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>1</u> <u>1</u> / <u>0</u> <u>1</u> / <u>0</u> <u>9</u>
A4.	DATE OF VISIT:	$\frac{1}{M} \frac{1}{M} \frac{1}{D} \frac{1}{D} \frac{1}{V} \frac{1}{Y} \frac{1}{Y} \frac{1}{Y} \frac{1}{Y}$
A5.	INTERVIEWER'S INITIALS:	
A6.	Is this study visit an irregular (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.

B1.	What is your relationship to (<i>name of child</i>)?	

Mother	1	\rightarrow (Skip to C1)
Father		
Legal Guardian	3	\rightarrow (Skip to C1)
Other		

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

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

- C2. Does (*name of child*) attend school outside of the home? Yes..... 1 No...... 2 \rightarrow (Skip to D1)
- C3. During the past school year, approximately how many days has (*name of child*) missed from school because of not feeling well?

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. REFER TO QXQ FOR DETAILED DESCRIPTION.)

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. REFER TO QXQ FOR DETAILED DESCRIPTION.)

Yes	1
No	2
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.)

		Yes	<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.

____ people

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

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."

___ Years

Don't Know	-8
No Such Person	-1

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."



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.

			. .	
<u>YEAR</u>	<u>MONTH</u>	WEEK	X	
\$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	

D9a. What is the current employment status of (*name of child*) 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	ightarrow Skip to D9b
Unemployed not seeking work	4	ightarrow Skip to D9b
Student	5	ightarrow Skip to D9b
Retired	6	ightarrow Skip to D9b
Disability	7	ightarrow Skip to D9b
Don't Know	-8	ightarrow Skip to D9b
i. Is (name of child) MOTHER in the primary house	ehold	self-employed?
Yes	1	
No	2	
Don't Know	-8	

D9b. What is the current employment status of (name of child) 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 \rightarrow Skip to D10 4 Unemployed not seeking work..... \rightarrow Skip to D10 Student..... 5 \rightarrow Skip to D10 Retired..... 6 \rightarrow Skip to D10 Disability..... 7 \rightarrow Skip to D10 Don't Know..... -8 \rightarrow Skip to D10



i. Is (name of child)'s FATHER in the primary household self-employed? Yes..... 1 No..... 2 Don't Know..... -8 D10. 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 D11. Has the child lived at the current zip code for more than 1 year? Yes..... 1 (skip to D12) Don't Know...... -8 (Skip to Section E) 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 Don't Know..... -8 D12. Approximately, how many years has the child lived at the current zip code? ____ . ___ years



-8

Don't Know.....

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</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.

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	\rightarrow (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.)

E3. How many living full siblings does (name of child) have?

____ full (living) siblings



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

				START F07s1	<u>1</u>
	Date of Birth			Date of Birth	
a. Sibling 1	///		e. Sibling 5	/ / /	
	Don't Know	-8		Don't Know8	
b. Sibling 2	///		f. Sibling 6	///	
	Don't Know	-8		Don't Know8	
c. Sibling 3	$-\underline{M} - \underline{M} -$		g. Sibling 7	$-\underline{M} - \underline{M} -$	
	Don't Know	-8		Don't Know	
d. Sibling 4	///		h. Sibling 8	// /	
	Don't Know	-8		Don't Know8	

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 child*) living or deceased biological family members been told by a health care professional that they had kidney disease in the past year?

	•		
No	2	\rightarrow	(Skip to E8)
Don't know	-8	\rightarrow	(Skip to E8)

b. Which family members?

C. What type of kidney disease?

	Yes	<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 Specify	5 (specify)	-8
⁴ Grandparents	1	2	(#5)	1	2	3	4	5 (specify)	-8
⁵ Aunts/Uncles	1	2	(#6)	1	2	3	4 Specify	5 (specify)	-8
6 Cousins	1	2	(E6)	1	2	3	4	5 (specify)	-8



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

E6.	a.	In the past year, have any of (name o been told by a health care professiona Yes			or deceased biological family members I the SAME kidney disease?
		No	2	\rightarrow	(Skip to E7)
		Don't know	-8	\rightarrow	(Skip to E7)
	b.	Which biological family members?	<u>Yes</u>	<u>No</u>	
		(Circle "Yes" or "No" for EACH	of the	followi	ing.)
		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.	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?	<u>Yes</u>	<u>No</u>	
		(Circle "Yes" or "No" for EACH	of the	followi	ing.)
		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 Pressur	re 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 ag	e of 50			<u>Yes</u>	<u>No</u>	<u>Don't</u> 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 t	the age	e of 50		Yes	<u>No</u>	<u>Don't</u> <u>Know</u>
	Yes	1		Mother	1	2	-8
	No	$2 \rightarrow$	(Skip to E9)	Father	1	2	-8
	Don't know	- 8 →	(Skip to E9)	Sibling (full brother			
				or sister)	1	2	-8
				Grandparents	1	2	-8
				Aunts/Uncles	1	2	-8
				Cousins	1	2	-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	ers ? 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 (U
						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) liv biological f	ving o family nspla	or de y me	e any of (name ceased mbers had a treatment for	b. Which biologi family member (Circle "Yes", "N or "Don't Know" EACH of the foll	ers ? o", for	c. At what ag transplant performed	-	
		Yes	1			1. Mother		У	rs old	
		No	2	\rightarrow	(Skip to E11)	Yes	1	Don't Kno	w	-8
		Don't Know	-8	\rightarrow	(Skip to E11)	No	2	ightarrow (skip to 2)		
						Don't Know	-8			
						2. Father		у	rs old	
						Yes	1	Don't Kno	w	-8
						No	2	ightarrow (skip to 3)		
						Don't Know	-8			
						3. Sibling (full brother or sister)		y	rs old	
						Yes	1	Don't Kno		-8
						No	2	ightarrow (skip to 4)		
						Don't Know	-8			
						4.Grandparents		Y	rs old	
						Yes	1	Don't Kno		-8
						No	2	ightarrow (skip to 5)		
						Don't Know	-8			
						5. Aunts/Uncles		V	rs old	
						Yes	1	Don't Kno		-8
						No	2	ightarrow (skip to 6)		
						Don't Know	-8			
						6. Cousins		y	rs old	
						Yes	1	Don't Kno		-8
						No	2	ightarrow (skip to E11)		
						Don't Know	-8			



E11.	In the past year, has the birth mother been pregna Yes No			(skip to E13)
E12.	In the past year, have any of the birth mother's pre	•		C C
	(Circle "Yes", "No" or "Don't Know"	for E	EACH	of the following)
	Stillbirth (fetus died at birth) Miscarriage	<u>Yes</u> 1 1	<u>No</u> 2 2	<u>Don't Know</u> -8 -8
E13.	In the past year, has (<i>name of child</i>) birth mother	had	recurre	nt Urinary Tract Infections (UTI)?
	Yes			
	No	2		
	Don't Know	8		
E14.	In the past year, has (name of child) birth father h		ecurren	t Urinary Tract Infections (UTI)?
	Yes			
	No			
	Don't Know	8		
E15.	In the past year, have any of (name of child) sibli	ngs h	nad rec	urrent Urinary Tract Infections (UTI)?
	Yes	1		
	No	. 2		
	Don't Know	8		
	N/A, child does not have any siblings	1		
	E OF THE FOLLOWING QUESTIONS MAY BE EM SECTION OF QUESTIONS WHEN THE CHILD IS			

SECTION F: CHILD'S DEVELOPMENTAL HISTORY

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

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

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



Is (<i>name of child</i>) currently breast-fed? Yes
Was (name of child) breast-fed?Yes1No $2 \rightarrow$ (Skip to F3)Don't Know8 \rightarrow (Skip to F3)
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 Know8
name of child) currently bottle-fed?
Yes $1 \rightarrow$ (Skip to F4) No 2 Don't Know8 \rightarrow (Skip to F4)
Was (<i>name of child</i>) bottle-fed? Yes



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.	n the past year, has <i>(name of child)</i> had any wetness or leakage of urine (accidents) during ne day or night?
	Yes 1
	No $2 \rightarrow$ (Skip to c)
	Don't Know8 \rightarrow (Skip to c)
	a. In the past year, is (name of child) wet during the day?
	Yes 1
	No 2
	Don't Know8
	b. In the past year, is (name of child) wet during the night?
	Yes 1
	No 2
	Don't Know8
	c. In the past year, has (name of child) catheterized the bladder (i.e., put a tube in the bladder)?
	Yes 1
	No
	Don't Know
	i. In the past year, has (name of child) catheterized through the urethra?
	Yes 1
	No 2
	Don't Know8
	ii. In the past year, has (name of child) catheterized through a stoma?
	Yes 1
	No 2
	Don't Know8
F5.	t the last CKiD study visit, was (name of child) toilet trained?
10.	Yes $1 \rightarrow$ (Skip to F6)
	No
	Don't Know8 \rightarrow (Skip to F6)



a. b.	Yes No Don Whe	ame of child) currently toilet trained? 't Know en was (<i>name of child</i>) toilet trained?			(Skip to F6) (Skip to F6)
	Age	years			
C.	Yes. No	r toilet training, did bed-wetting occur? 't Know			(Skip to d) (Skip to d)
	i.	Does bed-wetting still occur?			
		Yes No	1 2	\rightarrow	(Skip to iii)
		Don't Know	-8	\rightarrow	(Skip to c)
	ii.	At what age did bed-wetting stop? (Please circle "1" for years and "2" for Age 1 = years 2 = months	mo	nth	s)
		Don't Know			
	iii.	Were medical reasons the cause of bed-		ng?	
		Yes No	1 2		
		Don't Know	-8		
d.	Yes. No	r toilet training, did bed-soiling occur?			,
	i.	Does bed-soiling still occur?			
		Yes	1	\rightarrow	(Skip to iii)
		No	2		
		Don't Know	-8	\rightarrow	(Skip to F6)

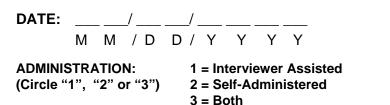


	 ii. At what age did bed-soiling (Please circle "1" for yea Age 1 = years 2 = months Don't Know iii. Were medical reasons the Yes No	rs and " cause of	8 [•] bed-soiling? 1 2		
	ne past year, has (<i>name of child</i>) e ccle "Yes", "No" or "Don't Know				
a.	Feeding problem	1	2	-8	
b.	Eating disorder	1	2	-8	
С.	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	
F7. Which hand does (<i>name of child</i>) primarily use to write? Primarily right 1 Primarily left					
F8. At a	the last CKiD study visit, was (<i>nan</i> Yes No Don't Know Is (<i>name of child</i>) currently 4 ye Yes No Don't Know.	ars of ag	1 – 2 8 le or older? 1 2 –	→ (END FORM)→ (END FORM)	

F9. 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.

	,	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:



INITIALS: _____

