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:	<u>0</u> <u>1</u> / <u>0</u> <u>1</u> / <u>0</u> <u>6</u>
A4.	DATE OF VISIT:	$\frac{1}{M} \frac{1}{M} \frac{1}{D} \frac{1}{D} \frac{1}{Y} \frac{1}{Y} \frac{1}{Y} \frac{1}{Y} \frac{1}{Y}$
A5.	INTERVIEWER'S INITIALS:	
A6.	Is this study visit an accelerated visit?	Yes 1 No 2

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 your child's family background and family medical history since their last study visit. 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. <u>Please take as much time as you need, so I can gather information that is as accurate as possible</u>.

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.

What is your relationship to (name of child)?		
Mother	1	\rightarrow (Skip to C1)
Father	2	\rightarrow (Skip to C1)
Legal Guardian	3	\rightarrow (Skip to C1)
Other	4	

a. If **OTHER**, specify your relationship:

. . ..

B1.

(Such as: grandmother, stepfather, uncle, etc.)

SECTION C: 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".

C1. In the past year, what is the **highest** grade that (*name of child*) has COMPLETED?

> ____ Grade Don't Know......-8

C2.	C2. Does (<i>name of child</i>) attend school outside of the home?			
	Yes	1		
	No	2	\rightarrow	(Skip to D1)

During the past school year, approximately how many days has (name of child) missed from C3. school because of not feeling well?

> ____ Days

C4. Does (name of child) have an individualized educational plan? (An individualized educational plan includes special education and related services designed to address specific educational needs of children with disabilities.)

Yes	1
No	2
Don't Know	-8

C5. Does (name of child) have a 504 plan 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.)

Yes	1
No	
Don't Know	-8

SECTION D: 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.

D1. 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</u> <u>household</u> is the home in which the child lives at least half of the time.

D2. 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

D3. How many adults live in the primary household? Include **all persons at least 18 years of age**, including siblings and non-relatives.

____ adults

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

D4. Which of the following adults (18 years or older) live in the primary household? (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.	Other	1	2	-8



D5. How many people under the age of 18 (including this child), live in the primary household (at least half the time)? Include **all persons under the age of 18**, including siblings and non-relatives.

D6. Do any of the people that live 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.

D7. 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."

D8. 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 D9: ALLOW PARENT 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 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	<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

SECTION E: 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 birth father as the child</u>.*

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.

E1. 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	ightarrow (Skip to F1)



E2. 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 \rightarrow (If "0", skip to E5)
Don't Know
How many living full siblings does (<i>name of child</i>) have? full (living) siblings
Don't Know

E3.

E4. 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	/ / /	
	Don't Know	-8		Don't Know	-8
b. Sibling 2	$-\underline{\qquad} -\underline{\qquad} -\qquad$		f. Sibling 6	$-\underline{M} - \underline{M} -$	
	Don't Know	-8		Don't Know	-8
c. Sibling 3	///		g. Sibling 7		
	Don't Know	-8		Don't Know	-8
d. Sibling 4	$-\underline{M} - \underline{M} -$		h. Sibling 8	$-\underline{M} - \underline{M} -$	
	Don't Know	-8		Don't Know	-8

END F07s1

START 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 child*) 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	\rightarrow	(Skip to E8)
Don't know	-8	\rightarrow	(Skip to E8)

b. Which family members?

C. What type of kidney disease?

	· · · · · · · · · · · · · · · · · · ·						sy alcoace i			
		<u>Yes</u>	<u>Nc</u>	<u>)</u>	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 Specify	5 (specify)	-8
2	Father	1	2	(#3)	1	2	3	4	5 (specify)	-8
3	Sibling (full brother or sister)	1	2	(#4)	1	2	3	4		-8
4	Grandparents	1	2	(#5)	1	2	3	4	5 (specify)	-8
5	Aunts/Uncles	1	2	(#6)	1	2	3	4	5 (specify)	-8
6	Cousins	1	2	(E6)	1	2	3	4	5 (specify)	-8



	Next, I membe	am going to ask you some more que ers.	estions	about	(name of child) biological family
E6.	a.	In the past year, have any of (name o been told by a health care profession			or deceased biological family members I the SAME kidney disease?
		Yes	1		
		No	2	\rightarrow	(Skip to E7)
		Don't know	-8	\rightarrow	(Skip to E7)
	b.	Which biological family members? (Circle "Yes" or "No" for EACH of t	<u>Yes</u> the follo	<u>No</u> owing.)	
		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	
E7.	a.	In the past year, have any of (name o had a kidney biopsy?	of child) living	or deceased biological family members
		Yes	1		
		No	2	\rightarrow	(Skip to E8)
		Don't know	-8	\rightarrow	(Skip to E8)
	b.	Which biological family members? (Circle "Yes" or "No" for EACH of t	<u>Yes</u> the follo	<u>No</u> owing.)	
		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	



E8. a. In the past year, have any of (*name of child*) 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)

1.	High Blood Pressu	e or	Нур	ertension		<u>Yes</u>	<u>No</u>	<u>Don't</u> Know
	Yes	1			Mother	1	2	-8
	No	2	\rightarrow	(Skip to 2)	Father	1	2	-8
	Don't know	-8	\rightarrow	(Skip to 2)	Sibling (full brother			
					or sister)	1	2	-8
					Grandparents	1	2	-8
					Aunts/Uncles	1	2	-8
					Cousins	1	2	-8

2.	High Cholesterol					<u>Yes</u>	<u>No</u>	<u>Don't</u> Know
	Yes	1			Mother	1	2	-8
	No	2	\rightarrow	(Skip to 3)	Father	1	2	-8
	Don't know	-8	\rightarrow	(Skip to 3)	Sibling (full brother			
					or sister)	1	2	-8
					Grandparents	1	2	-8
					Aunts/Uncles	1	2	-8
					Cousins	1	2	-8

3.	Diabetes (high bloc	od su	igar o	or sugar diabe	tes)	<u>Yes</u>	<u>No</u>	<u>Don't</u> Know
	Yes	1			Mother	1	2	-8
	No	2	\rightarrow	(Skip to 4)	Father	1	2	-8
	Don't know	-8	\rightarrow	(Skip to 4)	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 a	ge of	f 50			<u>Yes</u>	<u>No</u>	<u>Don't</u> Know
	Yes	1			Mother	1	2	-8
	No	2	\rightarrow	(Skip to 5)	Father	1	2	-8
	Don't know	-8	\rightarrow	(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 a	age	of 50		<u>Yes</u>	<u>No</u>	<u>Don't</u> Know
5.	Heart Attack before Yes	the a	age	of 50	Mother	<u>Yes</u> 1	<u>No</u> 2	
5.		1	age ∕	of 50 (Skip to E9)	Mother Father			Know
5.	Yes	1 2	•			1	2	<u>Know</u> -8
5.	Yes No	1 2	\rightarrow	(Skip to E9)	Father	1	2	<u>Know</u> -8
5.	Yes No	1 2	\rightarrow	(Skip to E9)	Father Sibling (full brother	1 1	2 2	<u>Know</u> -8 -8
5.	Yes No	1 2	\rightarrow	(Skip to E9)	Father Sibling (full brother or sister)	1 1	2 2 2	<u>Know</u> -8 -8 -8



E9.	a.	In the past y of child) liv biological f dialysis as disease?	ving of famil	or de y me	mbers had	b. Which biologi family member (Circle "Yes", "N or "Don't Know" EACH of the follo	e rs ? o", for		At what age was treatment started	?
		Yes	1			1. Mother			yrs old	
		No	2	\rightarrow	(Skip to E10)	Yes	1		Don't Know	-8
		Don't Know	-8	\rightarrow	(Skip to E10)	No	2	ightarrow (skip to 2	2)	
						Don't Know	-8			
						2. Father			yrs old	
						Yes	1		Don't Know	-8
						No	2	ightarrow (skip to 3	3)	
						Don't Know	-8			
						3. Sibling (full brother or sister)			yrs old	
						Yes	1		Don't Know	-8
						No	2	ightarrow (skip to 4	4)	
						Don't Know	-8	, (p	-)	
						4.Grandparents			yrs old	
						Yes	1		Don't Know	-8
						No	2	ightarrow (skip to $ m s$		-
						Don't Know	-8		,	
						5. Aunts/Uncles			yrs old	
						Yes	1		Don't Know	-8
						No		\rightarrow (skin to (0
						Don't Know			5)	
							5			
						6. Cousins Yes	1		yrs old Don't Know	-8
						Yes		ightarrow (skip to I		-0
						Don't Know		→ (skip to i	= 10)	
							-0			



E10.	a.	of child) livi biological fa	ing o amily splai	have any of (<i>name</i> or deceased y members had a nt as treatment for	b. Which biolog i family memb (Circle "Yes", "N or "Don't Know" EACH of the fol	ers ? o", for	c. At what age was transplant performed?
		Yes	1		1. Mother		yrs old
		No	2	ightarrow (Skip to E11)	Yes	1	Don't Know8
		Don't Know	-8	ightarrow (Skip to E11)	No	2	ightarrow (skip to 2)
					Don't Know	-8	
					2. Father		yrs old
					Yes	1	Don't Know8
					No	2	ightarrow (skip to 3)
					Don't Know	-8	
					3. Sibling (full brother or sister)		yrs old
					Yes	1	Don't Know8
					No	2	ightarrow (skip to 4)
					Don't Know	-8	
					4.Grandparents		yrs old
					Yes	1	Don't Know8
					No	2	ightarrow (skip to 5)
					Don't Know	-8	
					5. Aunts/Uncles		yrs old
					Yes	1	Don't Know8
					No	2	ightarrow (skip to 6)
					Don't Know	-8	
					6. Cousins		yrs old
					Yes	1	Don't Know8
					No	2	ightarrow (skip to E11)
					Don't Know	-8	



E11.	In the past year, has the birth mother been pregna Yes	1		
	No	2		(skip to E13)
E12.	In the past year, have any of the birth mother's pre	gnan	ncies re	sulted in the following?
	(Circle "Yes", "No" or "Don't Know" for EACH	of the	e follov	wing)
		Yes		<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 child) birth mother	had	recurre	nt Urinary Tract Infections (UTI)?
	Yes			
	No	2		
	Don't Know	8		
E14.	In the past year, has (<i>name of child</i>) birth father h	nad re	ecurren	t Urinary Tract Infections (UTI)?
	Yes		Joanon	
	No	-		
	Don't Know			
E15.	In the past year, have any of (<i>name of child</i>) sibli	nae h	ad roc	urrent Uripany Tract Infections (UTI)?
L15.	Yes	•		
		-		
	No			
	Don't Know	8		
	N/A, child does not have any siblings	1		
SOMI	E OF THE FOLLOWING QUESTIONS MAY BE EM	BAR	ASSIN	G TO THE CHILD. ASK
THIS	SECTION OF QUESTIONS WHEN THE CHILD IS	ΝΟΤ	IN THE	E ROOM.

SECTION F: CHILD'S DEVELOPMENTAL HISTORY

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

F1. At the first CKiD study visit, was (name of child) older than 5 years of age?

Yes	$1 \rightarrow$ (Skip to F4)
No	2



	b.	Is (<i>name of child</i>) currently breast-fed? Yes
	C.	Was (name of child) breast-fed? Yes1No $2 \rightarrow$ (Skip to F3)Don't Know $-8 \rightarrow$ (Skip to F3)
	d.	How old was (<i>name of child</i>) 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
F3.	ls (r	name of child) currently bottle-fed?
		Yes $1 \rightarrow$ (Skip to F4)No2Don't Know-8 \rightarrow (Skip to F4)
	a.	Was (name of child) bottle-fed? Yes
	b.	How old was (<i>name of child</i>) 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 Know8
F4.	At th	the first CKiD study visit, was (<i>name of child</i>) toilet trained? Yes
	a.	Is (<i>name of child</i>) currently toilet trained? Yes



b.	When was (<i>name of child</i>) toilet trained? Age years	
C.	After toilet training, did bed-wetting occur? Yes No Don't Know	$2 \rightarrow$ (Skip to d)
	 Does bed-wetting still occur? Yes No Don't Know 	2
	 ii. At what age did bed-wetting stop? (Please circle "1" for years and "2" Age 1 = years 2 = months 	
	iii. Were medical reasons the cause of be Yes No Don't Know	1 2
d.	After toilet training, did bed-soiling occur? Yes No Don't Know	$2 \rightarrow$ (Skip to F5)
	i. Does bed-soiling still occur? Yes No Don't Know	2
	 ii. At what age did bed-soiling stop? (Please circle "1" for years and "2" Age 1 = years 2 = months Don't Know 	
	iii. Were medical reasons the cause of be YesNoDon't Know	1 2

F4.



F5. In the past year, has (*name of child*) experienced any of the following problems? (Circle "Yes", "No" or "Don't Know" for EACH of the following)

		Yes	<u>No</u>	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
F6.	Which hand does (name of child) primarily use to write?Primarily rightPrimarily left2			
F7.	At the first CKiD study visit, was (<i>name of child</i>) 4 years of age or older? Yes			

a. Is (*name of child*) currently 4 years of age or older? Yes..... 1 No..... $2 \rightarrow$ (END) Don't Know..... $-8 \rightarrow$ (END)



During (*name of child*) first 4 years, were any problems noted in the areas listed below? Indicate yes, no or don't know for each of the following. F8.

		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:

____/ ____/ ____ M M / D D / Y Y ADMINISTRATION:

(Circle "1", "2" or "3")

1 = Interviewer Assisted 2 = Self-Administered

ΥY

3 = Both

INITIALS: _____

