

# POST-KRT VISIT GENERAL HISTORY (RF13)

## 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. 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.



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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 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

### SECTION D: PARTICIPANT'S FAMILY AND PRIMARY HOUSEHOLD

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.

D1. 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 D2) | -8 (Skip to D2)   |
| i. Specify: _____                    |            |                |                   |

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**CIRCLE THE NUMBER IN THE FAR RIGHT COLUMN THAT CORRESPONDS TO THEIR TOTAL INCOME.**

D2. 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>

D3. 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 D4)	2	-1 (skip to D4)	-8 (skip to D4)
Student.....	1 (skip to D4)	2	-1 (skip to D4)	-8 (skip to D4)
Unemployed but seeking work.....	1 (skip to D4)	2	-1 (skip to D4)	-8 (skip to D4)
Unemployed not seeking work.....	1 (skip to D4)	2	-1 (skip to D4)	-8 (skip to D4)
i. Is ( <i>name of participant</i> ) self-employed?				
Yes.....	1			
No.....		2		
Don't Know.....				-8

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- D4. What is the zip code where the participant currently lives at least half of the time?  
\_\_\_\_\_  
Don't Know..... -8
- D5. Has the participant lived at the current zip code for more than 1 year?  
Yes..... 1 **(skip to D6)**  
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)**
- D6. Approximately, how many years has the participant lived at the current zip code?  
\_\_\_\_ . \_\_\_\_ years  
Don't Know..... -8
- D7. 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)**
- D8. 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
- D9. 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 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.

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

- E1. 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?

Yes..... 1  
 No..... 2 → **(Skip to E4)**  
 Don't know..... -8 → **(Skip to E4)**

**b. Which family members?**

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

	b. Which family members?		c. What type of kidney disease?					
	Yes	No	Alport's Hereditary Nephritis	Polycystic Kidney Disease	Focal Segmental Glomerulosclerosis	Reflux Nephropathy (Kidney/bladder Reflux)	Other	Don't Know
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: _____	

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

- E2. 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 E3)  
Don't know..... -8 → (Skip to E3)
- 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 |
- E3. 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 E4)  
Don't know..... -8 → (Skip to E4)
- 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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- E4. 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

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	<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

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	<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	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 E5)	1	2	-8
	Don't know..... -8 → (Skip to E5)			
	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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- E5. 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 E6)  
 Don't Know.... -8 → (Skip to E6)
- 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 E6)  
 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

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- E6. 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 F1)  
 Don't Know.... -8 → (Skip to F1)
- 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 F1)  
 Don't Know..... -8
- c. At what age was transplant performed?  
 \_\_\_\_\_ yrs old  
 Don't Know..... -8

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### SECTION F: PARTICIPANT'S DEVELOPMENTAL HISTORY

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

- F1. Is (name of participant) currently on dialysis?  
Yes..... 1 → **(Skip to F3)**  
No..... 2

**FOR QUESTION F2 – F3, 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.**

- F2. 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 F3)**  
Don't Know..... -8 → **(Skip to F3)**
- 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

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- F3. At the last CKiD study visit, was (*name of participant*) toilet trained?
- Yes..... 1 → **(End Form)**  
No..... 2  
Don't Know..... -8 → **(End Form)**
- a. Is (*name of participant*) currently toilet trained?
- Yes..... 1  
No..... 2 → **(End Form)**  
Don't Know..... -8 → **(End Form)**
- 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

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- d. After toilet training, did bed-soiling occur?
- Yes..... 1
- No..... 2 → **(End Form)**
- Don't Know..... -8 → **(End Form)**
- i. Does bed-soiling still occur?
- Yes..... 1 → **(Skip to iii)**
- No..... 2
- Don't Know..... -8 → **(End Form)**
- 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

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**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