recognize people you know?	1	2	3	4	6
c. Learn new things?	1	2	3	4	6
d. <u>Over the last 4 weeks</u> , how much of a problem has it been to see different colors only as black and white? Would you say...	1	2	3	4	6
e. Remember details of your recent experiences?	1	2	3	4	6
f. Remember important experiences in your past?	1	2	3	4	6
g. Remember to take your medications as you should?	1	2	3	4	6
h. <u>Over the last 4 weeks</u> , how much of a problem has it been to concentrate on a task you need to do? Would you say...	1	2	3	4	6
i. Find the correct word during conversations?	1	2	3	4	6
j. Remember where you put things such as keys and glasses?	1	2	3	4	6
k. <u>Over the last 4 weeks</u> , how much of a problem has it been to find your way while driving? Would you say...	1	2	3	4	6
l. Keep track of things to do or shop for things you need without a list?	1	2	3	4	6

L. SLE Activity Questionnaire

L1. In the past 3 months, have you had a lupus flare
(a lupus flare is when your lupus gets worse)?

YES1
NO [L3]2

[IF YES:]

L2. Which of the following best describes your
flare? [READ CATEGORIES.]

mild flare.....1
moderate flare.....2
severe flare.....3

L3.				
In the past 3 months, how bad has each of these lupus symptoms been for you?	No Problem	Mild	Moderate	Severe
a. Lost weight without trying. [PAUSE] Would you say...	0	1	2	3
b. Fatigue	0	1	2	3
c. Fevers greater than 101°F, (38.5° C) taken by thermometer	0	1	2	3
d. Sores in mouth or nose in the past 3 months. Would you say...	0	1	2	3
e. Rash on cheeks or your face shaped like a butterfly	0	1	2	3
f. Other rash SPECIFY WHERE: _____ <input type="text"/>	0	1	2	3
g. Dark blue or purple spots you could feel on your skin	0	1	2	3
h. Rash or feeling sick after going out in the sun	0	1	2	3
i. Bald patches on scalp, or clumps of hair on pillow	0	1	2	3
j. Swollen glands (nodes) in the neck	0	1	2	3
k. Shortness of breath in the past 3 months. Would you say...	0	1	2	3
l. Chest pain with a deep breath	0	1	2	3
m. Fingers or toes turning dead white or very pale in the cold (Raynaud's)	0	1	2	3
n. Stomach or belly pain in the past 3 months. Would you say...	0	1	2	3
o. Persistent numbness or tingling in your arms or legs	0	1	2	3
p. Seizures	0	1	2	3
q. Stroke in the past 3 months. Would you say...	0	1	2	3
r. Forgetfulness	0	1	2	3
s. Feeling depressed	0	1	2	3
t. Unusual headaches in the past 3 months. Would you say...	0	1	2	3
u. Muscle pain	0	1	2	3
v. Muscle weakness	0	1	2	3
w. Pain or stiffness in joints in the past 3 months. Would you say...	0	1	2	3
x. Swelling in joints	0	1	2	3

L4. Please rate the disease activity of your lupus during the past 3 months on a scale of 0 to 10, where 0 is no activity and 10 is the most activity.

.

M. SF-8 — Quality of Life

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

<p>M1. Overall, how would you rate your health during the <i>past 4 weeks</i>? [READ CATEGORIES]</p>	<p>Excellent.....01 Very good.....02 Good.....03 Fair.....04 Poor.....05 Very poor.....06</p>
<p>M2. 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 all1 Very little.....2 Somewhat.....3 Quite a lot.....4 Could not do physical activities.....5</p>
<p>M3. 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 all1 A little bit.....2 Some.....3 Quite a lot.....4 Could not do daily work.....5</p>
<p>M4. How much <i>bodily</i> pain have you had during the <i>past 4 weeks</i>? [READ CATEGORIES]</p>	<p>None.....01 Very mild.....02 Mild.....03 Moderate.....04 Severe.....05 Very severe.....06</p>
<p>M5. During the <i>past 4 weeks</i>, how much energy did you have? [READ CATEGORIES]</p>	<p>Very much1 Quite a lot.....2 Some.....3 A little.....4 None.....5</p>
<p>M6. 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 all1 Very little.....2 Somewhat.....3 Quite a lot.....4 Could not do social activities.....5</p>
<p>M7. 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 all1 Slightly.....2 Moderately.....3 Quite a lot.....4 Extremely.....5</p>
<p>M8. 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 all1 Very little.....2 Somewhat.....3 Quite a lot.....4 Could not do daily activities.....5</p>

N. Closing and Future Contact Information

N1. Considering the **kinds** of questions we've asked in this interview, is there anything else you think we need to know?

TIME END: : ^{AM}
_{PM}

Thank you. These are all the questions I have. [CONTINUE WITH FUTURE CONTACT.]

FUTURE CONTACT: *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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O. Interviewer Remarks

O-1. The telephone interview was completed... by subject.....1
 by proxy.....2
 both.....3
 SPECIFY PROXY'S
 RELATIONSHIP TO SUBJECT:

O-1a. The telephone interview was completed... by telephone.....1
 in person.....2
 both.....3

O-2. Respondent's cooperation was: Very good1
 Good.....2
 Fair3
 Poor4
 Other5
 SPECIFY:

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

[IF O-3 is answered 3, 4 OR 5 ABOVE:]

O-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):

O-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:

O-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. Depression	1	2		8
C. Occupation.....	1	2		8
D. Work/Health Disability.....	1	2		8
E. Demographics/Insurance/Income.....	1	2		8
F. Stress/Racism	1	2		8
G. Reproductive History	1	2	6	8
H. Helplessness Scale	1	2		8
I. Quality of Social Support Scale (QSSS)	1	2		8
J. Smoking and Alcohol	1	2		8
K. Cognitive Symptoms.....	1	2		8
L. SLE Activity Questionnaire	1	2		8
M. SF-8 Quality of Life.....	1	2		8

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

IF MORE THAN ONE SESSION:

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