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: _1_   _0_ / _0_   _1_ / _1_   _2_

A4.   DATE OF VISIT: ___ ___/ ___ ___/ ___ ___ ___ ___
                            M   M   D   D   Y   Y   Y   Y

A5.   INTERVIEWER'S INITIALS: ___ ___ ___

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:

Thank you for participating in this study.

The following pages contain questions about the child's family background, birth history, developmental history and family medical history. I am going to ask you a series of questions. 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.

If at any point in the interview you want me to stop, let me know. As with all study information, your responses will be kept strictly confidential, and the responses you provide will in no way affect your child's clinical care. The first set of questions asks about you and your child's background. If you have trouble understanding anything I say, stop me and I will re-read the question.

Are you ready to begin?

SECTION B: INFORMATION ABOUT YOU

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

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

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: CHILD'S BACKGROUND

The next questions are about the child's background.

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

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

C2.   What is (*name of child*) gender?

Male**……………….……………………** 1
Female**……………...…………………..** 2

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

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

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

Yes**……………….…………………….** 1   **(Skip to C4)**

No**………………….…………………..** 2

b.   In what country was he or she born?

_____

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

___ ___ ___ ___ (Year)

Don't Know**……………..……….........** -8

C4.   a.   Is (*name of child*) of Hispanic or Latino/a Origin?

Yes, Mexican-American, Chicano**……………** 1
Yes, Puerto Rican**....................................** 2
Yes, Cuban **……………………………** 3
Yes, other Hispanic/Latino/a**.....................** 4
No, not of Hispanic or Latino/a origin **………** 5   **(Skip to C5)**
Don't Know**...** -8   **(Skip to C5)**

b. Which language does the child speak most frequently?
   English**……………………………………………** 1
   Spanish**………………………………………...** 2
   Both (child is bilingual)**..............................** 3

C5. Which of the following describe the race of (*name of child*)? **(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 D1)**

   i. If **Yes** to **Other**, specify race: _____

SECTION D: CHILD'S BIRTH

The next questions are about the birth of the child who is participating in the study. The following questions also ask about the child's biological parents. Biological parents are defined as the child's birth or blood-related father or mother.

D1. Was (*name of child*)'s birth weight in pound (lbs) or kilograms (kg)?
   lbs**……………………………………………....** 1
   kg**…………………………………………….** 2 **(Skip to b)**
   Don't Know**…………………….............** -8 **(Skip to D2)**

   a. What was (*name of the child*)'s birth weight in lbs and ounces?

   ___ ___ lbs ___ ___ oz **(Skip to D2)**

   b. What was (*name of child*)'s birth weight in kilograms?

   ___ . ___ kg

D2. What was (*name of child*) length at birth? (Round off to the nearest inch or centimeter. If ½ or greater round up.) **(Please circle "1" for inches or "2" for centimeters.)**

   ___ ___ ___ 1= inches
            2= cm
   Don't Know**……………………………………..** -8

D3. Was (*name of child*) born in a hospital?
   Yes**……………………………….................** 1
   No**……………………………………………** 2
   Don't Know**…………………………………..** -8

D4. How was (*name of child*) delivered?
   Vaginal birth (natural)**…………………..........** 1
   Cesarean section (c-section)**…………………** 2
   Don't Know**………………………………..** -8

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D5.   Was (*name of child*) 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 child*) born?

      ____ ____ weeks [this number should never exceed 20 weeks]

      Don't Know**……………………………………....**   -8

    b.   Was (*name of child*) considered "pre-mature" at the time of his/her birth?

      Yes**…………………………………………...**   1
      No**……………....…………………………...**   2
      Don't know …………………………………   -8

D6.   Was (*name of child*) a part of a multiple birth (e.g. a twin, triplet, etc.)?

      Yes**……………………………………….**   1
      No**……………………………………….**   2

D7.   Immediately after birth, did (*name of child*) 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 child*) have any kidney problems?

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

D9.   How long was (*name of child*) birth mother in the hospital after the delivery?

    ___ ___   1 = months   3 = days
            2 = weeks   -8 = don't know

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

    ___ ___   1 = months   3 = days
            2 = weeks   -8 = don't know

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

      ___ ___ years

      Don't Know**…………………………………..**   -8

D12. Is (*name of child*) 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 child*) 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 child*) biological father when the child was born?

        ___ ___ years

        Don't Know**………………………………..**   -8

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

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

D16. Which of the following describe the race of (*name of child*) 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: _____

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SECTION E: CHILD'S EDUCATION

The following questions are about the child's education. Specifically, the next question asks about the highest grade the child has completed. For example, if the child is currently in the 12th grade, then enter "11", or if the child is currently in the 6th grade, then enter "5". In addition, if the child is in the 1st grade, kindergarten or not yet in school, then enter "0".

E1.   What is the **highest** grade that (*name of child*) has COMPLETED?

      ___ ___Grade

      Don't Know**……………………………………….**   -8

E2.   Does (*name of child*) attend school outside of the home?

      Yes**……………………………….............**   1

      No**………………….................................**   2   → **(Skip to F1)**

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

      ___ ___ Days

      Don't Know**……………………………………….**   -8

The next two questions refer to service(s) the child is currently receiving unless this form is completed during the summertime when school is not in session. If this form is completed during the summer months, please refer to the service(s) the child received during the past school year.

E4.   Does (*name of child*) 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

E5.   Does (*name of child*) 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: CHILD'S FAMILY AND PRIMARY HOUSEHOLD

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

F1.   What is the current relationship between (*name of child*) **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

The following questions ask about the child's <u>primary household</u>. The <u>primary household</u> is the home in which the child lives at least half of the time.

F2.   How many days per week does (*name of child*) live in the primary household? Indicate a number between 4 and 7.

_____ days

Don't Know**…………………………………….**   -8

F3.   How many people (including *name of child*), 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<u>? An adult</u> 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 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.	Other**...**	1	2	-8
	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

The following questions are about the education level of the child's parents in the <u>primary household</u>. Remember, primary household is defined as the home in which the child lives at least half of the time.

F7.   What is the highest grade or level of school that (*name of child*) 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 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 child*) 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 doctoral degree enter "20 years."

    ___ ___ Years

    Don't Know**………………………………….** -8

    No Such Person**………………………….....** -1

For F9: ALLOW PARENT 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 child*) 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.

YEAR	MONTH	WEEK	
$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

F9a.   What is the current employment status of (*name of child*)'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 child*)'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 child*)'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 child*)'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 child*)?

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 F10**
Unemployed not seeking work…………………....	4	→ **Skip to F10**
Student…………………………………………....	5	→ **Skip to F10**
Retired…………………………………………....	6	→ **Skip to F10**
Disability…………………………………………	7	→ **Skip to F10**
Not Applicable……………………………………..	-1	→ **Skip to F10**
Don't Know………………………………………….	-8	→ **Skip to F10**

i. Is (*name of child*) self-employed?

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

F10. What is the current zip code of the child's **primary household** (i.e., the home in which the child lives at least half of the time)?

___ ___ ___ ___ ___ ___

Don't Know**……………………………..**   -8

F11. Has the child 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 child lived at the current zip code?

___ ___ months

Don't Know**……………………………..**   -8

b. What was the zip code of the child's previous primary household?

___ ___ ___ ___ ___ ___

Don't Know**……………………………..**   -8

c. Approximately, how many years did the child 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 child lived at the current zip code?

___ ___ . ___ years

Don't Know**……………………………..**   -8

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SECTION G: CHILD'S FAMILY HISTORY

The health conditions and illnesses experienced by close family members can provide important information about the child's health. The following questions ask about the medical history of the child's biological family. The child's biological family includes his or her birth mother, birth father, grandparents, aunts, uncles, full brothers, full sisters and 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 <u>and</u> birth father as the child.*

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 child'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 I say, stop me and I will re-read the question.

G1.   Do you have knowledge of the health history of any members of (*name of child*) 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 child*) 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 child*) have any **living half** siblings in the study?

  Yes**……………………………………………..**   1
  No**………………………………………….....**   2   →   **(Skip to G3)**

  i. How many **living half** siblings does (*name of child*) have participating in the study?

  ___ ___ living half siblings

G3.   a.   How many **full** siblings does (*name of child*) have? (Full siblings are defined as brothers and sisters, who have the same birth mother and birth father as the child. 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 child*) have?

  ___ ___ full (living) siblings → **(If "0", skip to G4)**

  Don't Know **………………………………....**   -8   →   **(Skip to G4)**

  c.   Does (*name of child*) have any **living full** siblings in the study?

  Yes**……………………………………………..**   1
  No**………………………………………….....**   2   →   **(Skip to G4)**

  i. How many **living full** siblings does (*name of child*) have participating in the study?

  ___ ___ living full siblings

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

Date of Birth   **Date of Birth**

a. Sibling 1   __ __/ __ __/ __ __ __ __   e. Sibling 5   __ __/ __ __/ __ __ __ __
                M M   D D   Y Y Y Y   M M   D D   Y Y Y Y
                Don't Know**............................** -8   Don't Know**............................** -8

b. Sibling 2   __ __/ __ __/ __ __ __ __   f. Sibling 6   __ __/ __ __/ __ __ __ __
                M M   D D   Y Y Y Y   M M   D D   Y Y Y Y
                Don't Know**............................** -8   Don't Know**............................** -8

c. Sibling 3   __ __/ __ __/ __ __ __ __   g. Sibling 7   __ __/ __ __/ __ __ __ __
                M M   D D   Y Y Y Y   M M   D D   Y Y Y Y
                Don't Know**............................** -8   Don't Know**............................** -8

d. Sibling 4   __ __/ __ __/ __ __ __ __   h. Sibling 8   __ __/ __ __/ __ __ __ __
                M M   D D   Y Y Y Y   M M   D D   Y Y Y Y
                Don't Know**............................** -8   Don't Know**............................** -8

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 child***) **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?

	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)** Specify: _____	-8
2 Father**...............**	1	2	**(#3)**	1	2	3	4	5 **(specify)** Specify: _____	-8
3 Sibling (full brother or sister)	1	2	**(#4)**	1	2	3	4	5 **(specify)** Specify: _____	-8
4 Grandparents**...**	1	2	**(#5)**	1	2	3	4	5 **(specify)** Specify: _____	-8
5 Aunts/Uncles**....**	1	2	**(#6)**	1	2	3	4	5 **(specify)** Specify: _____	-8
6 Cousins**............**	1	2	**(G6)**	1	2	3	4	5 **(specify)** Specify: _____	-8

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Next, I am going to ask you some more questions about (*name of child*) biological family members.

G6. a. Including living and deceased, have any of **(*name of child*) biological family members** been told by a health care professional that they had the SAME kidney disease as the child?

Yes**...** 1

No**...** 2 → **(Skip to G7)**

Don't know**..** -8 → **(Skip to G7)**

b. Which biological family members? <u>Yes</u> <u>No</u>

(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. Grandparents**...........................** 1 2
5. Aunts/Uncles**...........................** 1 2
6. Cousins**...................................** 1 2

G7. a. Including living and deceased, have any of **(*name of child*) 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? <u>Yes</u> <u>No</u>

(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. Grandparents**...........................** 1 2
5. Aunts/Uncles**...........................** 1 2
6. Cousins**...................................** 1 2

G8.   a.   Including living and deceased, have any of (*name of child*) **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**.)

1. High Blood Pressure or Hypertension

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

	Yes	No	Don't Know
Mother**....................**	1	2	-8
Father**.....................**	1	2	-8
Sibling (full brother or sister)**.................**	1	2	-8
Grandparents**.........**	1	2	-8
Aunts/Uncles**..........**	1	2	-8
Cousins**..................**	1	2	-8

2. High Cholesterol

Yes**......................** 1
No**........................** 2 → **(Skip to 3)**
Don't know**...........** -8 → **(Skip to 3)**

	Yes	No	Don't Know
Mother**....................**	1	2	-8
Father**.....................**	1	2	-8
Sibling (full brother or sister)**.................**	1	2	-8
Grandparents**.........**	1	2	-8
Aunts/Uncles**..........**	1	2	-8
Cousins**..................**	1	2	-8

3. Diabetes (high blood sugar or sugar diabetes)

Yes**......................** 1
No**........................** 2 → **(Skip to 4)**
Don't know**...........** -8 → **(Skip to 4)**

	Yes	No	Don't Know
Mother**....................**	1	2	-8
Father**.....................**	1	2	-8
Sibling (full brother or sister)**.................**	1	2	-8
Grandparents**.........**	1	2	-8
Aunts/Uncles**..........**	1	2	-8
Cousins**..................**	1	2	-8

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

4. Stroke before the age of 50

					Yes	No	Don't Know
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
				Grandparents**........**	1	2	-8
				Aunts/Uncles**.........**	1	2	-8
				Cousins**.................**	1	2	-8

5. Heart Attack before the age of 50

					Yes	No	Don't Know
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
				Grandparents**.........**	1	2	-8
				Aunts/Uncles**.........**	1	2	-8
				Cousins**..................**	1	2	-8

G9.   a.   Including living and deceased, have any of (*name of child*) **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.)**

c.   At what age was treatment started?

1. Mother

Yes**...................** 1

No**.....................** 2 → **(skip to 2)**

Don't Know**.......** -8

___ ___ yrs

Don't Know**......** -8

2. Father

Yes**...................** 1

No**.....................** 2 → **(skip to 3)**

Don't Know**.......** -8

___ ___ yrs

Don't Know**......** -8

3. Sibling (full brother or sister)

Yes**...................** 1

No**.....................** 2 → **(skip to 4)**

Don't Know**.......** -8

___ ___ yrs

Don't Know**......** -8

4. Grandparents

Yes**...................** 1

No**.....................** 2 → **(skip to 5)**

Don't Know**.......** -8

___ ___ yrs

Don't Know**......** -8

5. Aunts/Uncles

Yes**...................** 1

No**.....................** 2 → **(skip to 6)**

Don't Know**.......** -8

___ ___ yrs

Don't Know**......** -8

6. Cousins

Yes**...................** 1

No**.....................** 2 → **(skip to G10)**

Don't Know**.......** -8

___ ___ yrs

Don't Know**......** -8

G10. a. Including living and deceased, have any of **(*name of child*) 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

Yes**...................** 1

No**.....................** 2

Don't Know**.......** -8

2. Father

Yes**...................** 1

No**.....................** 2

Don't Know**.......** -8

3. Sibling (full brother or sister)

Yes**...................** 1

No**.....................** 2

Don't Know**.......** -8

4. Grandparents

Yes**...................** 1

No**.....................** 2

Don't Know**.......** -8

5. Aunts/Uncles

Yes**...................** 1

No**.....................** 2

Don't Know**.......** -8

6. Cousins

Yes**...................** 1

No**.....................** 2

Don't Know**.......** -8

c. At what age was transplant performed?

___ ___ yrs

Don't Know**.........** -8

→ **(skip to 2)**

___ ___ yrs

Don't Know**.........** -8

→ **(skip to 3)**

___ ___ yrs

Don't Know**.........** -8

→ **(skip to 4)**

___ ___ yrs

Don't Know**.........** -8

→ **(skip to 5)**

___ ___ yrs

Don't Know**.........** -8

→ **(skip to 6)**

___ ___ yrs

Don't Know**.........** -8

→ **(skip to G11)**

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.)

	Yes	No	Don't Know
Stillbirth (fetus died at birth)**.........................**	1	2	-8
Miscarriage**…....................................**	1	2	-8

G12.   What is the height of (*name of child*) birth
       mother?   ___ feet ___ ___ inches

                                                         Don't Know**……………......**   -8

G13.   What is the weight of (*name of child*) birth
       mother?   ___ ___ ___ lbs

                                                         Don't Know**………………...**   -8

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

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

G15.   What is the height of (*name of child*) birth
       father?   ___ feet ___ ___ inches

                                                         Don't Know**………………...**   -8

G16.   What is the weight of (*name of child*) birth
       father?   ___ ___ ___ lbs

                                                         Don't Know**………………...**   -8

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

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

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

           Yes**……………………………….........**   1
           No**……………………………………**   2
           Don't Know**………………………………**   -8
           N/A, child does not have any siblings**………**   -1

SOME OF THE FOLLOWING QUESTIONS MAY BE EMBARASSING TO THE CHILD. ASK THIS SECTION OF QUESTIONS WHEN THE CHILD IS NOT IN THE ROOM.

SECTION H: CHILD'S DEVELOPMENTAL HISTORY

The following questions are to learn more about the child'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 child*) first perform the following activities?

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

H2.   a.   Is (*name of child*) older than 5 years of age?

            Yes……………………………….............. 1 → **(Skip to H2c)**
            No……………………………………… 2

       b.   Is (*name of child*) currently breast-fed?

            Yes……………………………….............. 1 → **(Skip to H3)**
            No……………………………………… 2
            Don't Know…………………………….… -8 → **(Skip to H3)**

       c.   Was (*name of child*) breast-fed?

            Yes……………………………….............. 1
            No……………………………………… 2 → **(Skip to H3)**
            Don't Know…………………………….… -8 → **(Skip to H3)**

       d.   How old was (*name of child*) 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 = years
                              2 = months
                              3 = weeks
                              4 = days
            Don't Know........................... -8

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

Yes**…………………………….................** 1 → **(Skip to H4)**

No**………………………………………** 2

Don't Know**……………………………....** -8 → **(Skip to H4)**

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

Yes**……………………………….......** 1

No**………………………………………** 2 → **(Skip to H4)**

Don't Know**……………………………....** -8 → **(Skip to H4)**

  b. How old was (*name of child*) 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 = years
                 2 = months
                 3 = weeks
                 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 child*) 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 child*) wet during the day?

Yes**……………………………….......** 1

No**…………………………………………** 2

Don't Know**……………………………....** -8

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

Yes**……………………………….......** 1

No**………………………………………** 2

Don't Know**……………………………....** -8

c. Does *(name of child)* 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 child)* catheterize through the urethra?

   Yes**………………………………….......** 1

   No**…………………………………….** 2

   Don't Know**……………………………** -8

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

   Yes**………………………………….......** 1

   No**…………………………………….** 2

   Don't Know**……………………………** -8

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

Yes**………………………………….................** 1

No**………………………………………………** 2 → **(Skip to H6)**

Don't Know**………………………………......** -8 → **(Skip to H6)**

a. When was (*name of child*) 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

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.   Has (*name of child*) 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**....................**	1	2	-8
f.	Unclear speech**.....................**	1	2	-8
g.	Sleep problem**.......................**	1	2	-8
h.	Colic**....................................**	1	2	-8

H7.   Which hand does (*name of child*) primarily use to write?

Primarily right**...**   1

Primarily left**..**   2

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

H8.   Is (*name of child*) 4 years of age or older?

Yes**...**   1

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

H9. During (*name of child*) first 4 years, were any problems noted in the areas listed below?
(Circle "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

TO BE COMPLETED BY CLINICAL SITE:

DATE: ___ ___/ ___ ___/ ___ ___ ___ ___   **INITIALS:** ___ ___ ___
  M   M / D   D / Y   Y   Y   Y

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

CKiD
Chronic Kidney Disease
in Children