

GENERAL HISTORY (GH)

Chronic Kidney Disease in Children (CKiD)

SECTION A: GENERAL INFORMATION

A1. PARTICIPANT ID: AFFIX ID LABEL OR ENTER NUMBER IF ID LABEL IS NOT AVAILABLE

|_| - |_|_| - |_|_|_|

A2. CKiD VISIT #:

0 1 a

A3. FORM VERSION:

0 8 / 0 1 / 2 1

A4. DATE OF VISIT:

___ / ___ / ___
M M D D Y Y Y Y

A5. SITE COORDINATOR'S INITIALS: _____

A6. INDICATE PERSON COMPLETING THE FORM

Child/young adult.....	1
Parent or other adult.....	2
Both (Parent and Child/young adult)	3

For each question, fill in the answer or circle the number that best matches the respondent's answer. Circle -8 for "Don't Know" responses. If a participant declines to answer a question, document -7 to the right of the response choice(s). For missing data, document -9 to the right of the response choice(s). Please document the reason for missing data (i.e., the question was accidentally skipped.)

Read each question and follow skip patterns as they appear on the form. Review the QxQ for detailed descriptions of questions.

INTRODUCTION TO PARTICIPANT/PARENT OR OTHER ADULT:

Thank you for participating in this study.

The following pages contain questions about the participant's family background, birth history, developmental history and family medical history. Some of the questions may be difficult for you to answer and exact dates may be hard to remember. **Please take as much time as you need, so I can gather information that is as accurate as possible.**

As with all study information, your responses will be kept strictly confidential, and the responses you provide will in no way affect the participant's clinical care. The first set of questions asks about the person completing the form and the participant's background. If you have trouble understanding anything, please feel free to ask for further clarification.

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SECTION B: INFORMATION ABOUT YOU

The following questions are about your relationship to the participant who is participating in the study.

B1. What is your relationship to (*name of participant*)?

- Mother..... 1 → **(Skip to C1)**
- Father..... 2 → **(Skip to C1)**
- Legal Guardian..... 3 → **(Skip to C1)**
- Self..... 5 → **(Skip to C1)**
- Other..... 4

a. If **OTHER**, specify your relationship: _____
(Such as: grandmother, stepfather, uncle, etc.)

SECTION C: PARTICIPANT'S BACKGROUND

The next questions are about the participant's background.

C1. What is (*name of participant*) date of birth?

___ ___ / ___ ___ / ___ ___ ___ ___
M M D D Y Y Y Y

C2. What is (*name of participant*) gender at birth?

- Male..... 1
- Female..... 2

C3. Was (*name of participant*) born in the United States of America (USA)?

- Yes..... 1 **(Skip to C4)**
- No..... 2

a. Was (*name of participant*) born in Canada?

- Yes..... 1 **(Skip to C4)**
- No..... 2

b. In what country was he or she born?

c. When did (*name of participant*) move to the U.S. or Canada?

___ ___ ___ ___ (Year)

Don't Know..... -8

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- D3. Was (*name of participant*) born in a hospital?
Yes..... 1
No..... 2
Don't Know..... -8
- D4. How was (*name of participant*) delivered?
Vaginal birth (natural)..... 1
Cesarean section (c-section)..... 2
Don't Know..... -8
- D5. Was (*name of participant*) born BEFORE due date?
Yes..... 1
No..... 2 **(Skip to D6)**
Don't Know..... -8 **(Skip to D6)**
- a. How many weeks BEFORE due date was (*name of participant*) born?
____ weeks [this number should never exceed 20 weeks]
Don't Know..... -8
- b. Was (*name of participant*) considered "pre-mature" at the time of his/her birth?
Yes..... 1
No..... 2
Don't Know..... -8
- D6. Was (*name of participant*) a part of a multiple birth (e.g. a twin, triplet, etc.)?
Yes..... 1
No..... 2
- D7. Immediately after birth, did (*name of participant*) spend time in the intensive care unit (ICU or NICU) before being allowed to go home?
Yes..... 1
No..... 2
Don't Know..... -8
- D8. Immediately after birth, did (*name of participant*) have any kidney problems?
Yes..... 1
No..... 2
Don't Know..... -8
- D9. How long was (*name of participant*) birth mother in the hospital after the delivery?
____ 1 = month(s) 3 = day(s)
 2 = week(s) -8 = don't know

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D10. How long was (*name of participant*) in the hospital after the delivery?

___ ___ 1 = month(s) 3 = day(s)
 2 = week(s) -8 = don't know

D11. What was the age of (*name of participant*) biological mother when the participant was born?

___ ___ years
 Don't Know..... -8

D12. Is (*name of participant*) biological mother of Hispanic or Latina Origin?

Yes, Mexican-American, Chicano..... 1
 Yes, Puerto Rican..... 2
 Yes, Cuban 3
 Yes, other Hispanic/Latina..... 4
 No, not of Hispanic or Latina origin 5
 Don't Know..... -8

D13. Which of the following describe the race of (*name of participant*) biological mother? (Circle "Yes", "No" or "Don't Know" for EACH of the following. You may select "Yes" for more than one race.)

	Yes	No	Don't Know	
a. White.....	1	2	-8	
b. Black / African American.....	1	2	-8	
c. American Indian / Alaskan Native.....	1	2	-8	
d. Asian.....	1	2	-8	
e. Native Hawaiian / Pacific Islander.....	1	2	-8	
f. Other.....	1	2	-8	(If No or Don't Know to "Other", skip to D14)
i. If Yes to Other , specify race: _____				

D14. What was the age of (*name of participant*) biological father when the participant was born?

___ ___ years
 Don't Know..... -8

D15. Is (*name of participant*) biological father of Hispanic or Latino Origin?

Yes, Mexican-American, Chicano..... 1
 Yes, Puerto Rican..... 2
 Yes, Cuban 3
 Yes, other Hispanic/Latina..... 4
 No, not of Hispanic or Latino origin..... 5
 Don't Know..... -8

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D16. Which of the following describe the race of (*name of participant*) biological father? (Circle “Yes”, “No” or “Don’t Know” for EACH of the following. You may select “Yes” for more than one race.)

	Yes	No	Don’t Know
a. White.....	1	2	-8
b. Black / African American.....	1	2	-8
c. American Indian / Alaskan Native.....	1	2	-8
d. Asian.....	1	2	-8
e. Native Hawaiian / Pacific Islander.....	1	2	-8
f. Other.....	1	2	-8

(If No or Don’t Know to “Other”, skip to E1)

1. If Yes to Other, specify race: _____

SECTION E: PARTICIPANT’S EDUCATION

The following questions are about the participant’s education. Specifically, the next question asks about the highest grade or level of school the participant has completed. For example, if the participant is currently in the 12th grade, then enter “11”, or if the participant is currently in the 6th grade, then enter “5”. In addition, if the participant is in the 1st grade, kindergarten or pre-school/pre-K, then enter “0” or if participant is a sophomore in college, then enter “13”.

E1. What is the **highest** grade or level of school that (*name of participant*) has COMPLETED?

____ Grade

Don’t Know..... -8

Not Applicable/child less than 5 years old
and does not attend pre-school/pre-k..... -1

E2. Does (*name of participant*) attend school (including pre-school and pre-K) outside of the home?

Yes..... 1

No..... 2 → (Skip to F1)

E3. During the past school year, approximately how many days has (*name of participant*) missed from school because of not feeling well?

____ Days

Don’t Know..... -8

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The next two questions refer to service(s) the participant is currently receiving. If this form is completed during the summer months, please refer to the service(s) the participant received during the past school year.

- E4. Does (*name of participant*) have an individualized educational plan (IEP)? (An individualized educational plan includes special education and related services designed to address specific educational needs of children with disabilities. **REFER TO QxQ FOR DETAILED DESCRIPTION.**)

Yes..... 1
No..... 2
Don't Know..... -8
Not Applicable/child less than 5 years old..... -1 → **(Skip to F1)**

- E5. Does (*name of participant*) have a 504 plan (or equivalent for Canadian sites) at school? (A 504 plan is a program designed to assist students with physical or emotional disabilities or other special needs in a regular school environment. **REFER TO QxQ FOR DETAILED DESCRIPTION.**)

Yes..... 1
No..... 2
Don't Know..... -8

SECTION F: PARTICIPANT'S FAMILY AND PRIMARY HOUSEHOLD

The following questions are to learn more about the participant's home and with whom he or she lives.

- F1. What is the current relationship between (*name of participant*) biological parents?

Not married, living together..... 1
Married, living together..... 2
Married, separated..... 3
Widowed..... 4
Divorced..... 5
Never married, not living together 6
Decline to answer..... -7
Don't Know..... -8

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The following questions ask about the participant's primary household. The primary household is the parent/guardian's home in which the participant lives at least half of the time. If the participant does not live with a parent/guardian (living independently, attending college or boarding school, emancipated, etc.), then the primary household is the parent/guardian's home where the participant used to live at least half the time prior to living independently.

F2. How many days per week does (*name of participant*) live in the parent/guardian's primary household? (For participants who do not live with a parent/guardian, indicate the number of days the participant lived in parent/guardian's home prior to living independently.)

Indicate a number between 4 and 7.

___ days

Don't Know..... -8

F3. How many people live in the primary household at least half the time?

___ ___ people

Don't Know..... -8

F4. How many adults live in the primary household at least half the time? An adult is a person at least 18 years of age. Include **all persons at least 18 years of age**, including siblings and non-relatives. Include participant if 18 years of age.

___ ___ adults

Don't Know..... -8

F5. Which of the following adults (18 years of age or older) live in the primary household at least half the time? (**Circle "Yes", "No" or "Don't Know" for EACH of the following.**)

	Yes	No	Don't Know
a. Birth Mother.....	1	2	-8
b. Birth Father.....	1	2	-8
c. Step Mother/ Adoptive Mother.....	1	2	-8
d. Step Father/ Adoptive Father.....	1	2	-8
e. Participant.....	1	2	-8
f. Other.....	1	2 (Skip to F6)	-8 (Skip to F6)
i. Specify: _____			

F6. Do any of the people, adults or children, living in the primary household at least half the time routinely smoke cigarettes, cigars, cigarillos or little cigars?

Yes..... 1

No..... 2

Don't Know..... -8

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The following questions are about the education level of the participant's parent(s)/guardian(s) in the **primary household**. Remember, primary household is defined as the home in which the participant lives at least half of the time or lived prior to living independently.

- F7. What is the highest grade or level of school that (*name of participant*) MOTHER (including birth, adoptive or stepmother) in the **primary household** has COMPLETED? For example, if completed high school enter "12 years", if completed 4-year college degree enter "16 years", and if completed a 4-year doctoral degree enter "20 years."

___ ___ Years

Don't Know..... -8

No Such Person..... -1

- F8. What is the highest grade or level of school that (*name of participant*) FATHER (including birth, adoptive or stepfather) in the **primary household** has COMPLETED? For example, if completed high school enter "12 years", if completed 4-year college degree enter "16 years", and if completed a 4-year doctoral degree enter "20 years."

___ ___ Years

Don't Know..... -8

No Such Person..... -1

For F9: ALLOW RESPONDENT TO CIRCLE THE NUMBER IN THE FAR RIGHT COLUMN THAT CORRESPONDS TO THEIR TOTAL INCOME.

- F9. Please estimate the total income (before taxes) of all members of the **primary household**. Include **total income from wages, business, or investments** for all members of (*name of participant*) primary household, by year, month, or week. Do **NOT** include social security, disability insurance, or other governmental assistance. **Circle** the number in the FAR RIGHT COLUMN that corresponds to the total income.

<u>YEAR</u>	<u>MONTH</u>	<u>WEEK</u>	
\$6,000 OR LESS.....	\$500 OR LESS.....	\$115 OR LESS.....	1
\$6,001 TO \$12,000.....	\$501 TO \$1,000.....	\$116 TO \$231	2
\$12,001 TO \$18,000.....	\$1,001 TO \$1,500.....	\$232 TO \$346	3
\$18,001 TO \$24,000.....	\$1,501 TO \$2,000.....	\$347 TO \$461	4
\$24,001 TO \$30,000.....	\$2,001 TO \$2,500.....	\$462 TO \$577	5
\$30,001 TO \$36,000.....	\$2,501 TO \$3,000.....	\$578 TO \$692	6
\$36,001 TO \$75,000.....	\$3,001 TO \$6,250.....	\$693 TO \$1442	7
MORE THAN \$75,000.....	MORE THAN \$6,250.....	MORE THAN \$1442.....	8
Don't know.....			-8

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F9a. What is the current employment status of (*name of participant*)'s MOTHER (including birth, adoptive or stepmother) in the **primary household**?

- Working full-time (35 hours or more per week)..... 1
- Working part-time (less than 35 hours per week)..... 2
- Unemployed but seeking work..... 3 → **Skip to F9b**
- Unemployed not seeking work..... 4 → **Skip to F9b**
- Student..... 5 → **Skip to F9b**
- Retired..... 6 → **Skip to F9b**
- Disability..... 7 → **Skip to F9b**
- No such person in household/Not Applicable..... -1 → **Skip to F9b**
- Don't Know..... -8 → **Skip to F9b**

i. Is (*name of participant*)'s MOTHER in the **primary household** self-employed?

- Yes..... 1
- No..... 2
- Don't Know..... -8

F9b. What is the current employment status of (*name of participant*)'s FATHER (including birth, adoptive or stepfather) in the **primary household**?

- Working full-time (35 hours or more per week)..... 1
- Working part-time (less than 35 hours per week)..... 2
- Unemployed but seeking work..... 3 → **Skip to F9c**
- Unemployed not seeking work..... 4 → **Skip to F9c**
- Student..... 5 → **Skip to F9c**
- Retired..... 6 → **Skip to F9c**
- Disability..... 7 → **Skip to F9c**
- No such person in household/Not Applicable..... -1 → **Skip to F9c**
- Don't Know..... -8 → **Skip to F9c**

i. Is (*name of participant*)'s FATHER in the **primary household** self-employed?

- Yes..... 1
- No..... 2
- Don't Know..... -8

F9c. What is the current employment status of (*name of participant*)?

(Circle "Yes", "No", "Not applicable (N/A)" or "Don't Know" for EACH of the following.)

	<u>Yes</u>	<u>No</u>	<u>N/A</u>	<u>Don't Know</u>
Working full-time (35 hours or more per week).....	1	2	-1	-8
Working part-time (less than 35 hours per week)	1	2	-1	-8
Disability Income.....	1 (skip to F10)	2	-1 (skip to F10)	-8 (skip to F10)
Student.....	1 (skip to F10)	2	-1 (skip to F10)	-8 (skip to F10)
Unemployed but seeking work.....	1 (skip to F10)	2	-1 (skip to F10)	-8 (skip to F10)
Unemployed not seeking work.....	1 (skip to F10)	2	-1 (skip to F10)	-8 (skip to F10)

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- i. Is (*name of participant*) self-employed?
Yes..... 1
No..... 2
Don't Know..... -8

F10. What is the zip code of the where the participant currently lives at least half of the time)?

____ _
Don't Know..... -8

F11. Has the participant lived at the current zip code for more than 1 year?

- Yes..... 1 (**skip to F12**)
No..... 2
Don't Know..... -8 (**Skip to Section G**)

a. Approximately how many months has the participant lived at the current zip code?

____ _ months
Don't Know..... -8

b. What was the zip code where the participant previously lived?

____ _
Don't Know..... -8

c. Approximately, how many years did the participant live at the previous zip code?

____ . ____ years (**Skip to Section G**)
Don't Know..... -8 (**Skip to Section G**)

F12. Approximately, how many years has the participant lived at the current zip code?

____ . ____ years
Don't Know..... -8

F13. Is the participant's zip code and their parents/guardians' zip code the same?

- Yes..... 1 (Skip to Section G)
No..... 2
Don't Know..... -8 (Skip to Section G)

F14. What is the current zip code of the parent(s)/guardian(s) (i.e., the parent(s)/guardian(s) home where the participant used to live at least half the time prior to living independently)?

____ _
Don't Know..... -8

F15. Approximately, how long have the parent(s)/guardian(s) lived at the current zip code?

____ _ year(s) ____ _ month(s)
Don't Know..... -8

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SECTION G: PARTICIPANT'S FAMILY HISTORY

The health conditions and illnesses experienced by close family members can provide important information about the participant's health. The following questions ask about the medical history of the participant's biological family. The participant's biological family includes his or her birth mother, birth father, grandparents, aunts, uncles, full brothers, full sisters and first cousins. (This does not include great aunts, great uncles and great grandparents.) *Full brothers and full sisters are defined as siblings who have the same birth mother and birth father as the participant.*

Some people who lost their parents at an early age, or who were adopted, may not have information on their birth family. If you are familiar with the health history of any of the members of the participant's biological or birth family, please answer the following questions about these relatives' health to the extent that you are able. If you are uncertain of the answer to any question, please select "Don't Know." If you have trouble understanding anything, please feel free to ask for further clarification. If more than one parent, sibling, grandparent, aunt, uncle, or cousin has kidney disease or other health issues indicated below, ask your site coordinator for further instructions.

- G1. Do you have knowledge of the health history of any members of (*name of participant*) birth family (i.e. parents, grandparents, aunts, uncles, siblings and cousins)?
Yes..... 1
No..... 2 → **(Skip to H1)**
- G2. a. How many **living half** siblings does (*name of participant*) have (Half siblings are defined as brothers and sisters, who have only one parent, either mother or birth father in common. Do not include deceased siblings.)?
___ ___ living half siblings → **(If "0", skip to G3)**
Don't Know..... -8 → **(Skip to G3)**
- b. Does (*name of participant*) have any **living half** siblings in the study?
Yes..... 1
No..... 2 → **(Skip to G3)**
- i. How many **living half** siblings does (*name of participant*) have participating in the study?
___ ___ living half siblings
- G3. a. How many **full** siblings does (*name of participant*) have? (Full siblings are defined as brothers and sisters, who have the same birth mother and birth father as the participant. Include deceased siblings.)
___ ___ full (living and deceased) siblings → **(If "0", skip to G5)**
Don't Know..... -8 → **(Skip to G5)**
- b. How many **living full** siblings does (*name of participant*) have?
___ ___ full (living) siblings → **(If "0", skip to G4)**
Don't Know..... -8 → **(Skip to G4)**
- c. Does (*name of participant*) have any **living full** siblings in the study?
Yes..... 1
No..... 2 → **(Skip to G4)**
- i. How many **living full** siblings does (*name of participant*) have participating in the study?
___ ___ living full siblings

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G4. Please provide the year of birth for EACH of (*name of participant*) full siblings (brothers & sisters).

START GHs1

	Year of Birth		Year of Birth
a. Sibling 1	_____ Y Y Y Y Don't Know..... -8	e. Sibling 5	_____ Y Y Y Y Don't Know..... -8
b. Sibling 2	_____ Y Y Y Y Don't Know..... -8	f. Sibling 6	_____ Y Y Y Y Don't Know..... -8
c. Sibling 3	_____ Y Y Y Y Don't Know..... -8	g. Sibling 7	_____ Y Y Y Y Don't Know..... -8
d. Sibling 4	_____ Y Y Y Y Don't Know..... -8	h. Sibling 8	_____ Y Y Y Y Don't Know..... -8

END GHs1

The next questions ask about the family members who were told they had kidney disease and the type of kidney disease they had.

G5. a. Including living and deceased, have any of (*name of participant*) biological family members been told by a health care professional that they had kidney disease?

- Yes..... 1
 No..... 2 → **(Skip to G8)**
 Don't know..... -8 → **(Skip to G8)**

b. Which family members?

c. What type of kidney disease?

	b. Which family members?		c. What type of kidney disease?					Don't Know
	Yes	No	Alport's Hereditary Nephritis	Polycystic Kidney Disease	Focal Segmental Glomerulosclerosis	Reflux Nephropathy (Kidney/bladder Reflux)	Other	
1 Mother.....	1	2 (#2)	1	2	3	4	5 (specify)	-8
							Specify: _____	
2 Father.....	1	2 (#3)	1	2	3	4	5 (specify)	-8
							Specify: _____	
3 Sibling (full brother or sister).....	1	2 (#4)	1	2	3	4	5 (specify)	-8
							Specify: _____	
4 Grandparent(s)...	1	2 (#5)	1	2	3	4	5 (specify)	-8
							Specify: _____	
5 Aunt(s)/Uncle(s)..	1	2 (#6)	1	2	3	4	5 (specify)	-8
							Specify: _____	
6 Cousin(s).....	1	2 (G6)	1	2	3	4	5 (specify)	-8
							Specify: _____	

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Next, the following questions ask about (*name of participant*) biological family members.

- G6. a. Including living and deceased, have any of (*name of participant*) biological family members been told by a health care professional that they had the SAME kidney disease as (*name of participant*)?
- Yes..... 1
- No..... 2 → (Skip to G7)
- Don't know..... -8 → (Skip to G7)
- b. Which biological family members? Yes No
(Circle "Yes" or "No" for EACH of the following.)
- | | | |
|--|---|---|
| 1. Mother..... | 1 | 2 |
| 2. Father..... | 1 | 2 |
| 3. Sibling (full brother or sister)..... | 1 | 2 |
| 4. Grandparent(s)..... | 1 | 2 |
| 5. Aunt(s)/Uncle(s)..... | 1 | 2 |
| 6. Cousin(s)..... | 1 | 2 |
- G7. a. Including living and deceased, have any of (*name of participant*) biological family members had a kidney biopsy?
- Yes..... 1
- No..... 2 → (Skip to G8)
- Don't know..... -8 → (Skip to G8)
- b. Which biological family members? Yes No
(Circle "Yes" or "No" for EACH of the following.)
- | | | |
|--|---|---|
| 1. Mother..... | 1 | 2 |
| 2. Father..... | 1 | 2 |
| 3. Sibling (full brother or sister)..... | 1 | 2 |
| 4. Grandparent(s)..... | 1 | 2 |
| 5. Aunt(s)/Uncle(s)..... | 1 | 2 |
| 6. Cousin(s)..... | 1 | 2 |

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- G8. a. Including living and deceased, have any of **(name of participant) biological family members** been told by a health care professional (any doctor, nurse, physician assistant or nurse practitioner) that they had... b. Which **biological family members?** (Circle "Yes", "No", or "Don't Know" for EACH of the following.)

	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>
1. High Blood Pressure or Hypertension			
Yes..... 1	1	2	-8
No..... 2 → (Skip to 2)	1	2	-8
Don't know..... -8 → (Skip to 2)			
Mother.....	1	2	-8
Father.....	1	2	-8
Sibling (full brother or sister).....	1	2	-8
Grandparent(s).....	1	2	-8
Aunt(s)/Uncle(s).....	1	2	-8
Cousin(s).....	1	2	-8

	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>
2. High Cholesterol			
Yes..... 1	1	2	-8
No..... 2 → (Skip to 3)	1	2	-8
Don't know..... -8 → (Skip to 3)			
Mother.....	1	2	-8
Father.....	1	2	-8
Sibling (full brother or sister).....	1	2	-8
Grandparent(s).....	1	2	-8
Aunt(s)/Uncle(s).....	1	2	-8
Cousin(s).....	1	2	-8

	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>
3. Diabetes (high blood sugar or sugar diabetes)			
Yes..... 1	1	2	-8
No..... 2 → (Skip to 4)	1	2	-8
Don't know..... -8 → (Skip to 4)			
Mother.....	1	2	-8
Father.....	1	2	-8
Sibling (full brother or sister).....	1	2	-8
Grandparent(s).....	1	2	-8
Aunt(s)/Uncle(s).....	1	2	-8
Cousin(s).....	1	2	-8

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(Circle “Yes”, “No” or “Don’t Know” for EACH of the following.)

4.	Stroke before the age of 50	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>
	Yes..... 1	Mother..... 1	2	-8
	No..... 2 → (Skip to 5)	Father..... 1	2	-8
	Don't know..... -8 → (Skip to 5)	Sibling (full brother or sister)..... 1	2	-8
		Grandparent(s)..... 1	2	-8
		Aunt(s)/Uncle(s)..... 1	2	-8
		Cousin(s)..... 1	2	-8
5.	Heart Attack before the age of 50	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>
	Yes..... 1	Mother..... 1	2	-8
	No..... 2 → (Skip to G9)	Father..... 1	2	-8
	Don't know..... -8 → (Skip to G9)	Sibling (full brother or sister)..... 1	2	-8
		Grandparent(s)..... 1	2	-8
		Aunt(s)/Uncle(s)..... 1	2	-8
		Cousin(s)..... 1	2	-8

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- G9. a. Including living and deceased, have any of **(name of participant) biological family members** had **dialysis** as treatment for kidney disease?
- Yes..... 1
 No..... 2 → **(Skip to G10)**
 Don't Know.... -8 → **(Skip to G10)**
- b. Which **biological family members?** **(Circle "Yes", "No", or "Don't Know" for EACH of the following.)**
1. Mother _____ yrs
 Yes..... 1
 No..... 2 → **(skip to 2)**
 Don't Know..... -8
2. Father _____ yrs
 Yes..... 1
 No..... 2 → **(skip to 3)**
 Don't Know..... -8
3. Sibling (full brother or sister) _____ yrs
 Yes..... 1
 No..... 2 → **(skip to 4)**
 Don't Know..... -8
4. Grandparent(s) _____ yrs
 Yes..... 1
 No..... 2 → **(skip to 5)**
 Don't Know..... -8
5. Aunt(s)/Uncle(s) _____ yrs
 Yes..... 1
 No..... 2 → **(skip to 6)**
 Don't Know..... -8
6. Cousin(s) _____ yrs
 Yes..... 1
 No..... 2 → **(skip to G10)**
 Don't Know..... -8
- c. At what age was treatment started?
 _____ yrs
 Don't Know..... -8

GENERAL HISTORY (GH)

- G10. a. Including living and deceased, have any of **(name of participant) biological family members** had a **kidney transplant** as treatment for kidney disease?
- Yes..... 1
 No..... 2 → **(Skip to G11)**
 Don't Know.... -8 → **(Skip to G11)**
- b. Which **biological family members?** **(Circle "Yes", "No" or "Don't Know" for EACH of the following.)**
1. Mother _____ yrs
 Yes..... 1 Don't Know..... -8
 No..... 2 → **(skip to 2)**
 Don't Know..... -8
2. Father _____ yrs
 Yes..... 1 Don't Know..... -8
 No..... 2 → **(skip to 3)**
 Don't Know..... -8
3. Sibling (full brother or sister) _____ yrs
 Yes..... 1 Don't Know..... -8
 No..... 2 → **(skip to 4)**
 Don't Know..... -8
4. Grandparent(s) _____ yrs
 Yes..... 1 Don't Know..... -8
 No..... 2 → **(skip to 5)**
 Don't Know..... -8
5. Aunt(s)/Uncle(s) _____ yrs
 Yes..... 1 Don't Know..... -8
 No..... 2 → **(skip to 6)**
 Don't Know..... -8
6. Cousin(s) _____ yrs
 Yes..... 1 Don't Know..... -8
 No..... 2 → **(skip to G11)**
 Don't Know..... -8
- c. At what age was transplant performed?

GENERAL HISTORY (GH)

G11. Have any of the birth mother's pregnancies resulted in the following?

(Circle "Yes", "No" or "Don't Know" for EACH of the following.)

	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>
Stillbirth (fetus died at birth).....	1	2	-8
Miscarriage.....	1	2	-8

G12. What is the current height of (*name of participant*) birth mother?

___ feet ___ inches

Don't Know..... -8

G13. What is the current weight of (*name of participant*) birth mother?

___ lbs

Don't Know..... -8

G14. Has (*name of participant*) birth mother had recurrent Urinary Tract Infections (UTI)?

Yes..... 1

No..... 2

Don't Know..... -8

G15. What is the current height of (*name of participant*) birth father?

___ feet ___ inches

Don't Know..... -8

G16. What is the current weight of (*name of participant*) birth father?

___ lbs

Don't Know..... -8

G17. Has (*name of participant*) birth father had recurrent Urinary Tract Infections (UTI)?

Yes..... 1

No..... 2

Don't Know..... -8

G18. Have any of (*name of participant*) siblings had recurrent Urinary Tract Infections (UTI)?

Yes..... 1

No..... 2

Don't Know..... -8

N/A, participant does not have any siblings... -1

GENERAL HISTORY (GH)

SECTION H: PARTICIPANT'S DEVELOPMENTAL HISTORY

The following questions are to learn more about the participant's development. It may be difficult to recall the exact age so please take as much time as you need, allowing us to gather the most accurate information.

H1. At what age did (*name of participant*) first perform the following activities?

	<u>Age</u>		<u>Don't Know</u>	<u>Not yet achieved</u>
a. Turn over.....	___ ___	months	-8	99
b. Sit alone.....	___ ___	months	-8	99
c. Crawl.....	___ ___	months	-8	99
d. Stand alone.....	___ ___	months	-8	99
e. Walk alone.....	___ ___	months	-8	99
f. Walk upstairs.....	___ ___	months	-8	99
g. Walk downstairs.....	___ ___	months	-8	99
h. Show interest in or attraction to sound (i.e., showed interest in shaking keys).....	___ ___	1=months 2=week(s) Don't know	-8	99
i. Understand first words.....	___ ___	months	-8	99
j. Speak first words.....	___ ___	months	-8	99
k. Speak in sentences (3 or more words).....	___ ___	months	-8	99

- H2. a. Is (*name of participant*) older than 5 years of age?
 Yes..... 1 → **(Skip to H2c)**
 No..... 2
- b. Is (*name of participant*) currently breast-fed?
 Yes..... 1 → **(Skip to H3)**
 No..... 2
 Don't Know..... -8 → **(Skip to H3)**
- c. Was (*name of participant*) breast-fed?
 Yes..... 1
 No..... 2 → **(Skip to H3)**
 Don't Know..... -8 → **(Skip to H3)**

GENERAL HISTORY (GH)

- d. How old was (*name of participant*) when he/she was weaned from breast feeding?
(Please circle "1" for years, "2" for months, "3" for weeks or "4" for days.)

Age ____ 1 = year(s) 3 = week(s)
2 = months 4 = days
Don't Know..... -8

- H3. Is (*name of participant*) currently bottle-fed?

Yes..... 1 → (Skip to H4)
No..... 2
Don't Know..... -8 → (Skip to H4)

- a. Was (*name of participant*) bottle-fed?

Yes..... 1
No..... 2 → (Skip to H4)
Don't Know..... -8 → (Skip to H4)

- b. How old was (*name of participant*) when he/she was weaned from bottle feeding?
(Please circle "1" for years, "2" for months, "3" for weeks or "4" for days.)

Age ____ 1 = year(s)
2 = months
3 = week(s)
4 = days
Don't Know..... -8

**FOR QUESTION H4 – H5, PLEASE PAY CLOSE ATTENTION TO THE SKIP PATTERNS.
FOLLOW EACH SKIP PATTERN CAREFULLY. IT IS IMPORTANT TO ANSWER EACH QUESTION
ACCORDING TO THE SKIP PATTERN.**

- H4. Does (*name of participant*) have any wetness or leakage of urine (accidents) during the day or night?

Yes..... 1
No..... 2 → (Skip to c)
Don't Know..... -8 → (Skip to c)

- a. Is (*name of participant*) wet during the day?

Yes..... 1
No..... 2
Don't Know..... -8

- b. Is (*name of participant*) wet during the night?

Yes..... 1
No..... 2
Don't Know..... -8

GENERAL HISTORY (GH)

c. Does (*name of participant*) catheterize the bladder (i.e., put a tube in the bladder)?

Yes..... 1

No..... 2 → **(Skip to H5)**

Don't Know..... -8 → **(Skip to H5)**

i. Does (*name of participant*) catheterize through the urethra?

Yes..... 1

No..... 2

Don't Know..... -8

ii. Does (*name of participant*) catheterize through a stoma?

Yes..... 1

No..... 2

Don't Know..... -8

H5. Is (*name of participant*) currently toilet trained?

Yes..... 1

No..... 2 → **(Skip to H6)**

Don't Know..... -8 → **(Skip to H6)**

a. When was (*name of participant*) toilet trained?

___ ___ years

b. After toilet training, did bed-wetting occur?

Yes..... 1

No..... 2 → **(Skip to C)**

Don't Know..... -8 → **(Skip to C)**

i. Does bed-wetting still occur?

Yes..... 1 → **(Skip to iii)**

No..... 2

Don't Know..... -8 → **(Skip to C)**

ii. At what age did bed-wetting stop?

(Please circle "1" for years or "2" for months.)

Age ___ ___ 1 = years

2 = months

Don't Know..... -8

iii. Were medical reasons the cause of bed-wetting?

Yes..... 1

No..... 2

Don't Know..... -8

GENERAL HISTORY (GH)

- c. After toilet training, did bed-soiling occur?
- Yes..... 1
- No..... 2 → **(Skip to H6)**
- Don't Know..... -8 → **(Skip to H6)**
- i. Does bed-soiling still occur?
- Yes..... 1 → **(Skip to iii)**
- No..... 2
- Don't Know..... -8 → **(Skip to H6)**
- ii. At what age did bed-soiling stop?
(Please circle "1" for years or "2" for months.)
- Age ____ 1 = years
 2 = months
- Don't Know..... -8
- iii. Were medical reasons the cause of bed-soiling?
- Yes..... 1
- No..... 2
- Don't Know..... -8

- H6. Is (*name of participant*) 4 years of age or older?
- Yes..... 1
- No..... 2 **(Skip to H9)**

- H7. During (*name of participant*) first 4 years, were any problems noted in the areas listed below?
(Circle "Yes", "No" or "Don't Know" for EACH of the following.)

	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>
a. Eating.....	1	2	-8
b. Excessive crying.....	1	2	-8
c. Failure to thrive.....	1	2	-8
d. Motor skills.....	1	2	-8
e. Separating from parents.....	1	2	-8
f. Sleeping too little.....	1	2	-8
g. Sleeping too much.....	1	2	-8
h. Temper tantrums.....	1	2	-8

GENERAL HISTORY (GH)

H8. Which hand does (*name of participant*) primarily use to write?

Primarily right..... 1

Primarily left..... 2

Ambidextrous (writes equally with both left and right hands) ... 3

If the participant is under 4 years old, please answer the next question based on whether a doctor or health care professional has told you that the participant has had any of the following problems.

H9. a. Is (*name of participant*) currently under 4 years old?

Yes..... 1

No..... 2 **(END FORM)**

H10. Has (*name of participant*) experienced any of the following problems?
(Circle "Yes", "No" or "Don't Know" for EACH of the following.)

	Yes	No	Don't Know
a. Feeding problem.....	1	2	-8
b. Eating disorder.....	1	2	-8
c. Underweight problem.....	1	2	-8
d. Overweight problem.....	1	2	-8
e. Walking difficulty (per healthcare professional)....	1	2	-8
f. Unclear speech (per healthcare professional).....	1	2	-8
g. Sleep problem.....	1	2	-8
h. Colic.....	1	2	-8

TO BE COMPLETED BY CLINICAL SITE:

DATE: ____/____/____
 M M / D D / Y Y Y Y

INITIALS: _____

ADMINISTRATION: 1 = Interviewer Assisted
 (Circle "1", "2" or "3") 2 = Self-Administered
 3 = Both