

FOLLOW-UP QUESTIONNAIRE FOR CASES ONLY (PART I)

ID No.				-				
Form Type	C	F	0	1				

General Instructions: Complete this questionnaire for all cases completing two-year follow-up.

I. CASE IDENTIFICATION

1. **Case's initials:** _____

2. **Date of interview:**

____ - ____ - ____
 Month Day Year

II. ACCESS TO HEALTH CARE SERVICES

I would like to ask you some questions about your health insurance.

3. Currently, what is your main health insurance plan?
INTERVIEWER READ LIST

- Private (1)
- Medicare (2)
- Medicaid (3)
- Other public plan (4)
- None (5)
- Don't know/No answer (6)

[hltinsr](#)

IF NONE OR DON'T KNOW, GO TO QUESTION 6.

A. Does your insurance plan allow you to pay less money if you visit certain doctors?

Yes No
 (1) (2)

[hltplan1](#)

B. Does your insurance plan allow you to pay less money if you visit a specific clinic or health center?

(1) (2)

[hltplan2](#)

C. Does your insurance plan limit your ability to receive care from a medical specialist of your choice?

(1) (2)

[hltplan3](#)

4. Does your health insurance limit your ability to receive care for your sarcoidosis? (1) (2) **lmtcar1**
Yes No
- IF YES, ANSWER QUESTIONS 4A, 4B AND 4C.
IF NO OR NOT APPLICABLE, GO TO QUESTION 5.**
- A. Has it limited your access to a specialist for sarcoidosis care? Yes No **lmtspec1**
(1) (2)
- (1) IF YES, specify: _____
- B. Has it limited your receiving tests that your doctor thought should be done for your sarcoidosis? (1) (2) **lmttest1**
- (1) IF YES, specify: _____
- C. Has it limited your receiving any medication that your doctor thought you should receive for sarcoidosis? (1) (2) **lmtmed1**
- (1) IF YES, specify: _____
5. Has sarcoidosis affected the cost of your insurance? (1) (2) **afctcos1**
6. Has sarcoidosis affected your ability to obtain health insurance? Yes No Not Applicable (1) (2) (3) **afctabil**
- A. IF YES, How? _____

Now I would like to ask you about your usual source of health care, that is the place you go when you are sick or need medical advice.

7. Is there one particular clinic, health center, doctor's office, other place that you usually go to if you are sick or need advice about your health? Yes No
 (1) (2) hltplce1
- A. IF YES, What type of place is it? (1) hlttype1
INTERVIEWER READ LIST
 Doctor's private office (1)
 Hospital emergency room (2)
 Hospital out-patient clinic (3)
 Non-hospital clinical center (4)
 Public health clinic (5)
 Don't know (6)
 Other (7)

Specify: _____

IF 7A IS ANSWERED, GO TO QUESTION 8.

- B. IF NO, Is there one particular place where you would go if you were sick or needed advice about your health? Yes No
 (1) (2) hltplce2

**IF YES, ANSWER 7C.
 IF NO, GO TO QUESTION 8.**

- C. What type of place is it? (1) hlttype2
INTERVIEWER READ LIST
 Doctor's private office (1)
 Hospital emergency room (2)
 Hospital out-patient clinic (3)
 Non-hospital clinical center (4)
 Public health clinic (5)
 Don't know (6)
 Other (7)

Specify: _____

8. Is your regular doctor a general practitioner, internist, family doctor or doctor who treats a variety of illnesses and gives preventive care or is he or she a specialist (a doctor who mainly treats just one type of health problem)? **INTERVIEWER READ LIST.**

- General practitioner/internist/family doctor/other doctor (1) hlt_phys
 Specialist (2)
 Don't have a regular doctor (3)
 Don't know (4)

9. During the period since your ACCESS baseline interview, was there any time when you wanted to see a doctor but could not? Yes (1) No (2) wntsedoc

A. IF YES, Why? INTERVIEWER READ LIST

- (1) There was a lack of money or insurance to pay for the care (1) (2) hltcare1
- (2) It was too far or too expensive to get to care (1) (2) hltcare2
- (3) You were not able to get an appointment for care (1) (2) hltcare3
- (4) Some other reason (1) (2) hltcare4

Specify: _____

10. During the period since your ACCESS baseline interview, have you delayed seeking medical care because of worry about the cost? Yes (1) No (2) cost_wry

A. IF YES, Approximately how many times? _____ how_wry

11. In the period since your ACCESS baseline interview, have you delayed or had difficulty getting medicine prescribed when you needed it? Yes (1) No (2) med_diff

A. IF YES, Was it because of:

INTERVIEWER READ LIST

- (1) Cost Yes (1) No (2) reas_md1
- (2) Did not feel it was needed/helpful (1) (2) reas_md2
- (3) Could not get to a drug store or other place to fill the prescription (1) (2) reas_md3
- (4) Other (1) (2) reas_md4

Specify: _____

12. During the period since your ACCESS baseline interview was there any time when you needed medical care specifically for sarcoidosis but could not get it? Yes (1) No (2) med_need

A. IF YES, about how many times? _____ how_need

13. If your regular doctor at your usual source of health care is a specialist, does he or she also provide care for your sarcoidosis? Yes (1) No (2) Not Applicable (3) sarccare

14. In the period since your ACCESS baseline interview, how many times have you made appointments to see a doctor for your sarcoidosis? _____

appt_no

**IF ZERO (00), GO TO QUESTION 15.
 IF NOT ZERO, ANSWER QUESTIONS 14A AND 14B.**

A. How many of these appointments did you miss? _____

misaptno

B. If you had to miss at least one appointment, what was the main reason?

INTERVIEWER READ LIST

- Cost (1)
- Lack of transportation (2)
- Weather (3)
- Other (4)

mis_reas

Specify: _____

15. During the period since your ACCESS baseline interview has your sarcoidosis affected any of your organs?

(1) (2) (3) orgafect
 Yes No Don't Know

**IF YES, ANSWER QUESTION 15A.
 IF NO OR DON'T KNOW, GO TO QUESTION 16.**

I will read slowly from a list of organs or problems. As I read each one, please tell me if that organ or problem has been affected by sarcoidosis during the period since the ACCESS baseline interview. If you don't know, please tell me that.

	Yes	No	Don't Know	
A. Were the major problems in your:				
1. Lungs, with persistent cough or shortness of breath or abnormal chest x-ray	(1)	(2)	(3)	mprob1
2. Nervous system - your nerves or brain	(1)	(2)	(3)	mprob2
3. Lymph nodes outside the chest, such as easily felt lumps or nodes under your skin in your neck, under your arms, or in your groin	(1)	(2)	(3)	mprob3
4. Eyes, with significant pain, redness or blurred vision	(1)	(2)	(3)	mprob4
5. Skin, with small or large nodules or bumps or raised areas	(1)	(2)	(3)	mprob5
6. Heart with abnormal heart rhythm or other abnormal heart tests	(1)	(2)	(3)	mprob6
7. Liver, with enlarged liver, or abnormal blood tests of liver function	(1)	(2)	(3)	mprob7
8. Spleen with enlarged organ in left upper portion of abdomen	(1)	(2)	(3)	mprob8

	Yes	No	Don't Know	
9. Bone-marrow or abnormal blood counts, with anemia, or low white cell counts or low platelet counts or bleeding	(1)	(2)	(3)	mprob9
10. Kidneys, with positive biopsy or bad kidney function	(1)	(2)	(3)	mprob10
11. Bones/joints with abnormal x-rays or swollen painful joints or arthritis	(1)	(2)	(3)	mprob11
12. Muscles with tenderness or weakness	(1)	(2)	(3)	mprob12
13. Ears/nose/throat/sinuses, with nasal obstruction or crusting or hoarseness	(1)	(2)	(3)	mprob13
14. Parotid salivary glands, with enlarged glands on the side of face, as with mumps	(1)	(2)	(3)	mprob14
15. Increased calcium in blood or urine or kidney stones	(1)	(2)	(3)	mprob15
16. Fever, fatigue and/or unintentional weight loss of more than ten pounds	(1)	(2)	(3)	mprob16
17. Other	(1)	(2)	(3)	mprob17

Specify: _____

16. During the period since your ACCESS baseline interview have you needed treatment for your sarcoidosis?	(1) Yes	(2) No	trt_need
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**IF YES, ANSWER QUESTION 16A.
 IF NO, GO TO QUESTION 17.**

I will read slowly from the same list of organs or problems. As I read each one, please tell me if you required treatment because of that organ or problem that was affected by sarcoidosis during the period since your ACCESS baseline interview. If you don't know, please tell me that.

	Yes	No	Don't Know	
A. Which were the major problems or organs affected that required treatment?				
1. Lungs, with persistent cough or shortness of breath or abnormal chest x-ray	(1)	(2)	(3)	orgprb1
2. Nervous system - your nerves or brain	(1)	(2)	(3)	orgprb2
3. Lymph nodes outside the chest, such as easily felt lumps or nodes under your skin in your neck, under your arms, or in your groin	(1)	(2)	(3)	orgprb3
4. Eyes, with significant pain, redness or blurred vision	(1)	(2)	(3)	orgprb4
5. Skin, with small or large nodules or bumps or raised areas	(1)	(2)	(3)	orgprb5
6. Heart with abnormal heart rhythm or other abnormal heart tests	(1)	(2)	(3)	orgprb6

	Yes	No	Don't Know	
7. Liver, with enlarged liver, or abnormal blood tests of liver function	(1)	(2)	(3)	orgprb7
8. Spleen with enlarged organ in left upper portion of abdomen	(1)	(2)	(3)	orgprb8
9. Bone-marrow or abnormal blood counts, with anemia, or low white cell counts or low platelet counts or bleeding	(1)	(2)	(3)	orgprb9
10. Kidneys, with positive biopsy or bad kidney function	(1)	(2)	(3)	orgprb10
11. Bones/joints with abnormal x-rays or swollen painful joints or arthritis	(1)	(2)	(3)	orgprb11
12. Muscles with tenderness or weakness	(1)	(2)	(3)	orgprb12
13. Ears/nose/throat/sinuses, with nasal obstruction or crusting or hoarseness	(1)	(2)	(3)	orgprb13
14. Parotid salivary glands, with enlarged glands on the side of face, as with mumps	(1)	(2)	(3)	orgprb14
15. Increased calcium in blood or urine or kidney stones	(1)	(2)	(3)	orgprb15
16. Fever, fatigue and/or unintentional weight loss of more than ten pounds	(1)	(2)	(3)	orgprb16
17. Other	(1)	(2)	(3)	orgprb17

Specify: _____

17. I am going to read from a list of medications used for treatment of sarcoidosis. As I read each medication please indicate if you have taken it for your sarcoidosis during the period since your ACCESS baseline interview. We are not asking about any medication you stopped taking prior to your baseline interview.

USE THE BAG OF MEDICATIONS BROUGHT BY THE PARTICIPANT TO HELP IN ANSWERING THESE QUESTIONS

(1) Generic Name of Medication	(2) Usage In the Period Since the ACCESS Baseline Interview		(3) Duration in Months			(4) Frequency		(5) Average Total Daily Dose	(6) Response to Therapy			
	None	Not Current	Current	≤ 6	7 - 12	13 - 24	> 24		Continuous	Off - On	Improve	Same
A. Oral corticosteroid Specify: _____	(1)	medusea (2)	(3)	(1)	meddura (2)	(3)	(4)	(1)	medfreqa (2)	(1)	medrespa (2)	(3)
B. Methotrexate	(1)	meduseb (2)	(3)	(1)	meddurpb (2)	(3)	(4)	(1)	medfreqb (2)	(1)	medrespb (2)	(3)
C. Azathioprine	(1)	medusec (2)	(3)	(1)	meddurpc (2)	(3)	(4)	(1)	medfreqc (2)	(1)	medrespc (2)	(3)
D. Cyclosporine	(1)	medused (2)	(3)	(1)	meddurqd (2)	(3)	(4)	(1)	medfreqd (2)	(1)	medrespd (2)	(3)
E. Immunosuppressives (chlorambucil or cytoxan, etc. Specify: _____)	(1)	medusee (2)	(3)	(1)	meddure (2)	(3)	(4)	(1)	medfreqe (2)	(1)	medrespe (2)	(3)
F. Anti-malarial (chloroquine or hydroxy-chloroquine [plaquenil]) Specify: _____	(1)	medusef (2)	(3)	(1)	meddurf (2)	(3)	(4)	(1)	medfreqf (2)	(1)	medrespf (2)	(3)
G. Have you taken any other medications for your sarcoidosis in the period since the ACCESS baseline interview? If YES, answer L and go to Question 18. If NO, answer L and go to Question 18.	med_oth Yes (1) No (2)											
H.	(1)	meduseh (2)	(3)	(1)	meddurh (2)	(3)	(4)	(1)	medfreqh (2)	(1)	medresph (2)	(3)
I.	(1)	medusei (2)	(3)	(1)	medduri (2)	(3)	(4)	(1)	medfreqi (2)	(1)	medrespi (2)	(3)
J.	(1)	medusej (2)	(3)	(1)	meddurj (2)	(3)	(4)	(1)	medfreqj (2)	(1)	medrespj (2)	(3)
K.	(1)	medusek (2)	(3)	(1)	meddurk (2)	(3)	(4)	(1)	medfreqk (2)	(1)	medrespk (2)	(3)
L. You indicated that you have been taking prednisone. Have you taken this medication in the last 12 months?	Yes (1) No (2) N/A (3)											

If participant used any medication for sarcoidosis in the period since the ACCESS baseline interview, continue with Question 18.

If participant did not use any medication for sarcoidosis, go to Question 30.

ASK QUESTION 18 ONLY IF CURRENT OR NOT CURRENT USAGE OF A SARCOIDOSIS MEDICATION HAS BEEN CHECKED IN QUESTION 17.

18. We would like to know for what problem related to your sarcoidosis you were taking the medication(s) we just discussed.

I am going to read slowly from a list of organs or problems. As I read each one, please tell me if you were taking medication for that organ or problem since your ACCESS baseline interview. If you don't know, please tell me that.

	Yes	No	Don't Know	
A. Lungs, with persistent cough or shortness of breath or abnormal chest x-ray	(1)	(2)	(3)	mintaka
B. Nervous system - your nerves or brain	(1)	(2)	(3)	mintakb
C. Lymph nodes outside the chest, such as easily felt lumps or nodes under your skin in your neck, under your arms, or in your groin	(1)	(2)	(3)	mintakc
D. Eyes, with significant pain, redness or blurred vision	(1)	(2)	(3)	mintakd
E. Skin, with small or large nodules or bumps or raised areas	(1)	(2)	(3)	mintake
F. Heart with abnormal heart rhythm or other abnormal heart tests	(1)	(2)	(3)	mintakf
G. Liver, with enlarged liver, or abnormal blood tests of liver function	(1)	(2)	(3)	mintakg
H. Spleen with enlarged organ in left upper portion of abdomen	(1)	(2)	(3)	mintakh
I. Bone-marrow or abnormal blood counts, with anemia, or low white cell counts or low platelet counts or bleeding	(1)	(2)	(3)	mintaki
J. Kidneys, with positive biopsy or bad kidney function	(1)	(2)	(3)	mintakj
K. Bones/joints with abnormal x-rays or swollen painful joints or arthritis	(1)	(2)	(3)	mintakk
L. Muscles with tenderness or weakness	(1)	(2)	(3)	mintakl
M. Ears/nose/throat/sinuses, with nasal obstruction or crusting or hoarseness	(1)	(2)	(3)	mintakm
N. Parotid salivary glands, with enlarged glands on the side of face, as with mumps	(1)	(2)	(3)	mintakn
O. Increased calcium in blood or urine or kidney stones	(1)	(2)	(3)	mintako
P. Fever, fatigue and/or unintentional weight loss of more than ten pounds	(1)	(2)	(3)	mintakp
Q. Other	(1)	(2)	(3)	mintakq

Specify: _____

19. When was the first time you began taking medication for your sarcoidosis?

mint_dy

_____ - _____ - _____
 Month Day Year

ASK QUESTION 20 ONLY IF CURRENT USAGE OF SARCOIDOSIS MEDICATION HAS BEEN CHECKED IN QUESTION 17.

20. I would like you to think about how you took your sarcoidosis medicines in the PAST WEEK:

		Number of Days						
		0	1	2	3	4	+5	
A.	On how many days did you <u>forget</u> to take some or all of it?	(1)	(2)	(3)	(4)	(5)	(6)	frgtdays
B.	On how many days did you <u>not take</u> some or all of it?	(1)	(2)	(3)	(4)	(5)	(6)	ntakdays
C.	On how many days did you take <u>more</u> of any of it than your doctor told you to?	(1)	(2)	(3)	(4)	(5)	(6)	tmordays

ASK QUESTIONS 21 THROUGH 29 ONLY IF THE CASE REPORTED TAKING MEDICATION FOR SARCOIDOSIS IN THE PERIOD SINCE THE BASELINE INTERVIEW IN RESPONSE TO QUESTION 17. IF THE CASE TOOK MEDICATION SOMETIME DURING THE PERIOD SINCE THE ACCESS BASELINE INTERVIEW, BUT IS NOT TAKING IT AT THE TIME OF THE INTERVIEW, TELL THE CASE HE/SHE SHOULD ANSWER THE QUESTION FOR THE TIME PERIOD THE MEDICATION WAS TAKEN.

21. Would you say that you take your sarcoidosis medicine just the way your doctor told you to take it? **INTERVIEWER READ LIST**

All of the time	(1)	med_frgt
Almost all of the time	(2)	
Most of the time	(3)	
Some of the time	(4)	
Almost never	(5)	
Never	(6)	

IF ALL OF THE TIME, GO TO QUESTION 24.

22. Was there any time in the period since your ACCESS baseline interview, you did not obtain your sarcoidosis medication because you could not afford it?

Yes	No	
(1)	(2)	nomed

23. When you don't take all the medication that was prescribed, what is the most important reason for taking less?

INTERVIEWER READ LIST

- | | | |
|--|-------|----------|
| Forgetful | (01) | intakles |
| Too busy | (02) | |
| Didn't need it | (03) | |
| Side effects | (04) | |
| Feeling pain, sick | (05) | |
| Don't think medication works | (06) | |
| Could not afford prescription/refill | (07) | |
| Did not have transportation to get the prescription/refill | (08) | |
| Other | (09) | |

IF OTHER, describe: _____

24. Has your doctor ever directly asked you about how well you take your sarcoidosis medicine? Yes (1) No (2) intakmed

25. How confident are you that you can control your sarcoidosis by taking your medicine each day? **INTERVIEWER READ LIST**

- | | | |
|----------------------|------|----------|
| Very confident | (1) | med_cntr |
| Somewhat confident | (2) | |
| Not at all confident | (3) | |

26. If you don't take your sarcoidosis medicine what are the chances that something bad will happen to your health in the next year?

INTERVIEWER READ LIST

- | | | |
|---------------------------|------|----------|
| Very little chance | (1) | med_none |
| Some chance | (2) | |
| Fifty-fifty chance | (3) | |
| Probably will happen | (4) | |
| Almost surely will happen | (5) | |

27. If you don't take your sarcoidosis medicine, what might happen?

A. Don't know

(1) dontknow

B. Possibly: _____

28. How often do people in your daily life help you by reminding you to take your sarcoidosis medicines? **INTERVIEWER READ LIST**

All of the time

(1)

reminder

Some of the time

(2)

Never

(3)

29. Most people forget to take their medicine occasionally. How often does this happen to you? **INTERVIEWER READ LIST**

All of the time

(1)

frgtoft

Almost all of the time

(2)

Most of the time

(3)

Some of the time

(4)

Almost never

(5)

Never

(6)

III. ADMINISTRATIVE MATTERS

30. Interviewer:

A. Signature: _____

B. ACCESS Staff No.: _____ - _____

31. Research Coordinator:

A. Signature: _____

B. ACCESS Staff No.: _____ - _____

32. Date form completed:

_____ - _____ - _____
Month Day Year

FORM 35
Follow-up Questionnaire for Cases Only (Part I)

<u>ITEM</u>	<u>NAME</u>	<u>TYPE (LENGTH)</u>	<u>CODES OR UNITS</u>
	REV	I (1)	Form revision
	newid	F (5.1)	Patient ID
3 *	HLTINSR	I (1)	Current health insurance 1=Private or Medicare 3=Medicaid or Other public plan 5=None/Don't know/No answer
3a	HLTPLAN1	I (1)	Pay less for certain MDs 1=Yes 2=No
3b	HLTPLAN2	I (1)	Pay less for certain clinics 1=Yes 2=No
3c	HLTPLAN3	I (1)	Limits choice of specialist 1=Yes 2=No
4 *	LMTCAR1	I (1)	Ins limits care for sarc 1=Yes 2=No
4a	LMTSPEC1	I (1)	Ins limits access to spec 1=Yes 2=No
4b	LMTTEST1	I (1)	Ins limits tests for sarc 1=Yes 2=No
4c	LMTMED1	I (1)	Ins limits medication for sarc X=Censored
5	AFCTCOS1	I (1)	Sarc affects cost of insurance 1=Yes 2=No
6	AFCTABIL	I (1)	Sarc affects ability to get ins 1=Yes 2=No 3=Not applicable
7 *	HLTPLCE1	I (1)	Go to one particular place 1=Yes 2=No
7a	HLTTYPE1	I (1)	Type of place 1=Doctor's private office 2=Hospital emergency room or Hospital out-patient clinic 4=Non-hospital clinical center or Public health clinic 6=Don't know 7=Other
7b	HLTPLCE2	I (1)	Place patient would go to X=Censored

* Refer to the form for skip pattern for this item.

FORM 35
Follow-up Questionnaire for Cases Only (Part I)
(continued)

<u>ITEM</u>	<u>NAME</u>	<u>TYPE (LENGTH)</u>	<u>CODES OR UNITS</u>
7c	HLTTYPE2	I (1)	Type of place X=Censored
8	HLT_PHYS	I (1)	Regular doctor 1=General practitioner/internist/family doctor/other doctor 2=Specialist 3=Don't have a regular doctor or Don't know
9	WNTSEDOC	I (1)	Wanted, but could not see MD 1=Yes 2=No
9a1	HLTCARE1	I (1)	Lack of money/insurance or Too far or expensive 1=Yes 2=No
9a2	HLTCARE2	I (1)	(see 9a1)
9a3	HLTCARE3	I (1)	Couldn't get appointment 1=Yes 2=No
9a4	HLTCARE4	I (1)	Some other reason 1=Yes 2=No
10	COST_WRY	I (1)	Worry about cost 1=Yes 2=No
10a	HOW_WRY	I (2)	How many times? 1=1 or 2 3=3 or more
11	MED_DIFF	I (1)	Difficulty with prescription 1=Yes 2=No
11a1	REAS_MD1	I (1)	Cost 1=Yes 2=No
11a2	REAS_MD2	I (1)	Not needed or helpful 1=Yes 2=No
11a3	REAS_MD3	I (1)	Couldn't get to store 1=Yes 2=No
11a4	REAS_MD4	I (1)	Other 1=Yes 2=No
12	MED_NEED	I (1)	Could not get care for sarc 1=Yes 2=No
12a	HOW_NEED	I (2)	How many times? 1=1 or more

FORM 35
Follow-up Questionnaire for Cases Only (Part I)
(continued)

<u>ITEM</u>	<u>NAME</u>	<u>TYPE (LENGTH)</u>	<u>CODES OR UNITS</u>
13	SARCCARE	I (1)	Specialist provides sarc care 1=Yes 2=No 3=Not Applicable
14 *	APPT_NO	I (2)	Appts for sarcoidosis 0= 0 or not answered 8=8 or more
14a	MISAPTNO	I (2)	Missed appts 0=0 or not answered 1=1 or more
14b	MIS_REAS	I (1)	Reason missed appt 1=Cost or Lack of transportation 2=Weather or Other
15 *	ORGAFFECT	I (1)	Sarc has affected organs 1=Yes 2=No 3=Don't know
15a1	MPROB1	I (1)	Lungs 1=Yes 2=No 3=Don't know
15a2	MPROB2	I (1)	Nervous System 1=Yes 2=No 3=Don't know
15a3	MPROB3	I (1)	Lymph Nodes outside chest 1=Yes 2=No 3=Don't know
15a4	MPROB4	I (1)	Eyes 1=Yes 2=No 3=Don't know
15a5	MPROB5	I (1)	Skin 1=Yes 2=No 3=Don't know
15a6	MPROB6	I (1)	Heart 1=Yes 2=No 3=Don't know
15a7	MPROB7	I (1)	Liver 1=Yes 2=No 3=Don't know
15a8	MPROB8	I (1)	Spleen 1=Yes 2=No 3=Don't know
15a9	MPROB9	I (1)	Bone marrow/abnormal blood cnt 1=Yes 2=No 3=Don't know
15a10	MPROB10	I (1)	Kidneys 1=Yes 2=No 3=Don't know
15a11	MPROB11	I (1)	Bones/joints X=Censored

* Refer to the form for skip pattern for this item.

FORM 35
Follow-up Questionnaire for Cases Only (Part I)
(continued)

<u>ITEM</u>	<u>NAME</u>	<u>TYPE (LENGTH)</u>	<u>CODES OR UNITS</u>
15a12	MPROB12	I (1)	Muscles 1=Yes 2=No 3=Don't know
15a13	MPROB13	I (1)	Ears/nose/throat/sinuses 1=Yes 2=No 3=Don't know
15a14	MPROB14	I (1)	Paratoid salivary glands 1=Yes 2=No 3=Don't know
15a15	MPROB15	I (1)	Incr calcium/Kidney stones 1=Yes 2=No 3=Don't know
15a16	MPROB16	I (1)	Fever/fatigue/weight loss 1=Yes 2=No 3=Don't know
15a17	MPROB17	I (1)	Other 1=Yes 2=No 3=Don't know
16 *	TRT_NEED	I (1)	Needed trt for sarc 1=Yes 2=No
16a1	ORGPRB1	I (1)	Lungs 1=Yes 2=No 3=Don't know
16a2	ORGPRB2	I (1)	Nervous System 1=Yes 2=No 3=Don't know
16a3	ORGPRB3	I (1)	Lymph Nodes outside chest 1=Yes 2=No 3=Don't know
16a4	ORGPRB4	I (1)	Eyes 1=Yes 2=No 3=Don't know
16a5	ORGPRB5	I (1)	Skin 1=Yes 2=No 3=Don't know
16a6	ORGPRB6	I (1)	Heart 1=Yes 2=No 3=Don't know
16a7	ORGPRB7	I (1)	Liver 1=Yes 2=No 3=Don't know
16a8	ORGPRB8	I (1)	Spleen 1=Yes 2=No 3=Don't know
16a9	ORGPRB9	I (1)	Bone marrow/abnormal blood cnt 1=Yes 2=No 3=Don't know

* Refer to the form for skip pattern for this item.

FORM 35
Follow-up Questionnaire for Cases Only (Part I)
(continued)

<u>ITEM</u>	<u>NAME</u>	<u>TYPE (LENGTH)</u>	<u>CODES OR UNITS</u>
16a10	ORGPRB10	I (1)	Kidneys 1=Yes 2=No 3=Don't know
16a11	ORGPRB11	I (1)	Bones/joints X=Censored
16a12	ORGPRB12	I (1)	Muscles 1=Yes 2=No 3=Don't know
16a13	ORGPRB13	I (1)	Ears/nose/throat/sinuses 1=Yes 2=No 3=Don't know
16a14	ORGPRB14	I (1)	Paratoid salivary glands 1=Yes 2=No 3=Don't know
16a15	ORGPRB15	I (1)	Incr calcium/Kidney stones 1=Yes 2=No 3=Don't know
16a16	ORGPRB16	I (1)	Fever/fatigue/weight loss 1=Yes 2=No 3=Don't know
16a17	ORGPRB17	I (1)	Other 1=Yes 2=No 3=Don't know
17a2	MEDUSEA	I (1)	Oral cortiosteriod usage 1=None 2=Not current 3=Current
17a3	MEDDURA	I (1)	Oral cortiosteriod duration 1=6 months or less 2=7 months or more
17a4	MEDFREQA	I (1)	Oral cortiosteriod frequency 1=Continuous 2=Off - On
17a6	MEDRESPA	I (1)	Oral cortiosteriod response 1=Improve 2=Same 3=Worse
17b2	MEDUSEB	I (1)	Methotrexate usage 1=None 2=Not current 3=Current
17b3	MEDDURB	I (1)	Methotrexate duration 1=6 months or less 2=7 months or more
17b4	MEDFREQB	I (1)	Methotrexate frequency 1=Continuous 2=Off - On
17b6	MEDRESPB	I (1)	Methotrexate response 1=Improve 2=Same 3=Worse
17c2	MEDUSEC	I (1)	Azathioprine usage 1=None 2=Not current 3=Current

FORM 35
Follow-up Questionnaire for Cases Only (Part I)
(continued)

<u>ITEM</u>	<u>NAME</u>	<u>TYPE (LENGTH)</u>	<u>CODES OR UNITS</u>
17c3	MEDDURC	I (1)	Azathioprine duration 1=6 months or less 2=7 months or more
17c4	MEDFREQC	I (1)	Azathioprine frequency 1=Continuous 2=Off - On
17c6	MEDRESPC	I (1)	Azathioprine response 1=Improve 2=Same 3=Worse
17d2	MEDUSED	I (1)	Cyclosporine usage 1=None 2=Not current 3=Current
17d3	MEDDURD	I (1)	Cyclosporine duration 1=6 months or less 2=7 months or more
17d4	MEDFREQD	I (1)	Cyclosporine frequency 1=Continuous 2=Off - On
17d6	MEDRESPD	I (1)	Cyclosporine response 1=Improve 2=Same 3=Worse
17e2	MEDUSEE	I (1)	Immunosuppressives usage 1=None 2=Not current 3=Current
17e3	MEDDURE	I (1)	Immunosuppressives duration 1=6 months or less 2=7 months or more
17e4	MEDFREQE	I (1)	Immunosuppressives frequency 1=Continuous 2=Off - On
17e6	MEDRESPE	I (1)	Immunosuppressives response 1=Improve 2=Same 3=Worse
17f2	MEDUSEF	I (1)	Anti-malarial usage X=Censored
17f3	MEDDURF	I (1)	Anti-malarial duration X=Censored
17f4	MEDFREQF	I (1)	Anti-malarial frequency X=Censored
17f6	MEDRESPF	I (1)	Anti-malarial response X=Censored
17g *	MED_OTH	I (1)	Other medication since baseline 1=Yes 2=No

* Refer to the form for skip pattern for this item.

FORM 35
Follow-up Questionnaire for Cases Only (Part I)
(continued)

<u>ITEM</u>	<u>NAME</u>	<u>TYPE (LENGTH)</u>	<u>CODES OR UNITS</u>
17h2	MEDUSEH	I (1)	Medication H usage X=Censored
17h3	MEDDURH	I (1)	Medication H duration X=Censored
17h4	MEDFREQH	I (1)	Medication H frequency X=Censored
17h6	MEDRESPH	I (1)	Medication H response X=Censored
17i2	MEDUSEI	I (1)	Medication I usage X=Censored
17i3	MEDDURI	I (1)	Medication I duration X=Censored
17i4	MEDFREQI	I (1)	Medication I frequency X=Censored
17i6	MEDRESPI	I (1)	Medication I response X=Censored
17j2	MEDUSEJ	I (1)	Medication J usage X=Censored
17j3	MEDDURJ	I (1)	Medication J duration X=Censored
17j4	MEDFREQJ	I (1)	Medication J frequency X=Censored
17j6	MEDRESPJ	I (1)	Medication J response X=Censored
17k2	MEDUSEK	I (1)	Medication K usage X=Censored
17k3	MEDDURK	I (1)	Medication K duration X=Censored
17k4	MEDFREQK	I (1)	Medication K frequency X=Censored
17k6	MEDRESPK	I (1)	Medication K response X=Censored
17l	MEDRESL	I (1)	Prednisone in last 12 months 1=Yes 2=No 3=N/A

FORM 35
Follow-up Questionnaire for Cases Only (Part I)
(continued)

<u>ITEM</u>	<u>NAME</u>	<u>TYPE (LENGTH)</u>	<u>CODES OR UNITS</u>
18a *	MINTAKA	I (1)	Lungs 1=Yes 2=No 3=Don't know
18b *	MINTAKB	I (1)	Nervous System 1=Yes 2=No 3=Don't know
18c *	MINTAKC	I (1)	Lymph Nodes outside chest 1=Yes 2=No 3=Don't know
18d *	MINTAKD	I (1)	Eyes 1=Yes 2=No 3=Don't know
18e *	MINTAKE	I (1)	Skin 1=Yes 2=No 3=Don't know
18f *	MINTAKF	I (1)	Heart 1=Yes 2=No 3=Don't know
18g *	MINTAKG	I (1)	Liver 1=Yes 2=No 3=Don't know
18h *	MINTAKH	I (1)	Spleen 1=Yes 2=No 3=Don't know
18i *	MINTAKI	I (1)	Bone marrow/abnormal blood cnt 1=Yes 2=No 3=Don't know
18j *	MINTAKJ	I (1)	Kidneys 1=Yes 2=No 3=Don't know
18k *	MINTAKK	I (1)	Bones/joints X=Censored
18l *	MINTAKL	I (1)	Muscles 1=Yes 2=No 3=Don't know
18m *	MINTAKM	I (1)	Ears/nose/throat/sinuses 1=Yes 2=No 3=Don't know
18n *	MINTAKN	I (1)	Paratoid salivary glands 1=Yes 2=No 3=Don't know
18o *	MINTAKO	I (1)	Incr calcium/Kidney stones 1=Yes 2=No 3=Don't know
18p *	MINTAKP	I (1)	Fever/fatigue/weight loss 1=Yes 2=No 3=Don't know

* Refer to the form for skip pattern for this item.

FORM 35
Follow-up Questionnaire for Cases Only (Part I)
(continued)

<u>ITEM</u>	<u>NAME</u>	<u>TYPE (LENGTH)</u>	<u>CODES OR UNITS</u>
18q *	MINTAKQ	I (1)	Other 1=Yes 2=No 3=Don't know
19	mint_dy	I ()	Days from enrollment to first took meds
20a *	FRGTDAYS	I (1)	Days forgot to take meds 1=0 2=1 3=2 4=3 5=4 6=5 or more
20b *	NTAKDAYS	I (1)	Days did not take meds 1=0 2=1 3=2 4=3 5=4 6=5 or more
20c *	TMORDAYS	I (1)	Days took more meds 1=0 2=1 3=2 4=3 5=4 6=5 or more
21 *	MED_FRGT	I (1)	Take medicine as directed 1=All of the time 2=Almost all of the time 3=Most of the time/Some of the time 5=Almost never 6=Never
22 *	NOMED	I (1)	Could not afford medication 1=Yes 2=No
23 *	INTAKLES	I (1)	Reason for taking less 01=Forgetful 02=Too busy Didn't need it Side effects Feeling pain, sick Don't think medication works Could not afford prescription/refill Did not have transportation to get prescription/refill Other
24 *	INTAKMED	I (1)	Doctor asked about adherence 1=Yes 2=No
25 *	MED_CNTR	I (1)	Med can control sarc 1=Very confident 2=Somewhat confident 3=Not at all confident

* Refer to the form for skip pattern for this item.

FORM 35
 Follow-up Questionnaire for Cases Only (Part I)
 (continued)

<u>ITEM</u>	<u>NAME</u>	<u>TYPE (LENGTH)</u>	<u>CODES OR UNITS</u>
26 *	MED_NONE	I (1)	Something bad will happen 1=Very little chance 2=Some chance 3=Fifty-fifty chance 4=Probably will happen 5=Almost surely will happen
27a *	DONTKNOW	I (1)	Don't know what will happen 1=Don't know
28	REMINDER	I (1)	Others give reminders 1=All of the time 2=Some of the time 3=Never
29	FRGTOFT	I (1)	How often forget meds 1=All of the time 2=Almost all of the time 3=Most of the time 4=Some of the time 5=Almost never 6=Never

* Refer to the form for skip pattern for this item.