APPENDIX  C

STRONG HEART FAMILY STUDY

Instructions and Recruitment Forms
STRONG HEART FAMILY STUDY
GENETICS OF CARDIOVASCULAR DISEASE IN AMERICAN INDIANS

DRAFT - General Instructions for SHS Staff - DRAFT

The purpose of the Strong Heart Family Study is to find genes that influence heart disease risk factors in American Indians. Ten large families, with an average of 30 members each, will be enrolled in the Strong Heart Family Study from each of three centers: Oklahoma, the Dakotas, and Arizona.

Describing the Strong Heart Family Study

The success of the Family Study will depend in part on our ability to explain the study to participants in a way that will make its value clear. The following paragraphs may help:

Heart disease and diabetes are serious health problems for American Indians and for other Americans as well. Medical research has established that both heart disease and diabetes tend to run in families: if you have close relatives with heart disease or diabetes, then you are more likely to develop these diseases yourself.

The reasons why heart disease and diabetes run in families are not well understood. Family members usually live in the same household for at least a part of their lives, and as a result they tend to have similar diets, similar exercise patterns, and similar exposure to smoking. Family members also share the same genes, and we think that some of these genes increase the risk of heart disease and diabetes. Family patterns of heart disease and diabetes probably result from a combination of environment and genes.

The goal of the Strong Heart Family Study is to study the family patterns of heart disease and diabetes in American Indians. We hope to recruit a few large families in your community, including parents, children, and grandchildren. For each participating family, we will draw a family tree. We will give each family member a physical examination and we will ask questions about diet and about other lifestyle factors that we believe are important for heart disease and diabetes. For each person, we will measure traits that are related to risk of heart disease and diabetes (such as cholesterol levels in the blood). All of the information on family members will be coded so that individuals and families can't be identified by name, and confidentiality will be strictly maintained.

We will analyze the family patterns of traits related to heart disease and diabetes, and we will try to determine whether genes influence each trait. If the effects of a gene can be detected, then we will try to pinpoint the location of the gene by studying the DNA obtained from white blood cells. In the long term, we hope to find the genes and determine how they contribute to heart disease and diabetes.

Discovering the genes that contribute to heart disease and diabetes is very important for reducing the burden of these diseases on families and communities. If these genes can be identified, then new treatments can be developed and new ways of preventing disease can be found. We will also be able to help people to modify their environments so that the effects of harmful genes are lessened. This will lead to a longer life and a better quality of life.
Choosing Families for the Study

From the family history forms that were completed for each participant in Strong Heart Study Phase II, preliminary family trees have been constructed by computer. For each center, families have been identified for which:

(1) there is a "core sibship" of at least five full siblings, of whom at least three are Strong Heart Study participants; and

(2) the SHS participants in the core sibship have a total of at least 12 offspring who are at least 18 years old.

The family trees also indicate which spouses of these siblings are Strong Heart Study participants.

In choosing families for the Family Study, an additional important criterion will be the family's interest in participating. However, as we recruit families, it is important to avoid "ascertainment bias". We want the families in the Family Study to be representative of their communities, and not selected specifically because they have health problems (nor do we want to exclude families simply because they have members with heart disease or diabetes). Sometimes families of patients with heart disease or diabetes are more willing to participate in family studies than are members of the community in general. To minimize possible problems with ascertainment bias, you will be provided with a list of families that meet our criteria. The families that are recruited should be chosen from this list, and recruitment should continue until ten families with a total of at least 300 members have been recruited. If the list does not provide you with a sufficient number of interested families or family members, a supplementary list of eligible families will be provided to you.

We may find that there are many more families and family members interested in participating than we can include in this pilot study. These families can be told that if the pilot study is successful, we hope to be able to expand it to include additional families.

Understanding the Family Tree Diagrams

An example of a small family tree is shown at the top of the next page. In a family tree diagram, males are represented by squares □ and females, by circles ○. Solid squares □ or circles ○ represent Strong Heart Study participants. Individuals who are no longer living are represented by a diagonal line through a square □ or circle ○. A marriage is represented by a horizontal line (a marriage line) joining a square and a circle □ or ○. A sibship, which is a group of brothers and sisters who share the same two parents, is represented by another horizontal line, the sibship line, with vertical lines dropping from it to the squares and circles that represent
Family tree diagrams can be extended to include additional relatives. The family tree below shows a three generation family with the grandparents in the top generation. They have four children, three of whom are Strong Heart Study participants. Each of the children is (or was) married. The daughter on the left, a Strong Heart Study participant, has four children. One of her brothers has three children and the other, a Strong Heart Study participant, has four. Her sister has been married twice. She has three children by her first husband and one by her second.

Additional information also can be included on the family tree: names, dates of birth, etc. are often written below the symbol representing each family member.

Family Trees Constructed from the Family History Forms

The family trees created from the Family History forms provide some basic information for eligible families. However, some important information is missing because it was not included on the Family History forms. For example,

- We know the names and dates of birth (and death) for the offspring of SHS participants, but we do not know the other parent of each of these offspring, and therefore we don't know whether the offspring are full sibs or half sibs.

- We have no information about the spouses and offspring of the non-SHS sibs of SHS participants.
The non-SHS members of the families are known only by their names (they have no SHS numbers) and the initial family trees were created by matching names between records. Therefore, we anticipate some mistakes in the initial family trees. For example,

- If names were misspelled or not clearly written on the Family History forms, then branches of the family tree may be missed (i.e., some of the relatives are not shown). In some cases, first and last names appear to have been interchanged. In these cases, relatives also are missed.

- In cases in which both a husband and wife are SHS participants, the wife (for example) may list six offspring and the husband, only five. We do not know whether the husband's list is incomplete or whether the wife had a child in another marriage.

As discussed below, during the recruitment and interview process, any inaccuracies in the initial family trees should be corrected and missing information should be added.

The Family Informant

We do not know which of the large families that we have identified will be most interested in participating in the Family Study and which family members are living. Before lengthy interviews are conducted with individual family members, the degree to which the families are interested in participating in the Family Study must be determined, and we must begin the process of verifying the accuracy of the family trees. For example, some individuals whom we believe to be full siblings may in fact share only one parent, and thus may be half siblings. An interview with an elder who is knowledgeable about the family (a "family informant") will be the first step in determining which families are likely to be interested and whether the family relationships as we have recorded them are correct.

If the family informant (1) verifies the accuracy of the family tree, and/or provides new information to indicate that the family meets the criteria listed above, and (2) expresses his/her belief that a large number of members of the core sibship and their relatives (at least 30 family members in all) will be interested in participating, then the family will be chosen for the Family Study.

Interviewing the Family Informant

The interview with the family informant will have to be unstructured. The first step is to describe the Family Study briefly to the informant. The next step will be to discuss the computer-generated family tree, describing the meaning of the symbols, and to ask the informant to verify the correctness and completeness of all of the information on it: each name and birth date, family relationships (e.g., whether individuals are full or half siblings), which individuals are no longer living, names of other individuals not included in the family tree (e.g., additional children, parents whose names aren't recorded), etc. As the informant corrects faulty information on the family tree or provides new information, the interviewer should mark the changes directly on the family tree. New symbols should be added for family members who need to be added to the family.
tree, and if any persons need to be deleted, their symbols and names should be crossed out on the family tree. Any information provided by the informant that should not be shared with other family members (and therefore should not be displayed on revised versions of the family tree) should be clearly marked confidential.

If the information provided by the family informant indicates that the family is not suitable for the Family Study, either because of inappropriate size or structure or because of likely lack of interest, the interviewer should thank the informant for his/her time and terminate the interview.

If, on the basis of the interview, the family remains a good candidate for the Family Study, then the interviewer should ask the informant for addresses of as many family members as possible. This information can set the stage for the recruitment of family members.

Faxing the Revised Family Tree to San Antonio

Immediately after the completion of the family informant interview, the family tree with its hand-entered corrections should be faxed to the Southwest Foundation in San Antonio (Dr. Jean MacCluer, fax number (210) 670-3317). Hand-written entries on the family tree must be clearly written so that the fax copies will be readable. A corrected family tree will be generated and immediately faxed back to the center for use in interviews with subsequent family members.

Recruiting Family Members

Each family targeted as a possible candidate for the Family Study has been identified because it contains a core sibship of at least size five, of whom at least three are Strong Heart Study participants. For families enrolled in the Family Study, every effort should be made to recruit and interview the following family members:

(1) All members of the core sibship, whether or not they are Strong Heart Study participants.

(2) All age-eligible (at least 18 years of age) offspring of core sibship members.

(3) All current and (if possible) previous spouses of core sibship members, if these spouses are parents of the offspring listed in (2).

(4) The parents of the core sibship.

(5) The parents of spouses of core sibship members, if the spouses are parents of the offspring listed in (2).

(6) Any age-eligible grandchildren of core sibship members.

(7) Any spouses of individuals listed in (2), if they are parents of age-eligible offspring.
In other words, the family members to be recruited include the core sibship members, their parents, children, and grandchildren, and any spouses who are parents of these family members. Our goal is to recruit at least 30 members per family. It is likely that in order to maintain good rapport with the families, some individuals will have to be enrolled who do not qualify under categories (1) - (7). For example, some family members may want their spouses to participate even though they have no children. These extra family members should be enrolled if the recruiter feels that it is necessary to maintain the good will and cooperation of the family, but such enrollments should not be encouraged.

**Interviewing Family Members**

For each enrolled family member, the SHS Family Study Participant Interview should be administered. The complete interview should be conducted for the first few family members examined and for any family members who are found to be particularly knowledgeable about their family. As more and more members of the family are interviewed, it will become apparent that some of the information being obtained is repetitive. For example, there is no need to ask each member of a large sibship for the full names and addresses of all of their siblings. However it is important that this information be complete and accurate for every family member, and that it be verified by more than one person. Therefore the interviewer must use judgement in deciding which family members should be given the complete interview and which ones should simply be asked to verify information provided by others and to fill in missing information.

**The SHS Family Study Participant Interview Form**

The SHS Family Study Participant Interview consists of five parts. Part I requests general demographic and background information about the participant and his/her family. Parts II to IV request more detailed information about the participant's children, brothers and sisters, and parents, respectively. Part V asks the participant to identify a family contact person who can be asked for additional information. The following conventions should be used for this interview:

**Names:** Whenever full names are requested, the interviewer should enter last, first, and middle names; Jr. or Sr. (if relevant); maiden name for married women; and nickname.

**Dates:** All dates should be recorded as month/day/year, with year coded as four digits, e.g., December 1, 1996 should be coded as 12/01/1996. The four-digit year is important because birth dates for members of multi-generation families can span more than a century.

**Household:** It is important to know which family members live in the same household because these family members may share certain environmental risk factors. When you interview the first member of a family, assign household number 1 to that person and write ○ next to the symbol for that person on the family tree. Ask which other family members live in the same household and write ○ next to each of their symbols as well. When you interview the next family member who is not in household ○, write ○ next to the symbols for that person and everyone
else in his/her household. Continue with additional family members, using ○, ○, and as many additional household numbers as are needed to specify all households in the family. Write the person's household number in the appropriate place on page 1 of the Family Study Participant Interview Form.

Addresses: Addresses of family members are requested for two reasons: (1) to enable recruiters to contact the family members, and (2) to help us to verify which family members now live in the same household and thus share certain environmental risk factors.

Information on relatives: For recording information on offspring and siblings of the participant, interviewers should use as many sheets labeled "Your Children" and "Your Brothers and Sisters" as needed. These sheets, which are color coded, will be available separately and won't be provided in the Interview Form itself. They should be stapled to the back of the Interview Form after the completion of the interview.

Information is requested for some relatives of family members even though these relatives will not be enrolled in the Family Study at this time. This information will be of value in linking families together, and perhaps in the future, in extending the study to more remote relatives. Thus it is important to record the names of (1) parents and grandparents of members of the top generation (i.e., of the parents of the core sibship); (2) spouses and offspring of members of the bottom generation (i.e., of the offspring of core sibship members); and (3) parents and siblings of spouses of the core sibship members. This information should be sought even for relatives who are no longer living.

Defining relationships: For a family study, it is important to distinguish between full and half siblings, and between biological and adoptive relationships. Therefore when you ask for information about a participant's brothers and sisters, it is important to ask whether the participant and the sibling have the same mother and the same father. If one parent is different, the name of that parent should be recorded in the space provided. Likewise, in recording information about a participant's offspring, you should ask for the name of the other parent of each offspring. And in recording information about a participant's spouse, please allow for the possibility that the participant may have a partner to whom he/she is not married. For the Family Study we need to know the natural parents of each person, but we do not need to know whether those parents are married.

Tribal affiliation and ethnicity: Questions are included in Part I about the tribal affiliation of the participant and the ethnic background of his/her grandparents. This information is requested because people of different backgrounds can have different genes, and we want to be certain to take this into account as we look for genes that increase the risk of heart disease. We will not use this information to analyze individual participants' degree of Indian ancestry.

Using the Family Tree as a Visual Aid
As the interviewer is questioning each family member, he/she probably will find it helpful to show the family tree to the participant. An up to date family tree serves as a useful visual aid for both the interviewer and the participant. As in the initial interview with the family informant, any corrections or additional information should be written by hand directly on the family tree and faxed to San Antonio, where it will be redrawn by computer and faxed back to the center.

A Note of Caution

Questions about family relationships should be asked with sensitivity to each family member's background. For example, if a family member is known to be adopted, special care must be taken in phrasing questions about the identity of the person's natural father and mother and about brothers and sisters who are blood relatives. Caution also must be used if the interviewer has information of which the family member is unaware. It is important that the interviewer **review the Interview Form before the interview** and note any questions that need to be asked with special care (or not asked at all, if that information can be obtained elsewhere).

If there are any sensitive issues (questions that couldn't be asked or information of which family members are unaware) or if there are any uncertainties concerning family relationships, please describe on page 12 of the SHS Family Study Participant Interview form, detach the page, and send it directly to Dr. MacCluer at the address shown below. These pages also can be faxed, but please call or email first to be certain that the fax can be retrieved immediately.

Dr. Jean W. MacCluer  
Department of Genetics  
Southwest Foundation for  
Biomedical Research  
**For express courier:**  
7620 N.W. Loop 410  
San Antonio, TX 78227-5301

Phone (210) 670-3290  
Fax (210) 670-3317  
Email jean@darwin.sfbr.org  
**For U.S. mail:**  
P.O. Box 760549  
San Antonio, TX 78245-0549
THE STRONG HEART STUDY III — FAMILY STUDY
CARDIOVASCULAR DISEASE IN AMERICAN INDIANS
GENETICS OF CARDIOVASCULAR DISEASE
FAMILY STUDY PARTICIPANT INTERVIEW

SHS Family Study I.D. [________] SHS. I.D.: [________]  
Social Security Number: [________]  
Community name: __________________________ Community Code: [____]  
Household Number: [____]  
*If there are notes or instructions for Dr. MacCluer on page 16, check here: [____]  

PART 1. YOU AND YOUR FAMILY

1. What is your full name (Last, first, middle, Jr./Sr., maiden name, nickname):  
   Last: [________]  
   First: [________]  
   Middle: [________] Jr./Sr. [____]  
   Maiden: [________]  
   Nickname: [________]  
   Gender: Male [____] Female [____]  
   Are you an SHS participant? Yes [____] No [____]  
   If Yes, have you changed your name since the SHS-II examination? Yes [____] No [____]  
   How old are you? [____] years  
   What is your date of birth? [____]/[____]/[____]  

2. What is your marital status?  
   (Enter up to 3 options with the most recent one in the left-most box) [____]  
   1 = Never married 4 = Separated  
   2 = Currently married 5 = Widowed  
   3 = Divorced 6 = Adult roommate/partner/significant other
3. If you are currently married or living with someone as if you were married, what is your spouse/partner's name? (If divorced or widowed, draw 2 lines through boxes)

Last: ____________________________
First: ____________________________
Middle: ____________________________ Jr./Sr. ______
Maiden ____________________________
Nickname: ____________________________

4. Did he/she also participate in the Strong Heart Study examination?
   Yes ___1    No ___2    Unsure ___9

5. What is your current mailing address?
   ______________________________________
   Street/P.O. Box
   ______________________________________
   Reservation/city/town:
   ______________________________________
   County:
   ______________________________________
   State and zip code: ____________

6. What is your residential address? (If different from mailing address)
   ______________________________________
   Street/P.O. Box
   ______________________________________
   Reservation/city/town:
   ______________________________________
   County:
   ______________________________________
   State and Zip code: ____________

7. What is your home telephone number? Or at what telephone number can we reach you or leave a message?
   0= If unlisted
   9= If no phone
   ____________________________
   area code

8. What is your work or other contact telephone number?
   0= If same as home phone
   9= If not applicable or unknown
   ____________________________
   area code
Since we are investigating heart disease in the American Indian population, we need to ask about your degree in Indian blood.

9. What do you estimate to be your degree of Indian blood? 

10. Blood quanta:
   Please write the name of each tribe in the spaces below, with the largest blood quantum first.

<table>
<thead>
<tr>
<th>Tribe</th>
<th>Tribal Code</th>
<th>Blood quantum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tribe 1:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tribe 2:</td>
<td></td>
<td></td>
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<tr>
<td>Tribe 3:</td>
<td></td>
<td></td>
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<tr>
<td>Tribe 4:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tribe 5:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other ethnic groups:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

11. What is your tribe of enrollment?
    Enter name and IHS tribal code: ____________________________

12. Now I would like to ask you some questions about your family. How many natural children have you had (including any who are deceased, but not those who are yours by marriage or adoption)? 

   # of children
13. I would like to ask you some questions about your natural father and mother. What is your natural father's name? (Record accurately. Verify spelling)

Last: ________________________________

First: ________________________________

Middle: ________________________________ Jr./Sr. ______

Nickname: ________________________________


15. Where was your natural father born?

____________________________________________________________________

Reservation/county/city/town:

____________________________________

State: _____________________________________________________________

Country (if not U.S.): ________________________________________________

16. Blood contents of your natural father: Please write the name of each tribe in the spaces below, with the largest blood content quantum first.

<table>
<thead>
<tr>
<th>Tribe 1: _____________________________</th>
<th>Tribal Code</th>
<th>Blood quantum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tribe 2: _____________________________</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tribe 3: _____________________________</td>
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<td></td>
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<tr>
<td>Tribe 4: _____________________________</td>
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<tr>
<td>Tribe 5: _____________________________</td>
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</tbody>
</table>

Other ethnic groups: _____________________________________________________________
17. What was your natural mother's name? *(Record accurately. Verify spelling)*

<table>
<thead>
<tr>
<th>Last:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>First:</td>
<td></td>
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<tr>
<td>Middle:</td>
<td></td>
</tr>
<tr>
<td>Maiden:</td>
<td></td>
</tr>
<tr>
<td>Nickname:</td>
<td></td>
</tr>
</tbody>
</table>

18. Is she living?  Yes [ ]  No [ ]  Unsure [ ]  Unknown [ ] *(Go to Q21)*

19. Where was your natural mother born?

| Reservation/county/city/town: |                                                  |

| State | Country (if not U.S.): |                                                  |

20. Blood contents of your natural mother: *Please write the name of each tribe in the spaces below, with the largest blood content quantum first.*

<table>
<thead>
<tr>
<th>Tribe 1:</th>
<th>Tribal Code</th>
<th>Blood quantum</th>
</tr>
</thead>
<tbody>
<tr>
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<tr>
<td>Tribe 2:</td>
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<td>Tribe 3:</td>
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<td>Tribe 4:</td>
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<tr>
<td>Tribe 5:</td>
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<td>Other ethnic groups:</td>
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</tbody>
</table>
21. Now I would like to ask you about your grandparents. To what tribe did each of your grandparents belong? *(If grandparent was not Indian, list his/her ethnic background)*
   Father’s father: ________________________________________________
   Father’s mother: ________________________________________________
   Mother’s father: ________________________________________________
   Mother’s mother: ________________________________________________

22. Where were your grandparents born?
   Father’s father: Reservation/county/city/town __________ state __________ country __________
   Father’s mother: Reservation/county/city/town __________ state __________ country __________
   Mother’s father: Reservation/county/city/town __________ state __________ country __________
   Mother’s mother: Reservation/county/city/town __________ state __________ country __________

*If person is NOT CURRENTLY married or living with someone as if they were married, skip to Q30.*

23. Now I would like to ask about your spouse/partner *(name from Q3)*. Where was he/she born?

   Reservation/county/city/town __________ state __________ country __________

24. Is he/she also American Indian?  Yes [____] 1  No [____] 2  Unsure [____] 9

25. To what tribe/ethnic group does he/she belong? ________________________________________________

26. What are the names of his/her parents?
   Spouse/partner’s father *(If unknown, leave blank)*
   Last: ___________________________ ___________________________ ___________________________
   First: ___________________________ ___________________________ ___________________________
   Middle: ___________________________ ___________________________ Jr./Sr. __________________________
   Nickname: ___________________________ ________________________________________________

27. Is he living?  Yes [____] 1  No [____] 2  Unsure [____] 9
28. Spouse/partner's mother *(If unknown, leave blank)*

Last: ____________________________

First: ____________________________

Middle: ____________________________

Maiden: ____________________________

Nickname: ____________________________

29. Is she living? Yes [____]  No [____]  Unsure [____]

30. Do you think most of your family members will be willing to participate in this family study? *(Record answer verbatim on lines below)*

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

If "Yes" or "Unsure" ➔ GO TO PART II

If "No" ➔ END INTERVIEW BY THANKING THIS PERSON FOR THEIR TIME
PART II. YOUR CHILDREN

Now, I would like to get some additional information about your children.

1. Earlier, you told me you have (number from part 1, Q12) children. Pause for reaction.
   Does this include any who may have died and exclude any adopted children?
   Record number of children, including those deceased, excluding adoptees:  

2. What are the names of your children?

For interviewer: Record names of all children, including those deceased. You may come back later to get the additional information on each child.

(1)

Last:  
First:  
Middle:  Jr./Sr.  
Maiden  
Nickname:  

Sex:  Male 1  Female 2  
Age:  Birthdate:  mo/ day/ yr  
Living? Yes 1  No 2  Unsure 9  Number of children:  
Address:  

Phone: (___) _______ - _______

Other parent:  Father 1  Mother 2 (Check one)

Last:  
First:  
Middle:  Jr./Sr.  
Maiden  
Nickname:  

Use the additional “Your Children” pages as needed.
PART II. YOUR CHILDREN: ADDITIONAL CHILDREN

CHILD NUMBER ___

Last: ____________________________________________
First: ____________________________________________
Middle: ____________________________________________ Jr./Sr. ___
Nickname: ________________________________________
Sex: Male ___ Female ___
Age: ____ Birthdate: ___/___/___
Living? Yes ___ No ___ Unsure ___ Number of children: ____
Address: __________________________________________
__________________________________________________
Phone: (___) _______ - _______

Other parent: Father ___ Mother ___ (Check one)
Last: ____________________________________________
First: ____________________________________________
Middle: ____________________________________________ Jr./Sr. ___
Maiden ____________________________________________
Nickname: ________________________________________

Use additional “Your Children” pages as needed.
PART III. YOUR BROTHERS AND SISTERS

1. Now I would like to get some information about your brothers and sisters. How many brothers and sisters do you have? You should include any brothers and sisters who may have died and also all of your half-brothers and half-sisters. Do not include any brothers and sisters who are not blood relations.

Record number of brothers and sisters, including those deceased and half-siblings: ___

2. What are the names of your brothers and sisters?

For interviewer: Record the names of all siblings, including those deceased. You may come back later and get the additional information needed on each individual.

() Last: ________________________________
First: ________________________________
Middle: ________________________________ Jr./Sr. ___
Maiden ________________________________
Nickname: ________________________________

Sex: Male [_____] Female [____]

Age: _______ Birthdate: [______] Mo. [______] Da. [______] Yr. [______]

Living? Yes [____] No [____] Unsure [____] Number of children: _______

Address: ________________________________ Number and Street ________________________________ Reservation/city/town/county State and Zip Code

Phone: (_____) _______ - _______

Parents (if half-sibling): 
Father [____] Mother [____] (Check one)

Last: ________________________________
First: ________________________________
Middle: ________________________________ Jr./Sr. ___
Maiden ________________________________
Nickname: ________________________________

Use the additional “Your Brothers and Sisters” pages as needed.
PART III. YOUR BROTHERS AND SISTERS:

SIBLING NUMBER [___]

Last: ________________________________
First: ________________________________
Middle: ____________________________ Jr./Sr. [___]
Maiden: ____________________________
Nickname: ____________________________

Sex: Male [___] Female [___]

Age: [___] Birthdate: [___]/[___]/[___]

Living? Yes [___] No [___] Unsure [___] Number of children: [___]

Address: ____________________________

Phone: (___) _______ - _______

Parents (if half-sibling): Father [___] Mother [___] (Check one)

Last: ________________________________
First: ________________________________
Middle: ____________________________ Jr./Sr. [___]
Maiden: ____________________________
Nickname: ____________________________

Use additional “Your Brothers and Sisters” pages as needed.
PART IV. YOUR PARENTS:

Now I would like to get some additional information about your parents.

1. What is your mother's full name?
   Last:  
   First:  
   Middle:  
   Maiden:  
   Nickname:  
   What is/was her birthday?  
   Is she living? Yes [ ]  No [ ]  Unsure [ ]

   Address:  
   Phone: (_____) _______ - _________

2. What is your father's full name?
   Last:  
   First:  
   Middle:  Jr./Sr.  
   Nickname:  
   What is/was his birthday?  
   Is he living? Yes [ ]  No [ ]  Unsure [ ]

   Address:  
   Phone: (_____) _______ - _________
Now let's return to your mother's side of the family.

3. What is the name of your mother's father?
   Last: ________________________________
   First: ______________________________
   Middle: ________________________________ Jr./Sr. ________
   Nickname: ____________________________

4. What is the name of your mother's mother?
   Last: ________________________________
   First: ______________________________
   Middle: ________________________________
   Maiden: ________________________________
   Nickname: ____________________________
   Now, let's go back to your father's side of the family.

5. What is the name of your father's father?
   Last: ________________________________
   First: ______________________________
   Middle: ________________________________ Jr./Sr. ________
   Nickname: ____________________________

6. What is the name of your father's mother?
   Last: ________________________________
   First: ______________________________
   Middle: ________________________________
   Maiden: ________________________________
   Nickname: ____________________________
PART V. FAMILY CONTACT PERSON

In case we wanted to get more information, who in your family knows the most about the other family members?

Name: ____________________________________________

Address: ____________________________________________

________________________________________________________________________

Phone: (____) _______ - _____________

How is this person related to you? ________________________________

________________________________________________________________________

INTERVIEWER’S SIGNATURE __________________________________________

DATE __________________________

INTERVIEWER’S ID: [____]
1. Full name (Last, first, middle, Jr./Sr., maiden name, nickname):
   Last: ____________________________
   First: ____________________________
   Middle: ____________________________ Jr./Sr. |______|
   Maiden: ____________________________
   Nickname: ____________________________

2. Gender: Male [___]1 Female [___]2

3. Date of birth |______|mo |______|day |______|yr

4. Birthplace:
   Number and Street ____________________________
   Reservation/city/town/county ____________________________
   State/Zip Code/Country ____________________________

5. Date of death |______|mo |______|day |______|yr

6. Place of last residence:
   Number and Street ____________________________
   Reservation/city/town/county ____________________________
   State/Zip Code/Country ____________________________

7. Cause of Death: ____________________________

8. Tribe of enrollment (Enter name and IHS tribal code)
   ____________________________ |______|
THE STRONG HEART STUDY III — FAMILY STUDY
CARDIOVASCULAR DISEASE IN AMERICAN INDIANS

GENETICS OF CARDIOVASCULAR DISEASE

SHS Family I.D.: ____________   SHS. I.D.: ____________
Participant's name: ____________________________

Notes for Dr. MacCluer:

INTERVIEWER: ____________________________ DATE: ____________________________

Please detach from form and send immediately to:

Dr. Jean W. MacCluer, Department of Genetics, Southwest Foundation for Biomedical Research
7620 N.W. Loop 410, San Antonio, TX 78227-5301
Phone: (210) 670-3290, Fax: (210)670-3317
E-mail: jean@darwin.sfbr.org
APPENDIX D

STRONG HEART FAMILY STUDY

Questionnaires and Data Forms
THE STRONG HEART STUDY III — FAMILY STUDY
CARDIOVASCULAR DISEASE IN AMERICAN INDIANS
PERSONAL INTERVIEW FORM I

SHS Family I.D. ___________ SHS. I.D.: ___________
Social Security Number: ___________—_______—__________
Community name: ________________________________ Community Code: ___________

A. DEMOGRAPHIC INFORMATION:

1. Your Name:
   a. Last: ______________________________________
   b. First: ______________________________________
   c. Middle: _____________________________________
   d. Nickname/Other Name: _________________________

2. Gender: Male [____] Female [____]

3. Date of Birth: ___________ / ___________ / ___________

4. What is your marital status? (Give the most recent status in left-most box)
   1 = Never married   4 = Separated
   2 = Currently married 5 = Widowed
   3 = Divorced       6 = Adult roommate/partner/significant other

5. If ever married, what was your maiden name?
   ________________________________________________________

6. If married, what is your spouse's name? (if not married, skip to Q8)
   ________________________________________________________
   ________________________________________________________

7. Did he/she also participate in the Strong Heart Study examination?
   Yes [____]  No [____]
8. To which IHS and non-IHS Hospital/Clinic do you usually go? List the one they go to most often first. Give names and codes. Do you want your Strong Heart report sent to the named hospitals?

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Chart number</th>
<th>IHS 1=yes, 2=no</th>
<th>Hospital Code</th>
<th>Send Report 1=yes, 2=no</th>
</tr>
</thead>
<tbody>
<tr>
<td>a.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

9. What is your current mailing address?

<table>
<thead>
<tr>
<th>a.</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Street/P.O. Box</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>b.</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>City/town</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>c.</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>County</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>d.</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>State and zip code:</td>
<td></td>
</tr>
</tbody>
</table>

10. Is this your residential address? (If different from mailing address)

Yes | 1 | No | 2 |

If no, what is your current address?

<table>
<thead>
<tr>
<th>a.</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Street/P.O. Box</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>b.</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>City/town</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>c.</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>County</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>d.</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>State and Zip code:</td>
<td></td>
</tr>
</tbody>
</table>

11. What is your home telephone number?
Or at what telephone number can we reach you or leave a message?
0= If unlisted

<table>
<thead>
<tr>
<th>12. What is your work or other contact telephone number? 0= If same as home phone</th>
</tr>
</thead>
<tbody>
<tr>
<td>9= If not applicable or unknown</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>area code</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>area code</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

Strong Heart Family Study - 06/20/97
Since we know that years of education may be a risk factor for some diseases, we need to ask about the years of education you have completed.

13. How many years of education have you completed?
   0-12= Vo-tech or years of school (GED = 12)
   14= Junior college
   16= Bachelors
   18= Masters
   19= Law degree
   20= Doctorate
   999= Unknown

Since we are investigating heart disease in the American Indian population, we need to ask about your degree of Indian blood.

14. What do you estimate to be your degree of Indian blood?

15. Blood quantum:
   Please write the name of each tribe in the spaces below.

   Tribe 1: ________________________________ Tribal Code: _______ Blood quantum: _______ /
   Tribe 2: ________________________________ Tribal Code: _______ Blood quantum: _______ /
   Tribe 3: ________________________________ Tribal Code: _______ Blood quantum: _______ /
   Tribe 4: ________________________________ Tribal Code: _______ Blood quantum: _______ /
   Tribe 5: ________________________________ Tribal Code: _______ Blood quantum: _______ /
   White — non-Hispanic __________________________ Tribal Code: _______ Blood quantum: _______ /
   White — Hispanic ___________________________ Tribal Code: _______ Blood quantum: _______ /
   Black ____________________________________ Tribal Code: _______ Blood quantum: _______ /
   Other, please specify: __________________________ Tribal Code: _______ Blood quantum: _______ /

16. What is your tribe of enrollment?
   Enter name and IHS tribal code: __________________________ Tribal Code: _______
THE STRONG HEART STUDY - PHASE III — FAMILY STUDY
CARDIOVASCULAR DISEASE IN AMERICAN INDIANS
PERSONAL INTERVIEW FORM II

SHS Family I.D.: _______ | SHS I.D.: _______ | _______

A. WEIGHT SATISFACTION
1. Are you satisfied with your present weight?
   Yes [ ] 1 (skip to B)  No [ ] 2  Unknown/unsure [ ] 9
2. Do you want to lose or gain weight?  Lose [ ] 1  Gain [ ] 2
3. How do you plan to do this?
   a) Eating  [ ] 1  [ ] 2  [ ] 3
   b) Physical activity  [ ] 1  [ ] 2  [ ] 3
   c) Medication  Yes [ ] 1  No [ ] 2
   d) Other, specify: ____________________________  Yes [ ] 1  No [ ] 2

B. DENTURE AND EATING PROBLEMS
4. How many natural teeth do you have?  All [ ] 1  Most [ ] 2  Some [ ] 3  None [ ] 4
5. Describe how you chew your food. (Please Choose only ONE):
   I use natural teeth to chew. [ ] 1  I use natural teeth with caps/crowns to chew. [ ] 2
   I have natural teeth and a denture or partial. I use them both together to chew. [ ] 3
   I use dentures to chew. [ ] 4  I chew with my gums. [ ] 5
6. Rate your ability to chew food (Please Choose only ONE)  Good [ ] 1  Fair [ ] 2  Poor [ ] 3

C. FAMILY INCOME:
7. Does your household income meet your family's needs?
   Yes [ ] 1  No [ ] 2  Unsure [ ] 9
8. What is your MAIN daily activity(s)?  (If more than one, order "1,2..."etc.)  [ ] 1  [ ] 2  [ ] 3
   1 = Caring for Family  4 = Looking for Work
   2 = Working for Pay/Profit  5 = Retired/Elderly
   3 = Going to School  6 = Other, please specify

______________________________

Strong Heart Family Study - 06/20/97
Personal Interview 2
9. Do you receive any income from...?  
   Yes        No         Yes        No       
   1) Wages/Salary |1|1  2) Profits - business |1|1  5) Retirement Benefits |1|1  
   3) Gaming/lottery winnings |1|2  4) Unemployment benefits/worker's comp/welfare |1|1  6) Social Security Benefits |1|2  
   7) Lease Payment |1|2  8) Other, specify: |1|1

10. Of the choices in Question 9, which source provides the most income?  
   (Choose one: if Missing/Refused/Unknown, code 9)

11. How many hours per week do you work at a job or jobs that pay you a salary or wage? (Fill in number of hours)

12. Which of the following categories best describes your annual household income from all sources? Please show a list.  
   Less than 5,000 |1|1  20,000 to 25,000 |1|5  Don't know/not sure |1|9  
   5,000 to 10,000 |1|2  25,000 to 35,000 |1|6  Refused |1|0  
   10,000 to 15,000 |1|3  35,000 to 50,000 |1|7  
   15,000 to 20,000 |1|4  Over 50,000 |1|8

D. TOBACCO:

13. During your lifetime have you smoked 100 cigarettes or more total?  
   Yes |1|1  No |1|2  (skip to SECTION E)

14. How old were you when you first started smoking fairly regularly?  
   (Indicate age at which you started smoking)  
   0 = Never smoked regularly  999 = Unknown

15. Do you smoke cigarettes now?  
   Yes |1|1  No |1|2

16. On the average, how many cigarettes do/did you usually smoke per day?  
   0= Less than one cigarette per day
   a) If less than one cigarette per day, number of cigarettes per month?

17. On which occasions are/were you most likely to smoke, or increase your smoking?  
   Please read the list and check the appropriate response.  
   Yes |1|1  No |1|2
   a) stressful times |1|1  b) casinos |1|1  
   c) wakes/funerals |1|1  d) when drinking alcohol |1|1  
   e) social meetings |1|1  f) when you have extra money |1|1  
   g) bingo |1|1  h) other, specify: _____________________________ |1|1  

---

Strong Heart Family Study - 06/20/97  
Personal Interview 2
18. On the occasions that your smoking increased, how many cigarettes do/did you smoke per day? 

---

19. If you currently smoke, would you like to change your smoking habit? Yes [___]1 No [___]2 (if No, skip to Q20)
a) If yes, would you prefer to...

   i) Reduce number of cigarettes per day [___]1 [___]2
   ii) Switch to lower "tar" or "nicotine" cigarettes [___]1 [___]2
   iii) Use nicotine patch/chewing gum [___]1 [___]2
   iv) Quit [___]1 [___]2
   v) Other, specify: __________________________ [___]1 [___]2

---

20. Did you quit smoking? Yes [___]1 No [___]2 (skip to Section E)
a) If you quit, when did you last smoke? (Just the year, please) 

---

b) What reason(s) did you have for quitting? Please check all that apply.

   Yes [___]1 No [___]2

   i) Doctor's advice [___]1 [___]2
   ii) Health concerns [___]1 [___]2
   iii) Expenses [___]1 [___]2
   iv) Per family pressure [___]1 [___]2
   v) Other [___]1 [___]2

   specify: __________________________

---

E. PASSIVE SMOKING:

21. When you were growing up, did your father or male guardian ever smoke cigarettes regularly?

   Yes [___]1
   No [___]2

   No father/male guardian [___]3
   Unknown [___]9

22. When you were growing up, did your mother or female guardian ever smoke cigarettes regularly?

   Yes [___]1
   No [___]2

   No mother/female guardian [___]3
   Unknown [___]9

23. Whether or not you smoke, on the average, how many hours a day are you exposed to the smoke of others? (If none, fill in 0; enter 1 for 30 minutes or more, enter 0 if less than 30 minutes) 

---
F. ALCOHOL:

The next few questions are about the use of beer, wine, or liquor.

PLEASE READ THE FOLLOWING TO THE PARTICIPANT:
"We are asking these questions about alcohol use, because alcohol consumption may be related to heart disease. We want to assure you that this information is strictly confidential. The Strong Heart Study will use this information only to determine to what extent alcohol use is a risk factor for heart disease. This information is analyzed as batches of numbers without any names. Please report your alcohol use as accurately as possible."

24. Have you ever consumed alcoholic beverages?
   Yes [ ] 1  No [ ] 2  (this section of the interview is finished, go to Question 31)
   a) If yes, when was your last drink? (Choose only one)
      [ ] 1  Within the last week
      [ ] 2  Within the last month
      [ ] 3  Within the last year. Number of months [ ] [ ] [ ] [ ]
      [ ] 4  More than a year ago
      (If over a year, this section of the interview is finished, please go to Question 31)

25. How many alcoholic drinks do you have in a typical week? (see chart below)
One Drink = 12 oz of Beer = 4 oz of Wine = 1 oz of Liquor.
Please choose the type(s) of beverage and write in the Number of Containers under the appropriate volume.

<table>
<thead>
<tr>
<th>Number of Containers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of Drink</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Beer</td>
</tr>
<tr>
<td>Wine</td>
</tr>
<tr>
<td>Liquor</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Container Size (Ounces)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 shot</td>
</tr>
<tr>
<td>1.5 jigger</td>
</tr>
<tr>
<td>4 glass</td>
</tr>
<tr>
<td>8 tumbler</td>
</tr>
<tr>
<td>12 can/btl</td>
</tr>
<tr>
<td>16(pt) can</td>
</tr>
<tr>
<td>26 fifth</td>
</tr>
<tr>
<td>32-34 qt. btl</td>
</tr>
<tr>
<td>40 btl</td>
</tr>
<tr>
<td>64 (2 gal) jug</td>
</tr>
<tr>
<td>128 (gal) jug</td>
</tr>
</tbody>
</table>

26. How many days in a typical month do you have at least one drink?
   (Indicate the number of days per month) [ ] [ ] [ ] [ ] [ ]
27. On the days when you drink any liquor, beer or wine, about how many drinks do you have, on average? (Indicate number of drinks per day)  

(# Drinks)

28. When you drink more than your usual amount, how many drinks do you have?

(# Drinks)

29. How many times during the PAST MONTH did you have 5 or more drinks on an occasion? Indicate times per month. (Enter zero if subject has quit drinking more than one month ago.)

(# Times/Month)

30. How many times during the PAST YEAR did you have 5 or more drinks on an occasion? (Enter zero if subject has quit drinking more than one year ago)

31. Within the last year, have you ever consumed other substances to get the effects of alcohol, such as...  

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Mouth wash</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>b. Cough syrup</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>c. Lysol</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>d. Hair spray</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>e. Other, ________________________</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

G. ADMINISTRATIVE INFORMATION:

32. How reliable was the participant in completing the questionnaire?

Very reliable | 1 |
Reliable | 2 |
Unreliable | 3 |
Very unreliable | 4 |
Uncertain | 5 |

33. Did the participant complete the interview?

Yes, completed the interview | 1 |
No, refused all questions | 2 |

34. Interviewer:  

35. Date of interview:  

mo / day / yr
THE STRONG HEART STUDY - PHASE III — FAMILY STUDY
CARDIOVASCULAR DISEASE IN AMERICAN INDIANS

GAMBLING QUESTIONS

SHS Family I.D. ___________________________________________ SHS. I.D.: __________________________

Now we will ask you a few questions about gambling, since more Indian communities have casinos and gambling may have an impact on the health of these communities.

1. Do you work at a casino/bingo hall? Yes [__]1  No [__]2

2. Overall, what effects do you think gambling has on the following:
   a. Tribal government, Beneficial [__]1  Harmful [__]2  No effects [__]3
   b. Tribal people, Beneficial [__]1  Harmful [__]2  No effects [__]3
   c. You personally, Beneficial [__]1  Harmful [__]2  No effects [__]3

3. What type(s) of gambling have you participated in during the last year?
   a) Slot machines? Yes [__]1  No [__]2
      (If Yes, how often. Please check)
      1 or more times a week [__]1  1 or more times a month [__]2  Less than once a month [__]3
   b) Lottery? Yes [__]1  No [__]2
      (If Yes, how often. Please check)
      1 or more times a week [__]1  1 or more times a month [__]2  Less than once a month [__]3
   c) Bingo? Yes [__]1  No [__]2
      (If Yes, how often. Please check)
      1 or more times a week [__]1  1 or more times a month [__]2  Less than once a month [__]3
   d) Card games (i.e. poker)? Yes [__]1  No [__]2
      (If Yes, how often. Please check)
      1 or more times a week [__]1  1 or more times a month [__]2  Less than once a month [__]3
   e) Other, specify: ________________________________
      (If Yes, how often. Please check)
      1 or more times a week [__]1  1 or more times a month [__]2  Less than once a month [__]3
      (Skip to Q9 if person does not gamble)

4. In the past year, have you lost more than you won? Yes [__]1  No [__]2

5. In the past year, have you made attempts to control, cut back, or stop gambling?
   a) If Yes, have your attempts been successful? Yes [__]1  No [__]2

6. In the past year, have you had to borrow money to pay basic living expenses (such as food, mortgage/rent), because of gambling losses? Yes [__]1  No [__]2

7. When you are gambling, how much alcohol do you drink that day? [__]1  [__]2
   # of drinks

8. In the past year, what is the largest amount you have bet on any single day? $________

9. Did the participant complete the interview? Yes, completed the interview [__]1  No, refused all questions [__]2

10. Interviewer: ____________________________________________

11. Date of interview: ________________________________
    [__]1  [__]2  [__]3  [__]4  [__]5  [__]6  [__]7  [__]8  [__]9  [__]10

Gambling Questionnaire
THE STRONG HEART STUDY III — FAMILY STUDY
CARDIOVASCULAR DISEASE IN AMERICAN INDIANS

MEDICAL HISTORY FORM

SHS Family I.D. ____________ SHS. I.D.: ____________

B. MEDICAL CONDITIONS:
"Now I'd like to ask you some questions about medical problems. Has a medical person EVER told you that you had any of the following conditions?

If "YES," how old were you when you were first told by a medical person that you had high blood pressure (for women, not during pregnancy)? Indicate the actual age. Don't know = 999 [__________]


If YES," where? ______________________


If YES," specify type of cancer: ______________________

7. Diabetes?
(if No or Unknown, skip to Q8)

a) If Yes, do you still have it now?

b) How old were you when you were first told by a medical person that you had diabetes? Indicate the actual age. Don't know = 999 [__________]

c) What type of treatment are you taking for your diabetes? (Check appropriate answer)
YES NO
i) insulin [1] [2]
ii) oral hypoglycemic agent [1] [2]
iii) by dietary control [1] [2]
iv) by exercise [1] [2]
v) do nothing [1] [2]
vi) other [1] [2]
8. Has a medical person ever told you that you had kidney failure?  
   YES | NO | UNKNOWN  
   __ | __ | __  
   a) If Yes, are one or both working well now?  
      __ | __ | __  
   b) How old were you when you were first told by a medical person that you had kidney failure? Indicate the actual age. Don't know =999  
      __  

9. Are you currently on renal dialysis?  
   __ | __ | __  

10. Have you ever had kidney transplant?  
    __ | __ | __  
    a) If Yes, is the new kidney working well?  
       __ | __ | __  
    b) If No, are you waiting for a kidney transplant?  
       __ | __ | __  

11. Cirrhosis of the liver?  
    __ | __ | __  

12. LUNG PROBLEMS  
    a) Emphysema?  
       __ | __ | __  
    b) Hay fever?  
       __ | __ | __  
    c) Chronic bronchitis?  
       __ | __ | __  
    d) Asthma?  
       __ | __ | __  
    If YES" for asthma, do you still have it now?  
       __ | __ | __  

13. Have you had a heart catheterization?  
    Yes | No |  
    __ | __ | __  
    (A heart catheterization is a study in which a tube is inserted into the heart through the groin or arm to see how the heart works)  
    __ | __ | __  
    a) If "YES," when and where (most recent)?  
       _mo_/_day_/_yr_  
           hospital/clinic:  

14. Have you ever had a diagnostic exercise test or Treadmill test to check your heart?  
    Yes | No |  
    __ | __ | __  
    __ | __ | __  
    a) If "YES," when and where?  
       _mo_/_day_/_yr_  
           hospital/clinic:  

Has a doctor ever told you that you had any of the following conditions?  
(If more than one episode, enter information for the MOST RECENT)  

15. Heart failure?  
    Yes | No |  
    __ | __ | __  
    __ | __ | __  
    a) If YES," when and where?  
       _mo_/_day_/_yr_  
           hospital/clinic:  
    b) If YES," do you still have heart failure now?  
       __ | __ | __  

16. Heart attack?  
    Yes | No |  
    __ | __ | __  
    __ | __ | __  
    a) If YES," when and where?  
       _mo_/_day_/_yr_  
           hospital/clinic:  

---

Strong Heart Family Study - 06/20/97  
Medical History Form
17. Any other heart trouble?  Yes [ ]  No [ ]  Unknown [ ]
If "YES," please specify type: ____________________________
   a) If YES, when and where? ____________________________
      hospital/clinic: ____________________________
18. Stroke?  Yes [ ]  No [ ]  Unknown [ ]
   a) If YES, when and where? ____________________________
      hospital/clinic: ____________________________
19. Have you ever had surgery on your chest? Yes [ ]  No [ ] (skip to Q20)
   a) Was it heart surgery? Yes [ ]  No [ ] (skip to Q20)
      If "Yes," which surgery have you had?
   i) Bypass? Yes [ ]  No [ ]
      If "Yes," when and where (most recent)? ____________________________
         hospital/clinic: ____________________________
   ii) Valvular repair/replacement? Yes [ ]  No [ ]
      If "Yes," when and where (most recent)? ____________________________
         hospital/clinic: ____________________________
   iii) Pacemaker? Yes [ ]  No [ ]
      If "Yes," when and where (most recent)? ____________________________
         hospital/clinic: ____________________________
   iv) Other? Yes [ ]  No [ ]
      If "Yes," when and where (most recent)? ____________________________
         hospital/clinic: ____________________________
      Please specify: ____________________________

C. ACCESS TO MEDICAL CARE:

20. Source of medical care: In the past 5 years, have you received any medical care at: What is your usual source of medical care: (Check only ONE)
   a) IHS facility [ ]  [ ]
   b) Tribal facility [ ]  [ ]
   c) Private facility [ ]  [ ]
   d) Private practitioner [ ]  [ ]
   e) Traditional healer [ ]  [ ]
   f) VA/military facility [ ]  [ ]
   g) Health maint. org. (HMO) [ ]  [ ]
   h) Other, list ____________________________ [ ]  [ ]
   i) Nowhere [ ]  [ ]

21. Do you receive most of your outpatient care in...?
   A hospital emergency room [ ]
   A clinic [ ]
   A private doctor's office [ ]
22. In addition to IHS coverage, what health insurance do you have? (Check all that apply)
   None ______1 Veteran/military hospital ______5
   Private health insurance ______2 HMO ______6
   Medicaid ______3 Other, list ____________________ ______7
   Medicare ______4

23. How do you get to your usual healthcare provider? (Check only one)
   Myself ______1
   Family member ______2
   Friend ______3
   Community health representative (CHR) ______4
   Paid driver ______5

24. How much does it usually cost, out of pocket, for transportation to your usual healthcare provider? $_____

25. On the average, how long does it take you to get to your usual source of medical care?
   Less than 15 minutes ______1 45 to 60 minutes ______4
   15 to 30 minutes ______2 1 to 2 hours ______5
   31 to 45 minutes ______3 More than 2 hours ______6

26. Does your usual source of medical care see patients by appointment?
   Yes ______1 No ______2

27. Once you get to your usual source of medical care, how long do you usually have to wait
to see a healthcare provider?
   Less than 15 minutes ______1 45 to 60 minutes ______4
   15 to 30 minutes ______2 1 to 2 hours ______5
   31 to 45 minutes ______3 More than 2 hours ______6

28. If you need to be seen before your appointment, can you walk in and be seen?
   Yes ______1 (go to a.) No ______2 (go to b.)
   a) As a walk-in, how long does it usually take you to be seen by a physician
      or a physician’s assistant?
      Less than 15 minutes ______1 45 to 60 minutes ______4
      15 to 30 minutes ______2 1 to 2 hours ______5
      31 to 45 minutes ______3 More than 2 hours ______6
   b) How long does it usually take you to get an extra appointment?
      2 days or less ______1 3 to 4 weeks ______4
      3 days to 1 week ______2 More than 4 weeks ______5
      1 to 2 weeks ______3

29. How much do you have to pay “out-of-pocket” to see your usual healthcare provider for an outpatient visit, excluding travel costs? $_____

30. Did the participant complete the interview?
   Yes, completed the interview ______1 No, refused all questions ______2

IS THE PARTICIPANT FEMALE? Yes ______1 (go to next page) No ______2

IF THE PARTICIPANT IS MALE, GO TO ROSE QUESTIONNAIRE

31. Interviewer:

32. Date of interview:

---

Strong Heart Family Study - 06/20/97  Medical History Form
THE STRONG HEART STUDY III — FAMILY STUDY

REPRODUCTION AND HORMONE USE (WOMEN ONLY)

SHS Family I.D. |________|________|________|________|________| SHS. I.D.: |________|________|________|________|

"The following questions are related to your childbearing history and childbearing organs".
(For Q1 - Q4, use 999 for Unknown)

1. How many times have you been pregnant? (gravidity) |________|
2. How many of your pregnancies resulted in a live birth (parity)? |________|
3. How many living children do you have? |________|
4. How many pregnancies did you lose? |________|
5. Have you ever used birth control pills? Yes |__| 1  No |__| 2 (go to Q8)
6. How old were you when you started to use birth control pills? 
   Indicate the age in years. 999=unknown |________|
7. How many years altogether did you use them? |________|
   Specify the duration in years. 0=less than 6 months, 1=6-12 months, 999=unknown.
8. Have your menstrual cycles stopped? Yes |__| 1  No |__| 2 (go to Q12)
9. If 'YES', have they stopped for 12 months or more? Yes |__| 1  No |__| 2
10. Was your menopause natural or did you have surgery? 
    Natural |__| 1 (go to Q11) Surgery |__| 2
    a) If SURGERY, was only your uterus removed? 
       Yes |__| 1  No |__| 2  Unknown |__| 9
11. How old were you when your periods stopped completely? 
    Indicate age in years 999=unknown |________|
"ESTROGEN is a female hormone that may be taken after a hysterectomy or menopause."

12. Except for birth control pills, have you ever taken estrogen - either pills, as a patch, or by shot, for any reason?  
   Yes | [ ]1  
   No | [ ]2  (go to Q15)

   a) If "YES," are you still taking estrogen? Yes | [ ]1  (go to Q12)  
      No | [ ]2

      i) If "No," why did you stop taking estrogen?  
         YES  NO  UNKNOWN
         Caused Bleeding | [ ]1  | [ ]2  | [ ]9
         Made breasts tender | [ ]1  | [ ]2  | [ ]9
         Made you feel bloated | [ ]1  | [ ]2  | [ ]9
         Made you feel "funny," didn't like the way you felt | [ ]1  | [ ]2  | [ ]9
         Do not like taking any medicines | [ ]1  | [ ]2  | [ ]9
         Too expensive | [ ]1  | [ ]2  | [ ]9
         Doctor's advice | [ ]1  | [ ]2  | [ ]9
         Concerned about long-term side effects | [ ]1  | [ ]2  | [ ]9
         Other

   b) Do/DID you use estrogen for
      YES  NO  NOT SURE
      i) post surgery (hysterectomy and removal of ovaries) | [ ]1  | [ ]2  | [ ]9
      ii) relief of menopause symptoms | [ ]1  | [ ]2  | [ ]9
      iii) prevent bone loss | [ ]1  | [ ]2  | [ ]9
      iv) protect against heart disease | [ ]1  | [ ]2  | [ ]9
      v) doctor's advice | [ ]1  | [ ]2  | [ ]9

13. How old were you when you started using estrogen?  
    Indicate age in years.  

14. How many years altogether did you take estrogen? 
    Specify duration in years.  
    (If less than 3 months, record 0. If more than 3 months but less than 1 year, record 1)

15. Did the participant complete the interview?  
    Yes, completed the interview | [ ]1
    No, refused all questions | [ ]2

16. Interviewer:

17. Date of interview:
   [ ] mo/ [ ] day/ [ ] yr
THE STRONG HEART STUDY III — FAMILY STUDY
ROSE QUESTIONNAIRE FOR ANGINA AND INTERMITTENT CLAUDICATION

Section A: Chest Pain on Effort

1. Have you ever had any pain or discomfort in your chest?
   Yes [1]  No [2]  (go to Section C)

2. Do you get it when you walk uphill, upstairs or hurry?
   Yes [1]  No [2]  (go to Section B)
   Never hurries or walks uphill or upstairs [3]  
   Unable to walk [4]  (go to Section B)

3. Do you get it when you walk at an ordinary pace on the level?
   Yes [1]  No [2]

4. What do you do if you get it while you are walking?
   Stop or slow down [1]  Carry on [2]  (go to Section B)
   (Record "stop or slow down" if subject carries on after taking nitroglycerine.)

5. If you stand still, what happens to it?
   Relieved [1]  Not relieved [2]  (go to Section B)

6. How soon?
   10 minutes or less [1]  More than 10 minutes [2]  (go to Section B)

7. Will you show me where it was?
   (Record all areas mentioned. Use the diagram below to show the location if participant cannot tell exactly.)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sternum (upper or middle)</td>
<td>[1]</td>
</tr>
<tr>
<td>Sternum (lower)</td>
<td>[1]</td>
</tr>
<tr>
<td>Left anterior chest</td>
<td>[1]</td>
</tr>
<tr>
<td>Left arm</td>
<td>[1]</td>
</tr>
<tr>
<td>Other:</td>
<td>[1]</td>
</tr>
</tbody>
</table>

8. Do you feel it anywhere else?
   Yes [1]  No [2]

If “YES,” record additional information: ____________________________
Section B: Possible Infarction

9. Have you ever had a severe pain across the front of your chest lasting for half an hour more? Yes [ ] No [ ]

Section C: Intermittent Claudication

10. Do you get pain in either leg on walking? Yes [ ] No [ ] (go to Q19) Unable to walk [ ] (go to Q19).

11. Does this pain ever begin when you are standing still or sitting? Yes [ ] (go to Q19) No [ ]

12. In what part of your leg did you feel it? Pain includes calf/calves [ ] Pain does not include calf/calves [ ] (go to Q19)
If calves not mentioned, ask: "Anywhere else?" Please specify: __________________________

13. Do you get it if you walk uphill or hurry? Yes [ ] No [ ] (go to Q19) Never hurries or walks uphill [ ]

14. Do you get it if you walk at an ordinary pace on the level? Yes [ ] No [ ]

15. Does the pain ever disappear while you are walking? Yes [ ] (go to Q19) No [ ]

16. What do you do if you get it when you are walking? Stop or slow down [ ] Carry on [ ] (go to Q19)

17. What happens to it if you stand still? Relieved [ ] Not Relieved [ ] (go to Q19)

18. How soon? 10 minutes or less [ ] More than 10 minutes [ ]

END OF ROSE QUESTIONNAIRE

19. Did the participant complete the interview? Yes, completed the interview [ ]
No, refused all questions [ ]

20. Interviewer: ______________________

21. Date of interview: __________/________/________
THE STRONG HEART STUDY III — FAMILY STUDY
RESPIRATORY QUESTIONS

SHS Family I.D.: ________________________ SHS. I.D.: ________________________

1. a) Do you usually have a cough? Yes [ ] 1 No [ ] 2 (skip to Q3)
b) Do you usually cough as much as 4 to 6 times a day, 4 or more days out of the week? Yes [ ] 1 No [ ] 2
c) Do you usually cough at all on getting up, or first thing in the morning? Yes [ ] 1 No [ ] 2
d) Do you usually cough like this on most days for 3 consecutive months or more during the year? Yes [ ] 1 No [ ] 2
e) How long have you had this cough? [_____] years/ [_____] months

2. Do you usually bring up phlegm from your chest when you cough? Yes [ ] 1 No [ ] 2

3. Does your chest ever sound wheezy or whistling:
   a) when you have a cold? [ ] 1 [ ] 2
   b) occasionally apart from colds? [ ] 1 [ ] 2
   c) most days? [ ] 1 [ ] 2
   d) most nights? [ ] 1 [ ] 2

4. Have you ever had an attack of wheezing that has made you feel short of breath? Yes [ ] 1 No [ ] 2

5. Are you troubled by shortness of breath when hurrying on level ground or walking up a slight hill? Yes [ ] 1 No [ ] 2 (go to Q10) Unable to walk [ ] 4 (go to Q10)

6. Do you have to walk slower on level ground than people of your age due to breathlessness? Yes [ ] 1 No [ ] 2

7. Do you ever have to stop for breath when walking at your own pace on level ground? Yes [ ] 1 No [ ] 2

8. Do you ever have to stop for breath after walking 100 yards (the length of a football field) or after a few minutes on level ground? Yes [ ] 1 No [ ] 2
9. Are you too breathless to leave the house or breathless after dressing or undressing?  
   Yes [___]1  No [___]2

10. Did you have any lung trouble before the age of 16?  
    Yes [___]1  No [___]2

11. Have you ever been told you snore?  
    Yes [___]1  No [___]2

12. Did the participant complete the interview?  
    Yes, completed the interview [___]1  
    No, refused all questions [___]2

13. Interviewer: ____________________________

14. Date of interview: ________________ 
   __________/________/________ yr
### THE STRONG HEART STUDY III — FAMILY STUDY
CARDIOVASCULAR DISEASE IN AMERICAN INDIANS
PHYSICAL EXAMINATION

<table>
<thead>
<tr>
<th>SHS Family I.D.</th>
<th>SHS. I.D.</th>
</tr>
</thead>
</table>

### I. TOBACCO, CAFFEINE, AND ALCOHOL USE

*Before examinations start, check TOBACCO AND CAFFEINE USE*

“Tobacco, alcohol, caffeine and activity levels can change the results of the examinations and laboratory tests we will do today. Because of this, we will ask you a few questions about them."

1. **Have you smoked or used chewing tobacco or snuff within the last 4 hours?**
   - Yes [ ]
   - No [ ] (skip to Q2)
   - **a)** How long ago did you last smoke or last use chewing tobacco or snuff?
     - Specify the lag by hours.
     - 
   - **b)** If less than an hour, specify the minutes.
     - 

2. **How many alcoholic drinks have you had in the last 24 hours?**
   - (0 = None, 999 = Refused)
     
3. **Have you done any vigorous physical activity in the last 24 hours?**
   - Yes [ ]
   - No [ ]

4. **Have you had any coffee, tea, caffeinated soft drink or chocolate within the last 4 hours?**
   - Yes [ ]
   - No [ ] (skip to instruction below)
   - **a)** How long ago did you last have any coffee, tea, caffeinated soft drink or chocolate?
     - Specify the lag by hours.
     - 
   - **b)** If less than an hour, specify the minutes
     - 

**Instructions:**

“We ask you not to use any tobacco, caffeine or alcohol until you have completed your visit with us today. We do this so that your test results are not affected by use of these substances. If you must use any of these, please tell us that you did before you leave.”
II. EXAMINATION OF EXTREMITIES FOR AMPUTATIONS

5. Are any extremities missing? Yes [ ] No [ ] (Skip to next Section)

If "YES" to amputation, Please code the cause of amputation:
1 = Diabetes
2 = Trauma
3 = Congenital
4 = Other, please specify
9 = Unknown

<table>
<thead>
<tr>
<th>Extremities</th>
<th>Check if Missing</th>
<th>Cause</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Right arm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b. Right hand</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. Right finger(s)</td>
<td># Missing</td>
<td></td>
</tr>
<tr>
<td>d. Left arm</td>
<td></td>
<td></td>
</tr>
<tr>
<td>e. Left hand</td>
<td></td>
<td></td>
</tr>
<tr>
<td>f. Left fingers</td>
<td># Missing</td>
<td></td>
</tr>
<tr>
<td>g. Right leg above knee</td>
<td># Missing</td>
<td></td>
</tr>
<tr>
<td>h. Right leg below knee</td>
<td></td>
<td></td>
</tr>
<tr>
<td>i. Right foot</td>
<td></td>
<td></td>
</tr>
<tr>
<td>j. Right toe(s)</td>
<td># Missing</td>
<td></td>
</tr>
<tr>
<td>k. Left leg above knee</td>
<td></td>
<td></td>
</tr>
<tr>
<td>l. Left leg below knee</td>
<td></td>
<td></td>
</tr>
<tr>
<td>m. Left foot</td>
<td></td>
<td></td>
</tr>
<tr>
<td>n. Left toe(s)</td>
<td># Missing</td>
<td></td>
</tr>
</tbody>
</table>

III. BLOOD PRESSURE

6. Right arm circumference, measured in centimeters (cm) Midway between acromion and olecranon

7. Cuff size (arm circumference in brackets)
   Pediatric (under 24cm) [ ]
   Large arm (33-41cm) [ ]
   Regular arm (24-32cm) [ ]
   Thigh (>41cm) [ ]

8. Pulse obliteration pressure

9. Seated Blood Pressure:
   a) First Blood Pressure Measurement
   b) Second Blood Pressure Measurement
   c) Third Blood Pressure Measurement

   Systolic BP

10. Were the above blood pressures taken from LEFT arm because of missing right arm or some other reason?
    Yes [ ] Specify: __________________________
    No [ ]

11. Recorder ID (For the SHS staff who took Bps):

   __________________________
IV. GIRTH MEASUREMENT:

<table>
<thead>
<tr>
<th></th>
<th>METRIC SYSTEM (centimeters/cm/kg)</th>
<th>BRITISH SYSTEM inches / pounds</th>
</tr>
</thead>
<tbody>
<tr>
<td>12. Height (Standing)</td>
<td>__________ cm</td>
<td>__________ in</td>
</tr>
<tr>
<td>13. Weight</td>
<td>__________ kg</td>
<td>__________ lb</td>
</tr>
<tr>
<td>14. Hip circumference</td>
<td>__________ cm</td>
<td>__________ in</td>
</tr>
<tr>
<td>15. Waist measurement at umbilicus</td>
<td>__________ cm</td>
<td>__________ in</td>
</tr>
</tbody>
</table>

V. PEDAL PULSES AND EDEMA

<table>
<thead>
<tr>
<th></th>
<th>PRESENT</th>
<th>ABSENT</th>
<th>MISSING LIMBS</th>
<th>UNABLE TO ASSESS</th>
</tr>
</thead>
<tbody>
<tr>
<td>16. Right posterior tibial pulse</td>
<td>__1</td>
<td>__2</td>
<td>__3</td>
<td>__4</td>
</tr>
<tr>
<td>17. Right dorsalis pedis pulse</td>
<td>__1</td>
<td>__2</td>
<td>__3</td>
<td>__4</td>
</tr>
<tr>
<td>18. Left posterior tibial pulse</td>
<td>__1</td>
<td>__2</td>
<td>__3</td>
<td>__4</td>
</tr>
<tr>
<td>19. Left dorsalis pedis pulse</td>
<td>__1</td>
<td>__2</td>
<td>__3</td>
<td>__4</td>
</tr>
<tr>
<td>20. Pedal edema</td>
<td>Absent</td>
<td>__1</td>
<td>Mild</td>
<td>__2</td>
</tr>
</tbody>
</table>

VI. IMPEDANCE MEASUREMENT

21. a) Was impedance taken? Yes __1 (go to b) No __2

   if No, due to: Amputation __1 Wound/dressing __2 Cast __3 Refusal __4

   Go to Question 22

   b) Taken on left side? Yes __1 No __2 (go to c)

   if Yes, due to: Amputation __1 Wound/dressing __2 Cast __3 Refusal __4

   c) Resistance __________

VI. DOPPLER BLOOD PRESSURE

Doppler blood pressure is measured in the posterior tibial artery. If not audible, use dorsalis pedis. Use left arm if left arm was used for standard blood pressure reading.

0 = neither posterior tibial artery nor dorsalis pedis artery was audible.
888 = participant refuses or if blood pressure is not taken for a medical reason or amputation.
999 = unable to obliterate.

<table>
<thead>
<tr>
<th></th>
<th>Right arm</th>
<th>Right ankle</th>
<th>Left ankle</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) First systolic B.P.</td>
<td>__________</td>
<td>__________</td>
<td>__________</td>
</tr>
<tr>
<td>b) Second systolic B.P.</td>
<td>__________</td>
<td>__________</td>
<td>__________</td>
</tr>
<tr>
<td>c) Location</td>
<td>Posterior tibial __1</td>
<td>Posterior tibial __1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Dorsalis pedis __2</td>
<td>Dorsalis pedis __2</td>
<td></td>
</tr>
</tbody>
</table>

23. Was an ECG performed? Yes __1 No __2

24. Was breath CO done? Yes __1 (go to a) No __2 (go to Q25)

   a) Ambient: __________ CO[ppm]: __________ __________ __________ __________

   Ambient valid entries: -9 to +9 1st 2nd 3rd 4th

   CO: valid entries Generally 0 to 99 (usually only the the 1st and 2nd entries will be completed)

VIII. ADMINISTRATIVE INFORMATION

25. Did the participant complete the interview? Yes, completed the interview __1 No, refused all questions __2

26. SHS Code of person completing this form __________

27. Date of Examination: __________/_________
THE STRONG HEART STUDY III — FAMILY STUDY

DIABETIC FOOT SCREEN

SHS Family I.D. [_________] SHS. I.D.: [_________]
IHS Chart Number [_________]

1. Is there an ulcer on:
   a) Right foot? Yes [__] No [__]
   b) Left foot Yes [__] No [__]

2. Is there a history of foot ulcer? Yes [__] No [__]

3. Is either foot numb? Yes [__] No [__]

4. Label: Sensory level with a "+" if the participant can feel the 10 gram filament and "-" if he/she cannot feel the 10 g filament. Test each site only once. Testing may not be accurate in areas where thick callous or bunion is present.
   a. Right top [__] [__]
   b. Right large toe [__] [__]
   c. Right middle toe [__] [__]
   d. Right small toe [__] [__]
   e. Right sole front [__] [__]
   f. Right sole right [__] [__]
   g. Right sole left [__] [__]
   h. Right sole back right [__] [__]
   i. Right sole back left [__] [__]
   j. Right heel [__] [__]

5. Unable to measure due to medical reasons? Yes [__] No [__]
   (If the right foot has been amputated, conduct exam on the left foot)

6. Measured on left foot? Yes [__] No [__]
   a) If "Yes," due to right foot:
      Amputation [__] Wound/dressing [__] Cast [__] Refusal [__]

7. RESULTS:
   a. Number of positive answers [__] [__]
   b. Number of sites tested [__] [__]

8. Did the participant complete the interview? Yes, completed the interview [__] No Foot Exam [__]

9. Examined by: [__] [__] [__]

10. Date of Examination: [__] [__] [__] [__] [__] [__]

Strong Heart Family Study - 06/20/97

Diabetic Foot Screen
THE STRONG HEART STUDY III — FAMILY STUDY
GTT CHECKLIST

SHS Family I.D.: ________ ________ ________ ________ SHS. I.D.: ________ ________ ________ ________

1. Fasting One Touch glucose result. 999 = not done

2. Is FASTING blood sample taken?
   Yes, and participant has been fasting
   Yes, but participant has NOT been fasting
   No, participant has not been fasting
   Other, specify ____________________________
   No, participant refused

3. When was the last time you ate (use military time)

4. Time of collection of fasting samples

5. Time of collection of urine sample

6. Was participant given 75 gram glucose beverage? Yes [ ] [ ] No [ ] [ ]
   a) If Yes, Time the 75 gram glucose beverage was consumed
   b) If No, why did participant not have OGTT? Check the appropriate answer(s)
      i) diabetes, on insulin treatment
      ii) diabetes, on oral agent
      iii) One Touch > 225 mg/dl
      iv) refusal to have OGTT done

7. Time of 2-hr blood sample

8. If the participant vomited after the glucose beverage was given, check here.

   If "Yes," when? (Indicate the time):

   Comments: ____________________________________________

9. SHS Code of person completing this form

10. Today's Date
    
    mo  day  yr
1. How is this questionnaire administered?
   By interviewer [____]1
   By self [____]2
   Refused [____]3
   
   This is a list of things which may or may not affect a person's chances of getting heart disease. After you read each one, answer as to how much you think it affects a person's chances of getting heart disease.

2. Cigarette Smoking? [____]0
4. High Blood Pressure? [____]0
5. Diabetes? [____]0
6. Worry, Anxiety, or Stress? [____]0
7. Being very overweight? [____]0
8. Eating a diet high in animal fat? (For example, foods that contain red meat, cheese, butter, lard, etc.) [____]0
9. Family history of heart disease? [____]0
10. Not exercising regularly? [____]0

11. Interviewer

12. Date completed
   mo/day/yr

---

Strong Heart Family Study - 06/20/97
Risk Factor Knowledge Survey
How is this questionnaire administered?

<table>
<thead>
<tr>
<th>By interviewer</th>
<th>By self</th>
<th>Refused</th>
</tr>
</thead>
<tbody>
<tr>
<td>____1</td>
<td>____2</td>
<td>____3</td>
</tr>
</tbody>
</table>

1. In general, would you say your health is:
   (Please Check Only One)
   - Excellent..............   ____1
   - Very good..............  ____2
   - Good..................... ____3
   - Fair..................... ____4
   - Poor..................... ____5

2. Compared to one year ago, how would you rate your health in general, now?
   (Please Check Only One)
   - Much better than one year ago............. ____1
   - Somewhat better than one year ago........ ____2
   - About the same............................ ____3
   - Somewhat worse than one year ago.......... ____4
   - Much worse than one year ago............. ____5

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(Please Circle One Number Per Line)

<table>
<thead>
<tr>
<th>Yes, Limited</th>
<th>Yes, Limited</th>
<th>No Not Limited</th>
</tr>
</thead>
<tbody>
<tr>
<td>a Lot</td>
<td>a Little</td>
<td>at All</td>
</tr>
</tbody>
</table>

3. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports............. ____1
4. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf............. ____1
5. Lifting or carrying groceries............................................. ____1
6. Climbing several flights of stairs................................. ____1
7. Climbing one flight of stairs.......................................... ____1
8. Bending, kneeling, or stooping........................................ ____1
9. Walking more than a mile................................................ ____1
10. Walking several blocks................................................... ____1
11. Walking one block......................................................... ____1
12. Bathing or dressing yourself......................................... ____1
During the PAST 4 WEEKS, have you had any of the following problems with your work or other regular daily activities AS A RESULT OF YOUR PHYSICAL HEALTH?

(Please Check One Answer Per Line)

13. Cut down on the amount of time you spend on work or other activities........................................... Yes | No
   | 1 | 2
14. Accomplish less than you would like........................................... Yes | No
   | 1 | 2
15. Were limited in the kind of work or other activities........................................... Yes | No
   | 1 | 2
16. Had difficulty performing the work or other activities (for example, it took extra effort)........................................... Yes | No
   | 1 | 2

During the PAST 4 WEEKS, have you had any of the following problems with your work or other regular daily activities AS A RESULT OF ANY EMOTIONAL PROBLEMS (such as feeling depressed or anxious)?

(Please Check One Answer Per Line)

17. Cut down on the amount of time you spend on work or other activities........................................... Yes | No
   | 1 | 2
18. Accomplish less than you would like........................................... Yes | No
   | 1 | 2
19. Didn’t do work or other activities as carefully as usual........................................... Yes | No
   | 1 | 2
20. During the PAST 4 WEEKS, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups
   (Please Check One Answer)
   Not at all........................................... Yes | No
     | 1 | 2
   Slightly........................................... Yes | No
     | 1 | 2
   Moderately........................................... Yes | No
     | 1 | 2
   Quite a bit........................................... Yes | No
     | 1 | 2
   Extremely........................................... Yes | No
     | 1 | 2
21. How much BODILY pain have you had during the PAST 4 WEEKS?
   (Please Check One Answer)
   None........................................... Yes | No
     | 1 | 2
   Very mild........................................... Yes | No
     | 1 | 2
   Mild........................................... Yes | No
     | 1 | 2
   Moderate........................................... Yes | No
     | 1 | 2
   Severe........................................... Yes | No
     | 1 | 2
   Very severe........................................... Yes | No
     | 1 | 2
22. During the PAST 4 WEEKS, how much did pain interfere with your normal work, (including both work outside the home and housework)?
   (Please Check One Answer)
   Not at all........................................... Yes | No
     | 1 | 2
   Slightly........................................... Yes | No
     | 1 | 2
   Moderately........................................... Yes | No
     | 1 | 2
   Quite a bit........................................... Yes | No
     | 1 | 2
   Extremely........................................... Yes | No
     | 1 | 2
These questions are about how you feel and how things have been with you during the PAST 4 WEEKS. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the PAST 4 WEEKS....

(Please Circle One Number Per Line)

| 23. Did you feel full of pep? | 1 | 2 | 3 | 4 | 5 | 6 |
| 24. Have you been a very nervous person? | 1 | 2 | 3 | 4 | 5 | 6 |
| 25. Have you felt so down in the dumps that nothing could cheer you up? | 1 | 2 | 3 | 4 | 5 | 6 |
| 26. Have you felt calm and peaceful? | 1 | 2 | 3 | 4 | 5 | 6 |
| 27. Did you have a lot of energy? | 1 | 2 | 3 | 4 | 5 | 6 |
| 28. Did you feel downhearted and blue? | 1 | 2 | 3 | 4 | 5 | 6 |
| 29. Did you feel worn out? | 1 | 2 | 3 | 4 | 5 | 6 |
| 30. Have you been a happy person? | 1 | 2 | 3 | 4 | 5 | 6 |
| 31. Did you feel tired? | 1 | 2 | 3 | 4 | 5 | 6 |

32. During the PAST 4 WEEKS, how much of the time has your PHYSICAL HEALTH or EMOTIONAL PROBLEMS interfered with your social activities (like visiting with friends, relatives, etc.)?

(Please Circle One Number)

All the time | 1 | Most of the time | 2 | Some of the time | 3 | a Little of the time | 4 | None of the time | 5 |

How TRUE or FALSE is each of the following statements?

(Please Circle One Number Per Line)

| 33. I seem to get sick a little easier than other people | 1 | 2 | 3 | 4 | 5 |
| 34. I am as healthy as anybody I know | 1 | 2 | 3 | 4 | 5 |
| 35. I expect my health to get worse | 1 | 2 | 3 | 4 | 5 |
| 36. My health is excellent | 1 | 2 | 3 | 4 | 5 |
| 37. Interview conducted in: English | 1 | Other | Specify: |
| 38. Interviewer |  |  |  |  |  |
| 39. Date completed |  |  |  |  |  |  |

Strong Heart Family Study - 06/20/97
Quality of Life Questionnaire
1. How is this questionnaire administered?
   By interviewer | 1 | By self | 2 | Refused | 3 |

Traditional Values/Culture:
2. Can you speak your native language?
   (interviewer should specify the language)? __________________________
   Yes, fluently | 1 | Yes, but not fluently | 2 | No | 3 (Skip to Q4)

3. How often do you speak your native language? (Please read options)
   Always | 1 | Almost always | 2 | Often | 3 |
   Seldom | 4 | Never | 5 | Not applicable | 6 |

The next several questions are about your own native lifestyle.
4. How much do you identify yourself with your own native culture?
   Not At All | 1 | A Little | 2 | Some | 3 | A Lot | 4 |

5. How much do you identify yourself with non-Indian culture?
   Not At All | 1 | A Little | 2 | Some | 3 | A Lot | 4 |

6. How comfortable do you feel in your own native culture?
   Not At All | 1 | A Little | 2 | Some | 3 | A Lot | 4 |

7. How comfortable do you feel in the non-Indian culture?
   Not At All | 1 | A Little | 2 | Some | 3 | A Lot | 4 |

8. Interviewer __________________________

9. Date completed ____________________________
   _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _
1. Please check all activities listed below that you have done more than 10 times in the past year:

- Jogging (outdoor, treadmill)...
- Swimming (laps, snorkeling)...
- Bicycling (stationary, outdoor)...
- Softball/Baseball...
- Canoeing/Rowing/Kayaking...
- Snow skiing (Nordic, X-country, downhill)...
- Strength/Weight training...
- Skating (roller, ice, blading)...
- Martial Arts (karate, judo, etc.)...
- Calisthenics/Toning exercises...
- Wood chopping...
- Walking for exercise...

For each activity you checked above, check the months during which you participated in those activities over the past year (12 months), then estimate the average amount of time you spent in each activity

<table>
<thead>
<tr>
<th>Activity No.</th>
<th>Jan</th>
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<th>Mar</th>
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<th>May</th>
<th>Jun</th>
<th>Jul</th>
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<th>Average of times per month</th>
<th>Average of minutes each time</th>
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2. In general, how many HOURS per DAY do you usually spend watching TV? _ _ _ _ _ # of hours

3. Over this past year, have you spent more than one week confined to a bed or chair as a result of an injury, illness or surgery? Yes _ _ _ _ _ No _ _ _ _ _ 
   If "Yes," how many weeks over this past year were you confined to a bed or chair? _ _ _ _ _ # of weeks
4. Do you have difficulty doing any of the following activities?
   a. Getting in or out of a bed or chair.  
      Yes [___]  No [___]  
   b. Walking across a small room without resting  
      Yes [___]  No [___]  
   c. Walking for 10 minutes without resting  
      Yes [___]  No [___]  

5. Did you ever compete in an individual or team sport (not including any time spent in sports 
   performed during school physical education classes)?  
   Yes [___]  No [___]  
   If "Yes," how many total years did you participate 
   in competitive sports? 
   
   # of years  

6. Have you had a job for more than one month over this past year, 
   from ________ month of last year to ________ month of this year?  
   List all jobs that the individual held over the past year, for more than one month. Account for 
   all 12 months of the past year. If unemployment/disabled/retired/homemaker/student during 
   all or part of the past year, list as such and probe for job activities of a normal 8-hour work-day, 
   5-day, work-week.  

<table>
<thead>
<tr>
<th>Job Name</th>
<th>Job Code</th>
<th>Walk/bicycle to/from work</th>
<th>AVG JOB SCHEDULE</th>
<th>Hrs spent sitting at work</th>
<th>Check the category that best describes job activities when not sitting</th>
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Out of the total number of "Hrs/Day," the individual reported working at this "job," how much of this time was 
usually spent sitting? Enter this number in "Hrs Sitting" col., then place a check (✓) in the category which best 
describes their job activities when they were not sitting.  

Category A  
(Includes all sitting activities)  
Sitting  
Standing still w/o heavy lifting  
Light cleaning - ironing, cooking, washing dusting  
Driving a bus, taxi, tractor  
Jewelry making/weaving  
General office work  
Occasional/short distance walking  

Category B  
(includes most indoor activities)  
Carrying light loads  
Continuous walking  
Heavy cleaning - mopping, sweeping, scrubbing, vacuuming  
Gardening - planting, weeding  
Painting/Plastering  
Plumbing/Welding  
Electrical work:  
Sheep herding  

Category C  
(heavy industrial work, outdoor construction, farming)  
Carrying moderate to heavy loads  
Heavy construction  
Farming - hoeing, digging  
mowing, raking  
Digging ditches, shoveling  
Chopping (axe), sawing wood  
Tree/pole climbing  
Water/coal/wood hauling  

Job Codes  
Employed (or volunteer):  
1. Student  
2. Home Maker  
3. Retired  
4. Disabled  
5. Unemployed  
6. Armed Services  
7. Office worker  
8. Non-office worker  

Interviewer:  
Date of interview: [___] [___] [___] [___] 

Strong Heart Family Study - 06/20/97  
Modifiable Activity Questionnaire
THE STRONG HEART STUDY III
CBC Results

SHS Family Study ID|SHS ID number:

Each Center's Results May Appear in Different Order, Please Be Careful When Entering the Results

1. WBC (10^9/L)
2. RBC (10^{12}/L)
3. HGB (g/dL)
4. HCT (%)
5. MCV (fL)
6. MCH (pg)
7. MCHC (g/dL)
8. RDW (%)
9. Platelet count (PLT .. 10^9/L)
10. MPV (fL)

DIFFERENTIAL

Each Center's Results May Appear in Different Order, Please Be Careful When Entering the Results

11. NEUT (%)
12. LYMPH (%)
13. MONO (%)
14. EOS (%)
15. BASO (%)
16. Code number of person completing this form
17. Date of data collection

mo day yr
STRONG HEART STUDY III

FAMILY STUDY

Screening for Pregnancy and Lactation

WOMEN ONLY

SHS Family Study ID ____________ SHS ID number: ____________

Administered to women < 50 years of age at time consent is obtained. It can be self-administered.

1. Are you pregnant? Yes [ ] 1  No [ ] 2  Not Sure [ ] 9
2. When was your last menstrual period?
   If unknown, leave the boxes blank
   [ ] 1 [ ] 2 [ ] 3 [ ] 4 [ ] 5 [ ] 6 [ ] 7 [ ] 8
   mo  [ ] day  [ ] yr
3. When did your last pregnancy end?
   Never pregnant = 01-01-1001
   Currently pregnant = 01-01-1900
   [ ] 1 [ ] 2 [ ] 3 [ ] 4 [ ] 5 [ ] 6 [ ] 7 [ ] 8
   mo  [ ] day  [ ] yr
4. Are you now breast feeding? Yes [ ] 1  No [ ] 2
5. If “yes”, how long you have been breast feeding (in months)? [ ]

Women who think they may be pregnant should not be examined or have blood drawn, because pregnancy changes the blood lipids. Women who think they may be pregnant should be referred for prenatal care. Women can participate in the Family Study six weeks post partum even if they are lactating.

6. Code number of person completing this form [ ]
7. Date of data collection [ ]
   mo  [ ] day  [ ] yr
THE STRONG HEART STUDY III  
CARDIOVASCULAR DISEASE IN AMERICAN INDIANS

ID number:

A. MEDICATION RECEPTION:

As you know, the Strong Heart Study will be describing prescription medications that its participants are using. We are particularly interested in medications your doctor prescribed for you that were filled by a pharmacist. These include pills, dermal patches, eye drops, creams, salves, and injections. The letter you received about this appointment included a plastic medications bag for all your current medications and asked you to bring them to the clinic.

Have you brought that bag with you?

Yes ___1  
No ___2 (Make arrangements to obtain)

Took no meds ___3 (Go to Section C)

Refused ___9 (Cite reasons for refusal in the space below)

Reasons for refusal: ____________________________

: Go to Section C

B. PRESCRIPTION MEDICATIONS

1. Copy the name of the medication, the strength in milligrams (mg), and the total number of doses prescribed per day, week or month. (Include pills, dermal patches, eye drops, creams, salves, and injections)

<table>
<thead>
<tr>
<th>Medication Name</th>
<th>Strength (mg)</th>
<th>Number Prescribed</th>
<th>PRN Medicine?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Print the first 20 letters only. Please print clearly</td>
<td>Write the decimal as one of the digits</td>
<td>Circle: day week month</td>
<td></td>
</tr>
</tbody>
</table>

2. On the average during the last two weeks, how many of these pills did you take a day/week/month?

Number unable to transcribe: ____________
C. OVER-THE-COUNTER MEDICATIONS

3. Copy the name of the medication, the strength in milligrams (mg), and the total number of doses prescribed per day, week or month. (Include pills, dermal patches, eye drops, creams, salves, and injections)

4. On the average during the last two weeks, how many of these pills did you take a day/week/month?

<table>
<thead>
<tr>
<th>Medication Name</th>
<th>Strength (mg)</th>
<th>Circle: day week month</th>
</tr>
</thead>
<tbody>
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<td>1</td>
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<td>❑ D W M</td>
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</tbody>
</table>

Comments:


5. Interviewer: [Signature]

6. Date of interview: [Date]
## APPENDIX 4 - THE STRONG HEART STUDY III
### DIETARY INTAKE - 24-HOUR RECALL

<table>
<thead>
<tr>
<th>Participant's ID Number (SHS)</th>
<th>Date of Visit</th>
<th>Social Security Number</th>
<th>Date of Birth</th>
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</table>

**Participant's Name**

**Initials**

**Interviewer's ID**

**Intake Day**

1 = Sun  
2 = Mon  
3 = Tue  
4 = Wed  
5 = Thu  
6 = Fri  
7 = Sat  

**Intake Day**

**Interviewer's opinion of information**

1 = Reliable  
2 = Unable to recall one or more meals  
3 = Unreliable for other reasons  

**Was amount eaten**

1 = Typical  
2 = Considerably less than usual  
3 = Considerably more than usual  

**Did you take any supplements (vitamins, minerals, etc)?**

1 = No  
2 = Yes  
(If "Yes," describe under Food and Beverage, below)

**Place of interview:**

1 = Clinic  
2 = Home  

**Explanation of (*) items in the COMMENTS space provided below**

| Line No. | Prepared: 1 = At home  
2 = Restaurant  
3 = Other |
|----------|-------------------------|
|          | Time eaten  
(a.m., p.m.) |
|          | Hour  
Minute |
| 01       |            |
| 02       |            |
| 03       |            |
| 04       |            |
| 05       |            |

**Salt added in preparation?**

1 = No  
2 = Yes  
9 = Unknown

**Was fat added in preparation?**

1 = No  
2 = Yes  
9 = Unknown

Please note type of fat used, in description

**Food and Beverage**

**amt.**

**Complete Description**

**COMMENTS (Give line no. when appropriate):**
<table>
<thead>
<tr>
<th>Line No.</th>
<th>Prepared: 1=At home, 2=Restaurant, 3=Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time eaten: a=a.m., p=p.m.</td>
<td></td>
</tr>
<tr>
<td>Hour</td>
<td>Minute</td>
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<th>Salt added in preparation? 1=No, 2=Yes, 9=Unknown</th>
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<th>Food and Beverage</th>
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<th>Was fat added in preparation? 1=No, 2=Yes, 9=Unknown</th>
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<th>Complete Description</th>
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COMMENTS (Give line no. when appropriate):
| Line No. | Prepared: 1=At home  
2=Restaurant  
3=Other | Time eaten  
a=a.m., p=p.m. | Salt added in preparation?  
1=No, 2=Yes, 9=Unknown | Was fat added in preparation?  
1=No, 2=Yes, 9=Unknown  
Please note type of fat used, in description | Food and Beverage | amt. | Complete Description |
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COMMENTS (Give line no. when appropriate):
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<th>Prepared:</th>
<th>1=At home</th>
<th>2=Restaurant, 3=Other</th>
<th>Salt added in preparation?</th>
<th>1=No, 2=Yes, 9=Unknown</th>
<th>Was fat added in preparation?</th>
<th>1=No, 2=Yes, 9=Unknown</th>
<th>Food and Beverage</th>
<th>amt.</th>
<th>Complete Description</th>
<th>Comments (Give line no. when appropriate):</th>
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