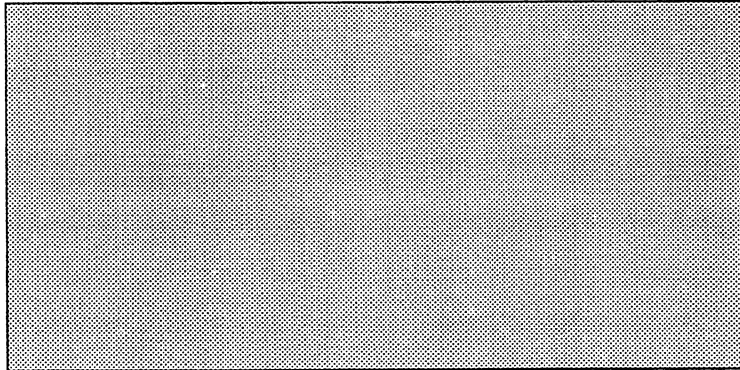


**PHASE FOUR  
QUESTIONNAIRE**

**REDS HTLV COHORT STUDY**



Sponsored by:

The National Heart, Lung, and Blood Institute  
National Institutes of Health

FOR BLOOD CENTER USE ONLY		
NURSE/COUNSELOR INITIALS:	_ _ _	
DATE:	_ _	-  _ _  -  _ _
	MO	DY YR

To Our Study Participants:

Thank you for participating in the HTLV Cohort Study of the Retrovirus Epidemiology Donor Study (REDS). We appreciate you taking the time to complete this questionnaire. Your responses to all questions will be kept strictly confidential. You are identified only by a study ID number on the cover; your name does not appear anywhere on the questionnaire. Please read the instructions below before continuing.

### **Instructions**

- Many questions ask about events or conditions that may have occurred since the date of your last REDS study interview. This date is printed on the front of this booklet and is referred to throughout the questionnaire as the "date of your last interview."
- Please answer each question to the best of your ability. For example, if you do not recall the exact month when you had a medical condition, give your best estimate. Your best guess is more helpful than a question left blank.
- Please mark only one response for each question, unless otherwise instructed.
- When a question asks you to provide a number, please record it in the boxes provided. Enter one digit in each box, with a "0" in any boxes that are not needed.

EXAMPLE: |0|3| times

- When a question asks you to record a date, please enter the month and year in the boxes provided. Enter one digit in each box.

EXAMPLE: January 1998 would be recorded as: |0|1| |9|8|  
Month Year

- If you need to change an answer, be sure to erase or cross it out completely.
- To ensure that your responses remain confidential, please do not write your name anywhere on this questionnaire.

Thank you again for your participation.

1. Since the "date of your last interview," have you had **unusual difficulty walking because of your legs** for more than one continuous month?

Yes → Did you see a doctor or other medical person for this?  
 No

Yes → What was the diagnosis, or what were you told?  
 No

\_\_\_\_\_  
\_\_\_\_\_

2. Since the "date of your last interview," have you had **unusual difficulty climbing stairs because of your legs** for more than one continuous month?

Yes → Did you see a doctor or other medical person for this?  
 No

Yes → What was the diagnosis, or what were you told?  
 No

\_\_\_\_\_  
\_\_\_\_\_

3. Since the "date of your last interview," have you had **unusual difficulty rising from a chair without using your hands** for more than one continuous month?

Yes → Did you see a doctor or other medical person for this?  
 No

Yes → What was the diagnosis, or what were you told?  
 No

\_\_\_\_\_  
\_\_\_\_\_

4. Since the "date of your last interview," have you had **swollen glands (lymph nodes) in your neck, groin, or under your arms** for more than one continuous month?

Yes → Did you see a doctor or other medical person for this?  
 No

Yes → What was the diagnosis, or what were you told?  
 No

\_\_\_\_\_  
\_\_\_\_\_

5. Since the "date of your last interview," and for more than one continuous month, have you had a **problem with urine leaking?**

Yes → Did you see a doctor or other medical person for this?  
 No

Yes → What was the diagnosis, or what were you told?  
 No

\_\_\_\_\_  
\_\_\_\_\_

6. Since the "date of your last interview," and for more than one continuous month, have you had a **strong urge to urinate so that you couldn't wait to get to the toilet?**

Yes → Did you see a doctor or other medical person for this?  
 No

Yes → What was the diagnosis, or what were you told?  
 No

\_\_\_\_\_  
\_\_\_\_\_

7. Since the "date of your last interview," and for more than one continuous month, have you had a **feeling that you still need to urinate after you have finished urinating?**

Yes → Did you see a doctor or other medical person for this?  
 No

Yes → What was the diagnosis, or what were you told?  
 No

\_\_\_\_\_  
\_\_\_\_\_



20. Since the "date of your last interview," did a skin doctor or dermatologist tell you for the first time that you had a **serious skin disease** (not including acne)?

- Yes → Was this mycosis fungoides or Sezary syndrome, also called cutaneous T-cell lymphoma or CTCL?
- No

Yes → When was this first diagnosed?

\_\_\_\_ | \_\_\_\_ |  
Month | Year

No → a. What was the diagnosis, or what were you told?

\_\_\_\_\_

b. When was this first diagnosed?

\_\_\_\_ | \_\_\_\_ |  
Month | Year

21. Since the "date of your last interview," did an eye doctor tell you for the first time that you had a **serious eye disease**?

- Yes → a. What kind of eye disease was it? (Check all that apply.)
- No

- Iritis, an inflammation of the colored part of the eye
- Uveitis, an inflammation of the inside of the eye
- Some other eye disease (please specify)

\_\_\_\_\_

b. When was this first diagnosed?

\_\_\_\_ | \_\_\_\_ |  
Month | Year

22. Since the "date of your last interview," did a doctor or other medical person tell you for the first time that you had **thyroid disease**?

- Yes → a. What kind of thyroid disease? (Check all that apply.)
- No

- Hyperactive thyroid
- Hypoactive thyroid
- Graves' disease
- Hashimoto's
- Other (please specify)

\_\_\_\_\_

b. When was this first diagnosed?

\_\_\_\_ | \_\_\_\_ |  
Month | Year

23. FOR FEMALES ONLY. (MALES, GO TO QUESTION 24.) Since the "date of your last interview," did a doctor or other medical person tell you that you had **vaginitis, or some other infection of the vagina**? (This does not need to be for the first time.)

- Yes → a. What kind of infection? (Check all that apply.)
- No

- Chlamydia
- Trichomonas
- Gardnerella
- Yeast infection
- Papillomavirus (HPV)
- Other (please specify)

\_\_\_\_\_

b. When was this first diagnosed?

\_\_\_\_ | \_\_\_\_ |  
Month | Year

24. Since the "date of your last interview," did a doctor or other medical person tell you for the first time that you had **any other major medical condition**?

- Yes → What was the diagnosis or what were you told? (Please report each condition on a separate line below.)
- No

1st Condition: \_\_\_\_\_

\_\_\_\_\_

When was this first diagnosed?

\_\_\_\_ | \_\_\_\_ |  
Month | Year

2nd Condition: \_\_\_\_\_

\_\_\_\_\_

When was this first diagnosed?

\_\_\_\_ | \_\_\_\_ |  
Month | Year

3rd Condition: \_\_\_\_\_

\_\_\_\_\_

When was this first diagnosed?

\_\_\_\_ | \_\_\_\_ |  
Month | Year

25. Since the "date of your last interview," have you been treated for **asthma**?

- Yes → When were you first treated for this (since the date of your last interview only)?  
 No

              
    Month    Year

26. Since the "date of your last interview," have you been treated for **pneumonia**?

- Yes → a. When were you first treated for this (since the date of your last interview only)?  
 No

              
    Month    Year

- b. For how many episodes have you been treated (since the date of your last interview only)?

      
    Number

27. Since the "date of your last interview," have you been treated for **bronchitis**?

- Yes → a. When were you first treated for this (since the date of your last interview only)?  
 No

              
    Month    Year

- b. For how many episodes have you been treated (since the date of your last interview only)?

      
    Number

- c. During each of the past two years (that is, 1996 and 1997), have you had a cough with sputum (phlegm) which lasted for more than 3 months?

- Yes  
 No

28. Since the "date of your last interview," have you been treated for a **bladder infection**?

- Yes → a. When were you first treated for this (since the date of your last interview only)?  
 No

              
    Month    Year

- b. For how many episodes have you been treated (since the date of your last interview only)?

      
    Number

29. Since the "date of your last interview," have you been treated for a **kidney infection**?

- Yes → a. When were you first treated for this (since the date of your last interview only)?  
 No

              
    Month    Year

- b. For how many episodes have you been treated (since the date of your last interview only)?

      
    Number

30. Since the "date of your last interview," have you been treated for **boils or abscesses on your skin** (not acne or pimples)?

- Yes → a. When were you first treated for this (since the date of your last interview only)?  
 No

              
    Month    Year

- b. For how many episodes have you been treated (since the date of your last interview only)?

      
    Number

31. Since the "date of your last interview," have you been treated for any other major infections, such as skin, fungal, viral, bacterial or parasitic infections?

- Yes → What kind of infection was it?  
 No (Please report each infection on a separate line below.)

1st Infection: \_\_\_\_\_

a. When were you first treated for this (since the date of your last interview only)?

\_\_\_\_|\_\_\_\_|    \_\_\_\_|\_\_\_\_|  
Month    Year

b. For how many episodes have you been treated (since the date of your last interview only)?

\_\_\_\_|\_\_\_\_|  
Number

2nd Infection: \_\_\_\_\_

a. When were you first treated for this (since the date of your last interview only)?

\_\_\_\_|\_\_\_\_|    \_\_\_\_|\_\_\_\_|  
Month    Year

b. For how many episodes have you been treated (since the date of your last interview only)?

\_\_\_\_|\_\_\_\_|  
Number

3rd Infection: \_\_\_\_\_

a. When were you first treated for this (since the date of your last interview only)?

\_\_\_\_|\_\_\_\_|    \_\_\_\_|\_\_\_\_|  
Month    Year

b. For how many episodes have you been treated (since the date of your last interview only)?

\_\_\_\_|\_\_\_\_|  
Number

32. At any time since the "date of your last interview," have you smoked cigarettes on a regular basis?

- Yes → a. Since the date of your last interview, approximately how many cigarettes would you usually smoke in a day?  
 No

\_\_\_\_|\_\_\_\_| OR  I usually smoked  
Number    less than one  
per day    cigarette per  
                 day.

b. Do you smoke cigarettes now?

- Yes  
 No → When did you stop smoking cigarettes on a regular basis?

\_\_\_\_|\_\_\_\_|    \_\_\_\_|\_\_\_\_|  
Month    Year

33. Over the entire time since the "date of your last interview," have you had a total of at least 12 drinks of any kind of alcoholic beverage?

- Yes → About how many alcoholic drinks per day, week, month or year do you usually drink? (Please pick only one of the following time periods to answer.)  
 No

Drinks per day    \_\_\_\_|\_\_\_\_|  
OR

Drinks per week    \_\_\_\_|\_\_\_\_|  
OR

Drinks per month    \_\_\_\_|\_\_\_\_|  
OR

Drinks per year    \_\_\_\_|\_\_\_\_|

34. Since the "date of your last interview," have you injected or "shot up" drugs that were not prescribed by a doctor?

- Yes
- No

35. How much school have you completed?

- 8th grade or less
- 9th, 10th, 11th or 12th grade (no diploma)
- High school graduate (high school diploma or equivalent, for example, GED)
- Some college or technical school
- Bachelor's degree, (for example BA, AB, BS)
- Master's or professional degree, (for example MS, PhD, or MD)

36. What was your total family income last calendar year (that is, 1997) from all sources, including wages, tips, Social Security, Aid to Families with Dependent Children, pensions, child support or any cash income from other sources?

- Less than \$10,000
- \$10,000 to \$19,999
- \$20,000 to \$29,999
- \$30,000 to \$39,999
- \$40,000 to \$49,999
- \$50,000 to \$74,999
- \$75,000 to \$99,999
- \$100,000 or more

37. How many individuals were supported by this income?

□ □  
Number

38. Finally, please enter today's date.

□ □ □ - □ □ □ - □ □ □  
Month Day Year

Thank you for participating in the  
REDS HTLV Cohort Study!

Please return your completed questionnaire and  
**signed yellow consent form** in the enclosed  
postage-paid envelope to:

American Red Cross Blood Services  
Southern California Region  
1130 South Vermont Ave.  
Los Angeles, CA 90006

212-739-5452