

# FOLLOW-UP GENERAL HISTORY (F13)

## 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 #:

\_\_ \_\_

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. Is this study visit an irregular (accelerated) visit? Yes..... 1  
No..... 2
- A7. 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 and family medical history since their last study visit. 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.

# FOLLOW-UP GENERAL HISTORY (F13)

## 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 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 in the 1<sup>st</sup> grade, kindergarten or pre-school/pre-K, then enter "0". If the participant is currently in the 12<sup>th</sup> grade, then enter "11", if participant is a sophomore in college, then enter "13" or if the participant is currently in the 6<sup>th</sup> grade, then enter "5". In addition, 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."

- C1. 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
- C2. Does (*name of participant*) attend school (including pre-school and pre-K) outside of the home?
- Yes..... 1
  - No..... 2 → **(Skip to D1)**
- C3. 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

## FOLLOW-UP GENERAL HISTORY (F13)

---

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.

- C4. 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 D1)**

- C5. Does (name of participant) have a 504 plan at school (or equivalent for Canadian sites)? (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 D: 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.

- D1. 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  
Refuse to answer..... -7  
Don't Know..... -8

## FOLLOW-UP GENERAL HISTORY (F13)

---

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.

D2. How many days per week does (*name of participant*) live in the primary household?  
 Indicate a number between 4 and 7. (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.)

\_\_\_ days  
 Don't Know..... -8

D3. How many people live in the primary household at least half the time?

\_\_\_ \_\_\_ people  
 Don't Know..... -8

D4. 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

D5. Which of the following adults (18 years of age and older) live in the primary household at least half the time? Include the participant, if applicable. (**Circle “Yes”, “No” or “Don’t Know” for EACH of the following.**)

	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>
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 D6)	-8 (Skip to D6)
i. Specify: _____			

D6. 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



## FOLLOW-UP GENERAL HISTORY (F13)

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.

- D7. 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

- D8. 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 D9: ALLOW RESPONDENT TO CIRCLE THE NUMBER IN THE FAR RIGHT COLUMN THAT CORRESPONDS TO THEIR TOTAL INCOME.**

- D9. 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.....	<b>1</b>
\$6,001 TO \$12,000.....	\$501 TO \$1,000.....	\$116 TO \$231.....	<b>2</b>
\$12,001 TO \$18,000.....	\$1,001 TO \$1,500.....	\$232 TO \$346.....	<b>3</b>
\$18,001 TO \$24,000.....	\$1,501 TO \$2,000.....	\$347 TO \$461.....	<b>4</b>
\$24,001 TO \$30,000.....	\$2,001 TO \$2,500.....	\$462 TO \$577.....	<b>5</b>
\$30,001 TO \$36,000.....	\$2,501 TO \$3,000.....	\$578 TO \$692.....	<b>6</b>
\$36,001 TO \$75,000.....	\$3,001 TO \$6,250.....	\$693 TO \$1442.....	<b>7</b>
MORE THAN \$75,000.....	MORE THAN \$6,250.....	MORE THAN \$1442.....	<b>8</b>
Don't know.....			<b>-8</b>

## FOLLOW-UP GENERAL HISTORY (F13)

---

D9a. What is the current employment status of (*name of participant*) 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 D9b**
- Unemployed not seeking work..... 4 → **Skip to D9b**
- Student..... 5 → **Skip to D9b**
- Retired..... 6 → **Skip to D9b**
- Disability..... 7 → **Skip to D9b**
- No such person in household/Not Applicable..... -1 → **Skip to D9b**
- Don't Know..... -8 → **Skip to D9b**

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

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

D9b. What is the current employment status of (*name of participant*) 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 D9c**
- Unemployed not seeking work..... 4 → **Skip to D9c**
- Student..... 5 → **Skip to D9c**
- Retired..... 6 → **Skip to D9c**
- Disability..... 7 → **Skip to D9c**
- No such person in household/Not Applicable..... -1 → **Skip to D9c**
- Don't Know..... -8 → **Skip to D9c**

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

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

D9c. What is the current employment status of (*name of participant*)?

	<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 D10)	2	-1 (skip to D10)	-8 (skip to D10)
Student.....	1 (skip to D10)	2	-1 (skip to D10)	-8 (skip to D10)
Unemployed but seeking work.....	1 (skip to D10)	2	-1 (skip to D10)	-8 (skip to D10)
Unemployed not seeking work.....	1 (skip to D10)	2	-1 (skip to D10)	-8 (skip to D10)

## FOLLOW-UP GENERAL HISTORY (F13)

---

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

D10. What is the zip code where the participant currently lives at least half of the time?

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

D11. Has the participant lived at the current zip code for more than 1 year?

Yes..... 1 (skip to D12)  
No..... 2  
Don't Know..... -8 (Skip to Section E)

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 E)**  
Don't Know..... -8 **(Skip to Section E)**

D12. Approximately, how many years has the participant lived at the current zip code?

\_\_\_\_ . \_\_\_\_ years  
Don't Know..... -8

D13. Is the participant's zip code and their parents/guardians' zip code the same?

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

D14. 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

D15. Approximately, how long have the parent(s)/guardian(s) lived at the current zip code?

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

## FOLLOW-UP GENERAL HISTORY (F13)

### SECTION E: 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.

- E1. 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 F1)**
- E2. 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 E3)**  
Don't Know ..... -8 → **(Skip to E3)**
- b. Does (*name of participant*) have any **living half** siblings in the study?  
Yes..... 1  
No..... 2 → **(Skip to E3)**
- i. How many **living half** siblings does (*name of participant*) have participating in the study?  
\_\_\_ \_\_\_ living half siblings
- E3. 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 E5)**  
Don't Know ..... -8 → **(Skip to E5)**
- b. How many **living full** siblings does (*name of participant*) have?  
\_\_\_ \_\_\_ full (living) siblings → **(If "0", skip to E4)**  
Don't Know ..... -8 → **(Skip to E4)**
- c. Does (*name of participant*) have any **living full** siblings in the study?  
Yes..... 1  
No..... 2 → **(Skip to E4)**
- i. How many **living full** siblings does (*name of participant*) have participating in the study?  
\_\_\_ \_\_\_ living full siblings



## FOLLOW-UP GENERAL HISTORY (F13)

E4. Please provide the year of birth for each of (*name of participant*) full siblings (brothers & sisters).

START F07s1

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

END F07s1

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

E5. a. In the past year, have any of (*name of participant*) living or deceased biological family members been told by a health care professional that they had kidney disease in the past year?

Yes..... 1  
 No..... 2 → **(Skip to E8)**  
 Don't know..... -8 → **(Skip to E8)**

**b. Which family members?**

**c. What type of kidney disease?**

	<u>Yes</u> <u>No</u>		Alport's Hereditary Nephritis	Polycystic Kidney Disease	Focal Segmental Glomerulosclerosis	Reflux Nephropathy (Kidney/bladder Reflux)	Other	Don't Know
	1	2						
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 (E6)	1	2	3	4	5 (specify)	-8
							Specify: _____	

## FOLLOW-UP GENERAL HISTORY (F13)

---

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

- E6. a. In the past year, have any of (*name of participant*) living or deceased 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 E7)
- Don't know..... -8 → (Skip to E7)
- 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 |
- E7. a. In the past year, have any of (*name of participant*) living or deceased biological family members had a kidney biopsy?
- Yes..... 1
- No..... 2 → (Skip to E8)
- Don't know..... -8 → (Skip to E8)
- 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 |

## FOLLOW-UP GENERAL HISTORY (F13)

---

- E8. a. In the past year, have any of (***name of participant***) living or deceased 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

## FOLLOW-UP GENERAL HISTORY (F13)

---

(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	1	2	-8
	No..... 2 → (Skip to 5)	1	2	-8
	Don't know..... -8 → (Skip to 5)			
	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
5.	Heart Attack before the age of 50	<u>Yes</u>	<u>No</u>	<u>Don't Know</u>
	Yes..... 1	1	2	-8
	No..... 2 → (Skip to E9)	1	2	-8
	Don't know..... -8 → (Skip to E9)			
	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

## FOLLOW-UP GENERAL HISTORY (F13)

- E9. a. In the past year, have any of (***name of participant***) living or deceased biological family members had dialysis as treatment for kidney disease?
- Yes..... 1  
 No..... 2 → (Skip to E10)  
 Don't Know.... -8 → (Skip to E10)
- b. Which biological family members?  
 (Circle "Yes", "No", or "Don't Know" for EACH of the following)
1. Mother  
 Yes..... 1  
 No..... 2 → (skip to 2)  
 Don't Know..... -8
2. Father  
 Yes..... 1  
 No..... 2 → (skip to 3)  
 Don't Know..... -8
3. Sibling (full brother or sister)  
 Yes..... 1  
 No..... 2 → (skip to 4)  
 Don't Know..... -8
4. Grandparents  
 Yes..... 1  
 No..... 2 → (skip to 5)  
 Don't Know..... -8
5. Aunts/Uncles  
 Yes..... 1  
 No..... 2 → (skip to 6)  
 Don't Know..... -8
6. Cousins  
 Yes..... 1  
 No..... 2 → (skip to E10)  
 Don't Know..... -8
- c. At what age was treatment started?
- \_\_\_\_ yrs old  
 Don't Know..... -8
- \_\_\_\_ yrs old  
 Don't Know..... -8
- \_\_\_\_ yrs old  
 Don't Know..... -8
- \_\_\_\_ yrs old  
 Don't Know..... -8
- \_\_\_\_ yrs old  
 Don't Know..... -8
- \_\_\_\_ yrs old  
 Don't Know..... -8

## FOLLOW-UP GENERAL HISTORY (F13)

- E10. a. In the past year, have any of (***name of participant***) living or deceased biological family members had a kidney transplant as treatment for kidney disease?
- Yes..... 1  
 No..... 2 → **(Skip to E11)**  
 Don't Know.... -8 → **(Skip to E11)**
- b. Which **biological family members**?  
 (Circle "Yes", "No", or "Don't Know" for EACH of the following)
1. Mother \_\_\_\_\_ yrs old  
 Yes..... 1  
 No..... 2 → **(skip to 2)**  
 Don't Know..... -8
2. Father \_\_\_\_\_ yrs old  
 Yes..... 1  
 No..... 2 → **(skip to 3)**  
 Don't Know..... -8
3. Sibling (full brother or sister) \_\_\_\_\_ yrs old  
 Yes..... 1  
 No..... 2 → **(skip to 4)**  
 Don't Know..... -8
4. Grandparents \_\_\_\_\_ yrs old  
 Yes..... 1  
 No..... 2 → **(skip to 5)**  
 Don't Know..... -8
5. Aunts/Uncles \_\_\_\_\_ yrs old  
 Yes..... 1  
 No..... 2 → **(skip to 6)**  
 Don't Know..... -8
6. Cousins \_\_\_\_\_ yrs old  
 Yes..... 1  
 No..... 2 → **(skip to E11)**  
 Don't Know..... -8
- c. At what age was transplant performed?  
 \_\_\_\_\_ yrs old  
 Don't Know..... -8

## FOLLOW-UP GENERAL HISTORY (F13)

---

E11. In the past year, has the birth mother been pregnant?

Yes..... 1  
No..... 2 **(skip to E13)**

E12. In the past year, 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

E13. In the past year, has (*name of participant*) birth mother had recurrent Urinary Tract Infections (UTI)?

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

E14. In the past year, has (*name of participant*) birth father had recurrent Urinary Tract Infections (UTI)?

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

E15. In the past year, 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

## FOLLOW-UP GENERAL HISTORY (F13)

### SECTION F: PARTICIPANT'S DEVELOPMENTAL HISTORY

The following questions are to learn more about the participant's development.

- F1. At the last CKiD study visit, was (*name of participant*) older than 5 years of age?  
Yes..... 1 → **(Skip to F4)**  
No..... 2
- F2. a. Is (*name of participant*) currently older than 5 years of age?  
Yes..... 1 → **(Skip to F2c)**  
No..... 2
- b. Is (*name of participant*) currently breast-fed?  
Yes..... 1 → **(Skip to F3)**  
No..... 2  
Don't Know..... -8 → **(Skip to F3)**
- c. Was (*name of participant*) breast-fed?  
Yes..... 1  
No..... 2 → **(Skip to F3)**  
Don't Know..... -8 → **(Skip to F3)**
- 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)  
2 = months  
3 = week(s)  
4 = days  
Don't Know..... -8
- F3. Is (*name of participant*) currently bottle-fed?  
Yes..... 1 → **(Skip to F4)**  
No..... 2  
Don't Know..... -8 → **(Skip to F4)**
- a. Was (*name of participant*) bottle-fed?  
Yes..... 1  
No..... 2 → **(Skip to F4)**  
Don't Know..... -8 → **(Skip to F4)**
- 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



## FOLLOW-UP GENERAL HISTORY (F13)

FOR QUESTION F4 – F5, 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.

F4. In the past year, has (*name of participant*) had 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. In the past year, is (*name of participant*) wet during the day?

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

b. In the past year, is (*name of participant*) wet during the night?

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

c. In the past year, has (*name of participant*) catheterized the bladder (i.e., put a tube in the bladder)?

- Yes..... 1  
No..... 2 → **(Skip to F5)**  
Don't Know..... -8 → **(Skip to F5)**

i. In the past year, has (*name of participant*) catheterized through the urethra?

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

ii. In the past year, has (*name of participant*) catheterized through a stoma?

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

## FOLLOW-UP GENERAL HISTORY (F13)

---

- F5. At the last CKiD study visit, was (*name of participant*) toilet trained?
- Yes..... 1 → **(Skip to F6)**  
No..... 2  
Don't Know..... -8 → **(Skip to F6)**
- a. Is (*name of participant*) currently toilet trained?
- Yes..... 1  
No..... 2 → **(Skip to F6)**  
Don't Know..... -8 → **(Skip to F6)**
- b. When was (*name of participant*) toilet trained?  
Age \_\_\_\_ years
- c. After toilet training, did bed-wetting occur?
- Yes..... 1  
No..... 2 → **(Skip to d)**  
Don't Know..... -8 → **(Skip to d)**
- 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 and "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

## FOLLOW-UP GENERAL HISTORY (F13)

---

d. After toilet training, did bed-soiling occur?

Yes..... 1  
No..... 2 → **(Skip to F6)**  
Don't Know..... -8 → **(Skip to F6)**

i. Does bed-soiling still occur?

Yes..... 1 → **(Skip to iii)**  
No..... 2  
Don't Know..... -8 → **(Skip to F6)**

ii. At what age did bed-soiling stop?

**(Please circle "1" for years and "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

F6. At the last CKiD study visit, was (*name of participant*) 4 years of age or older?

Yes..... 1 → **(Skip to F8)**  
No..... 2  
Don't Know..... -8

a. Is (*name of participant*) currently 4 years of age or older?

Yes..... 1  
No..... 2 → **( Skip to F9)**  
Don't Know..... -8 → **( Skip to F9)**

## FOLLOW-UP GENERAL HISTORY (F13)

F7. During (*name of participant*) first 4 years, were any problems noted in the areas listed below? Indicate yes, no or don't know for each of the following.

	Yes	No	Don't Know
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

F8. 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.**

F9. a. Is (*name of participant*) currently under 4 years old?

- Yes..... 1  
 No..... 2 (END FORM)

F10. 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