Chronic Kidney Disease in Children (CKiD)

SECTION A: GENERAL INFORMATION

A1.	PARTICIPANT ID: AFFIX ID LABEL OR	ENTER NUM	MBER IF ID LABEL IS NOT AVAILABLE	
		- _	_ -	
A2.	CKID VISIT #:			
A3.	FORM VERSION:	0 3	/ <u>0 1</u> / <u>1</u> <u>8</u>	
A4.	DATE OF VISIT:	<u>M</u> <u>M</u> /_	D D Y Y Y Y	
A5.	SITE COORDINATOR'S INITIALS:		_	
A6.	Is this study visit an irregular (accele	rated) visit?	Yes No	1
A7.	INDICATE PERSON COMPLETING TH	E FORM	Child/young adult Parent or other adult Both (Parent and Child/young adult)	1 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 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 you and the participant's background. If you have trouble understanding anything please feel free to ask for further clarification.



SECTION B: INFORMATION ABOUT YOU

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

B1.	Mother	ationship to (<i>name of parti</i>	1 -	→ (Skip to C1)→ (Skip to C1)
	Legal Gua Self	ardian	3 - 5 -	→ (Skip to C1) → (Skip to C1) → (Skip to C1)
	a. If OTHER	, specify your relationship:		
	(Such as	s: grandmother, stepfather,	uncle, etc.)	
	question asks abore For example, if the participant is current the 1st grade, kinds	ut the highest grade or le participant is currently i	cipant's educatevel of school then the 12 th graden enter "5". In a	ion. Specifically, the next ne participant has completed. then enter "11", or if the addition, if the participant is in
C1.	What is the hig	hest grade or level of scho	ol that (<i>name of</i>	participant) has COMPLETED?
	G	rade		
	Don't Kno	w	8	
		cable/child less than 5 year not attend pre-school/pre-k		
C2	2. Does (<i>name o</i> home?	f participant) attend school	(including pre-so	chool and pre-K) outside of the
				(011 (D4)
	No		2	→ (Skip to D1)
C		st school year, approximate chool because of not feelin		ys has (<i>name of participant</i>)
	!	Days		
	Don't Kno	ow	8	



The next two questions refer to service(s) the participant is currently receiving. If this form is completed during the summer months, please refer to the service(s) the participant received during the past school year.

C4.	Does (name of participant) have an individualized educational plan (IEP)? (An individualized educational plan includes special education and related services designed to address specific educational needs of children with disabilities. REFER TO QXQ FOR DETAILED DESCRIPTION.)
	Yes 1
	No 2
	Don't Know8
	Not Applicable/child less than 5 years old1 → (Skip to D1)
C5.	Does (name of participant) have a 504 plan at school (or equivalent for Canadian sites)? (A 504 plan is a program designed to assist students with physical or emotional disabilities or other special needs in a regular school environment. REFER TO QXQ FOR DETAILED DESCRIPTION.)
	Yes 1
	No 2
	Don't Know8
	SECTION D: PARTICIPANT'S FAMILY AND PRIMARY HOUSEHOLD
	llowing questions are to learn more about the participant's home and with whom she lives.
D1.	What is the current relationship between (name of participant) biological parents?
	Not married, living together 1
	Married, living together 2
	Married, separated 3
	Widowed 4



The following questions ask about the participant's primary household. The primary household is the parent/guardian's home in which the participant lives at least half of the time. If the participant does not live with a parent/guardian (living independently, attending college or boarding school, emancipated, etc.), then the primary household is the parent/guardian's home where the participant used to live at least half the time prior to living independently.

D2.	How many days per week does (<i>name of participant</i>) live in the primary household? Indicate a number between 4 and 7. (For participants who do not live with a parent/guardian, indicate the number of days the participant lived in parent/guardian's home prior to living independently.)							
		days						
		Don't Know	-8					
D3.	How	many people live in the primary household at le	ast ha	If the time?				
		people						
		Don't Know	-8					
D4.	least	many adults live in the primary household at least 18 years of age. Include all persons at least relatives. Include participant if 18 years of age.						
		adults						
		Don't Know	-8					
D5.	half	ch of the following adults (18 years of age and of the time? Include the participant, if applicable. CH of the following.)						
			<u>Yes</u>	<u>No</u>	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.	Participant	1	2	-8			
	f.	Otheri. Specify:	1	2 (Skip to D6)	-8 (Skip to D6)			
D6.		any of the people, adults or children, living in the inely smoke cigarettes, cigars, cigarillos or little Yes No Don't Know	cigars		east half the time			



The following questions are about the education level of the participant's parent(s)/guardian(s) in the <u>primary household</u>. Remember, primary household is defined as the home in which the participant lives at least half of the time or lived prior to living independently.

<i>υ</i> 7.	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 Know8 No Such Person1
D8.	What is the highest grade or level of school that (name of participant) FATHER (including birth, adoptive or stepfather) in the primary household has COMPLETED? For example, if completed high school enter "12 years", if completed 4-year college degree enter "16 years", and if completed doctoral degree enter "20 years."
	Years
	Don't Know8
	No Such Person1
	or D9: ALLOW RESPONDENT TO CIRCLE THE NUMBER IN THE FAR RIGHT COLUMN THAT CORRESPONDS TO THEIR TOTAL INCOME.
D9.	Please estimate the total income (before taxes) of all members of the primary household . Include total income from wages , business , or investments for all members of (name of participant) primary bounded by year, month, or weak. Do NOT include social acquirity

D9. Please estimate the total income (before taxes) of all members of the **primary household**. Include **total income from wages, business, or investments** for all members of (*name of participant*) primary household, by year, month, or week. Do **NOT** include social security, disability insurance, or other governmental assistance. **Circle** the number in the FAR RIGHT COLUMN that corresponds to the total income.

<u>YEAR</u>	<u>MONTH</u>	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
Don't know			-8



D9a.	What is the current employment status of (name of participal adoptive or stepmother) in the primary household? Working full-time (35 hours or more per week)	→ Sk → Sk → Sk → Sk → Sk → Sk	kip to D9b kip to D9b kip to D9b kip to D9b kip to D9b kip to D9b	
	i. Is (name of participant) MOTHER in the primary hou Yes		self-employed	?
D9b.	What is the current employment status of (name of participant adoptive or stepfather) in the primary household? Working full-time (35 hours or more per week)	→ Sk → Sk → Sk → Sk → Sk → Sk	ER (including lip to D9c ip to D9c	oirth,
	i. Is (<i>name of participant</i>)'s FATHER in the primary hou Yes		self-employed	?
D9c.	What is the current employment status of (name of participant Yes Working full-time (35 hours or more per week)	No 2 2 2 2 2 2	N/A -1 -1 -1 -1 -1 (skip to D10)	Don't Know -8 -8 -8 -8 -8 (skip to D10) -8 (skip to D10)
	Champio you had been my working monking in (skip to blo	, _	1 (SMP to D10)	5 (3mp to D10)



	i.	Is (name of participant) self-employed?
		Yes 1
		No
		Don't Know8
D10.	What	is the zip code where the participant currently lives at least half of the time?
		Don't Know8
D11.	Has th	ne participant lived at the current zip code for more than 1 year?
		Yes 1 (skip to D12)
		No
		Don't Know8 (Skip to Section E)
	a.	Approximately how many months has the participant lived at the current zip code?
		months
		Don't Know8
	b.	What was the zip code where the participant previously lived?
	D.	what was the zip code where the participant previously lived:
	•	
	C.	Approximately, how many years did the participant live at the previous zip code?
		years (Skip to Section E)
		Don't Know
D12.		eximately, how many years has the participant lived at the current zip code?
J 12.		
		years -8
D40		Don t Know
D13.		participant's zip code and their parents/guardians' zip code the same?
		Yes
		Don't Know8 (Skip to Section E)
D14.		is the current zip code of the parent(s)/guardian(s) (i.e., the parent(s)/guardian(s) home the participant used to live at least half the time prior to living independently)?
D.1.5		
D15.		eximately, how long have the parent(s)/guardian(s) lived at the current zip code?
		year(s) month(s)
		Don't Know



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.

೬ 1.		you have knowledge of the health history of any members of (<i>name of participant</i>) birth ly (i.e. parents, grandparents, aunts, uncles, siblings and cousins)?
		Yes
E2.	a.	How many living half siblings does (<i>name of participant</i>) have (Half siblings are defined as brothers and sisters, who have only one parent, either mother or birth father in common. Do not include deceased siblings.)?
		living half siblings → (If "0", skip to E3)
		Don't Know8 \rightarrow (Skip to E3)
	b.	Does (name of participant) have any living half siblings in the study?
		Yes 1
		No
		i. How many living half siblings does (name of participant) have participating in the study?
		living half siblings
E3.	a.	How many full siblings does (<i>name of participant</i>) have? (Full siblings are defined as brothers and sisters, who have the same birth mother and birth father as the participant. Include deceased siblings.)
		full (living and deceased) siblings \rightarrow (If "0", skip to E5) Don't Know8 \rightarrow (Skip to E5)
	b.	How many living full siblings does (name of participant) have?
		full (living) siblings \rightarrow (If "0", skip to E4)
		Don't Know8 \rightarrow (Skip to E4)
	C.	Does (name of participant) have any living full siblings in the study?
		Yes 1
		No
		i. How many living full siblings does (name of participant) have participating in the study?
		living full siblings



										<u> </u>	START F07s
		Date	of E	3irth				Date o	f Birth		
	a. Sibling 1		_/	/_		_	e. Sibling 5				
	G				Y Y Y Y		· ·			Y Y Y	
		Don't	t Kno	w		8		Don't Kı	now		8-
	b. Sibling 2		_/	/_		_	f. Sibling 6				
	J				Y Y Y Y		J	M M	D D	Y Y Y	Υ
		Don't	t Kno	W		8		Don't Kr	now		8-
	c. Sibling 3		/	/			g. Sibling 7	/	/		
	o. Olbiing o				<u>Y Y Y Y</u>		g. Clomig 7			Y Y Y	
		Don't	t Kno	w		8		Don't Kr	now		8
	d. Sibling 4		/	,			h. Sibling 8	/	/		
	d. Cloning 1				Y Y Y Y		n. Cibing C			Y Y Y	
		Don'f	t Kno	w		8		Don't Kı	now		8
											END F07s
E5.	and the type a. In the p memb	of kidı bast ye:	ney o ar, ha en to	disea ave a ld by	se they had ny of (nam d a health cal	d. e <i>of partic</i> i	ipant) living or conal that they ha	deceased	d biolog	gical fan	nily
E5.	and the type a. In the p memb Yes No	of kidi past yea ers bea	ney o	disea ave a ld by	se they had ny of (nam a health call 1 2 \rightarrow	d. e <i>of partic</i> i	ipant) living or on the one of th	deceased	d biolog	gical fan	nily
	and the type a. In the p memb Yes No	of kidi past yea ers bea	ney o	disea ave a ld by	se they had ny of (<i>name</i> a health can 1 $2 \rightarrow$ $-8 \rightarrow$	d. e of particate re profession (Skip to (Skip to	ipant) living or on the one of th	deceased	d biolog	gical fan	nily
	and the type a. In the p memb Yes No Don't k	of kidi past yea ers bea	ney o	disea ave a ld by	se they had ny of (<i>name</i> a health can 1 $2 \rightarrow$ $-8 \rightarrow$	d. e of particate re profession (Skip to (Skip to	ipant) living or one conal that they had be E8)	deceased d kidney (Reflux Nephropa (Kidney/blad	d biological disease	gical fan	nily
b.	and the type a. In the period with the period	of kidicast years bears bears inow	ney of ar, had	disea	ny of (name a health can 1 2 ->8 -> C. What ty Nephritis	d. e of particle re profession (Skip to (Skip to ype of kidne) Polycystic Kidney Disease	ipant) living or on all that they had be to be the construction of	Reflux Nephropa (Kidney/blad Reflux)	d biological disease	gical fan e in the p Other	nily ast year? Don't Kno
b.	and the type a. In the p memb Yes No Don't k	of kidicast years bears bears inow	ney of ar, had en to	disea ave a ld by	ny of (name a health can 1 2 -> 8 -> C. What ty Alport's Hereditary	d. e of partice re profession (Skip to (Skip to ype of kidney Polycystic Kidney	ipant) living or on the conal that they had be seen to	deceased d kidney (Reflux Nephropa (Kidney/blad	d biological disease the disea	gical fan e in the p Other	nily ast year? Don't Kno
b.	and the type a. In the period membor yes No Don't keep warmen was a second with the second membor membor membor was a second membor	of kidicast years bears in ow	ney of ar, had	disea ave a ld by	se they had ny of (name a health can a. 1 a. 2 → a8 → C. What ty Alport's Hereditary Nephritis	d. e of particle re profession (Skip to (Skip to ype of kidne) Polycystic Kidney Disease	ipant) living or on the conal that they had be been seen to be	Reflux Nephropa (Kidney/blad Reflux)	d biological disease	gical fan e in the p Other	nily ast year? Don't Kno
b.	and the type a. In the period with the period	of kidicast years bears in ow	ney of ar, had	disea ave a ld by	ny of (name a health can 1 2 ->8 -> C. What ty Nephritis	d. e of particle re profession (Skip to (Skip to ype of kidne) Polycystic Kidney Disease	ipant) living or on all that they had be to be the construction of	Reflux Nephropa (Kidney/blad Reflux)	d biological disease thy der	Other 5 (specify 5 (specify	Don't Kno
b. 1 2	and the type a. In the period membor Yes No Don't keep the work which family meep the work where th	of kidicast years bears from	ney (ar, har) en to? ?? 2	(#2)	se they had ny of (name a health can a. 1 a. 2 → a8 → C. What ty Alport's Hereditary Nephritis 1	d. e of particle re profession (Skip to (Skip to ype of kidne) Polycystic Kidney Disease 2	ipant) living or conal that they have been been been been been been been be	Reflux Nephropa (Kidney/blad Reflux) 4	d biological disease thy der	Other 5 (specify	Don't Kno
b. 1 2	and the type a. In the period membor yes No Don't keep with the period with the	of kidicast years bears from	ney (ar, har) en to? ?? 2	disea ave a ld by	se they had ny of (name a health can a. 1 a. 2 → a8 → C. What ty Alport's Hereditary Nephritis	d. e of particle re profession (Skip to (Skip to ype of kidne) Polycystic Kidney Disease	ipant) living or on the conal that they had be been seen to be	Reflux Nephropa (Kidney/blad Reflux)	thy der Specify:	Other 5 (specify 5 (specify	Don't Knot) -8) -8
b. 1 2	and the type a. In the period membory yes No Don't keep the work of the period with the period with the period membors. Mother	of kidicast years bears from the series of kidicast years from the series of the serie	ney (ar, har) en to? ?? 2	(#2)	se they had ny of (name a health can a. 1 a. 2 → a8 → C. What ty Alport's Hereditary Nephritis 1	d. e of particle re profession (Skip to (Skip to ype of kidne) Polycystic Kidney Disease 2	ipant) living or conal that they have been been been been been been been be	Reflux Nephropa (Kidney/blad Reflux) 4	thy der Specify:	Other 5 (specify 5 (specify	Don't Kno
b. 1 2	and the type a. In the period membor Yes No Don't keep the work which family meep the work where th	of kidicast years bears from the series of kidicast years from the series of the serie	ney of ar, had	(#2)	se they had ny of (name a health can a. 1 a. 2 → a8 → C. What ty Alport's Hereditary Nephritis 1	d. e of particle re profession (Skip to (Skip to ype of kidne) Polycystic Kidney Disease 2	ipant) living or conal that they have been been been been been been been be	Reflux Nephropa (Kidney/blad Reflux) 4	thy der Specify:	Other 5 (specify 5 (specify	Don't Kno
b. 1 2	and the type a. In the period membory yes No Don't keep the work of the period with the period with the period membors. Mother	of kidicast years bears from the series of kidicast years from the series of the serie	ney of ar, had	(#2) (#4)	se they had ny of (name a health can a health can a -8 -> C. What ty Alport's Hereditary Nephritis 1 1	d. e of particlere profession (Skip to (Skip to ype of kidner Polycystic Kidney Disease 2 2 2	ipant) living or conal that they had be be been been been been been been be	Reflux Nephropa (Kidney/blad Reflux) 4	thy der Specify: Specify:	Other 5 (specify 5 (specify	Don't Knot 1 -8 2 -8 3 -8
b. 1 2 3 4	and the type a. In the period membory yes No Don't keep the work of the period with the period with the period membors. Mother	of kidicast years bears inow Yes 1	ney (ar, haren to en to	(#2) (#4)	se they had ny of (name a health can a health can a -8 -> C. What ty Alport's Hereditary Nephritis 1 1	d. e of particlere profession (Skip to (Skip to ype of kidner Polycystic Kidney Disease 2 2 2	ipant) living or conal that they had be be been been been been been been be	Reflux Nephropa (Kidney/blad Reflux) 4	thy der Specify: Specify:	Other 5 (specify 5 (specify 5 (specify	Don't Kno
b. 1 2 3 4	and the type a. In the process of t	of kidicast years bears inow Yes 1	ney (ar, haren to en to	(#2) (#3) (#5)	se they had ny of (name a health can a health can a -8 -> C. What ty Alport's Hereditary Nephritis 1 1	d. e of particle re profession (Skip to (Skip to (Skip to ype of kidner) Polycystic Kidney Disease 2 2 2 2	ipant) living or conal that they have been been been been been been been be	Reflux Nephropa (Kidney/blad Reflux) 4 4	thy der Specify: Specify: Specify:	Other 5 (specify 5 (specify 5 (specify	Don't Kno



Specify: _

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

E6.	a.	In the past year, have any of (name of members been told by a health care properties of participant)?			iving or deceased biological family it they had the SAME kidney disease as				
		Yes	1						
		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	f the fo	ollowir	ng.)				
		1. Mother	1	2					
		2. Father	1	2					
		3. Sibling (full brother or sister)	1	2					
		4. Grandparent(s)	1	2					
		5. Aunt(s)/Uncle(s)	1	2					
		6. Cousin(s)	1	2					
E7.	a.	 a. In the past year, have any of (name of participant) living or deceased biomembers had a kidney biopsy? 							
		Yes	1						
		No	2	\rightarrow	(Skip to E8)				
		Don't know	-8	\rightarrow	(Skip to E8)				
	b.		<u>Yes</u>	<u>No</u>					
		(Circle "Yes" or "No" for EACH or	f the f	ollowir	ng.)				
		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					



- E8. a. In the past year, have any of (name of participant) living or deceased biological family members been told by a health care professional (any doctor, nurse, physician assistant or nurse practitioner) that they had.
- b. Which biological family members?
 (Circle "Yes", "No", or "Don't Know" for EACH of the following)

assis	stant or nurse practitioner) that they	ey had	ioliowilig <i>)</i>			
1.	High Blood Pressure or Hypertens	nsion		<u>Yes</u>	<u>No</u>	<u>Don't</u> Know
	Yes 1	I	Mother	1	2	-8
	No 2 → (Ski	ip to 2)	Father	1	2	-8
	Don't know8 \rightarrow (Ski	ip to 2)	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
2.	High Cholesterol			<u>Yes</u>	<u>No</u>	<u>Don't</u> Know
	Yes 1	I	Mother	1	2	-8
	No 2 → (Ski	ip to 3)	Father	1	2	-8
	Don't know8 \rightarrow (Ski	ip to 3)	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
3.	Diabetes (high blood sugar or sug	gar diabetes	3)	<u>Yes</u>	<u>No</u>	<u>Don't</u> Know
	Yes 1	I	Mother	1	2	-8
	No 2 → (Ski	ip to 4)	Father	1	2	-8
	Don't know8 \rightarrow (Ski		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

(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</u> Know
	Yes 1	Mother	1	2	-8
	No 2 \rightarrow (Skip to	5) Father	1	2	-8
	Don't know8 \rightarrow (Skip to	5) 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</u> Know
	Yes 1	Mother	1	2	-8
	No 2 \rightarrow (Skip to	E9) Father	1	2	-8
	Don't know8 \rightarrow (Skip to	E9) 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

If more than one grandparent, aunt, uncle or cousin has had dialysis, ask your site coordinator for further instructions.

E9.	a.	In the past year, have any of (name of participant) living or deceased biological family members had dialysis as treatment for kidney disease?	b. Which biological family members? (Circle "Yes", "No", or "Don't Know" for EACH of the following)	c. At what age was treatment started?
		Yes 1	1. Mother	yrs old
		No 2 \rightarrow (Skip to E10)	Yes 1	Don't Know8
		Don't Know8 \rightarrow (Skip to E10)	No 2	ightarrow (skip to 2)
			Don't Know8	
			2. Father	yrs old
			Yes 1	Don't Know8
			No 2	ightarrow (skip to 3)
			Don't Know8	
			3. Sibling (full brother or sister)	yrs old
			Yes 1	Don't Know8
			No 2	→ (skip to 4)
			Don't Know8	
			4.Grandparents	yrs old
			Yes 1	Don't Know8
			No 2	ightarrow (skip to 5)
			Don't Know8	
			5. Aunts/Uncles	yrs old
			Yes 1	Don't Know8
			No 2	ightarrow (skip to 6)
			Don't Know8	
			6. Cousins	yrs old
			Yes 1	Don't Know8
			No 2	ightarrow (skip to E10)
			Don't Know8	



If more than one grandparent, aunt, uncle or cousin has had a kidney transplant, ask your site coordinator for further instructions.

E10.	a.	In the past year, have any of (name of participant) living or deceased biological family members had a kidney transplant as treatment for kidney disease?	b. Which biological family members? (Circle "Yes", "No", or "Don't Know" for EACH of the following)	c. At what age was transplant performed?
		Yes 1	1. Mother	yrs old
		No 2 \rightarrow (Skip to E11)	Yes 1	Don't Know8
		Don't Know8 \rightarrow (Skip to E11)	No 2	ightarrow (skip to 2)
			Don't Know8	
			2. Father	yrs old
			Yes 1	Don't Know8
			No 2	ightarrow (skip to 3)
			Don't Know8	
			3. Sibling (full brother or sister)	yrs old
			Yes 1	Don't Know8
			No 2	ightarrow (skip to 4)
			Don't Know8	
			4.Grandparents	yrs old
			Yes 1	Don't Know8
			No 2	ightarrow (skip to 5)
			Don't Know8	
			5. Aunts/Uncles	yrs old
			Yes 1	Don't Know8
			No 2	ightarrow (skip to 6)
			Don't Know8	
			6. Cousins	yrs old
			Yes 1	Don't Know8
			No 2	ightarrow (skip to E11)
			Don't Know8	



Ξ11.	In the past year, has the birth mother been pregnant?						
	Yes 1						
	No						
Ξ12.	In the past year, have any of the birth mother's pregnancies resulted in the following?						
	(Circle "Yes", "No" or "Don't Know" for EACH of the following)						
	<u>Yes</u> <u>No</u> <u>Don't Know</u>						
	Stillbirth (fetus died at birth) 1 2 -8						
	Miscarriage 1 2 -8						
≣13.	In the past year, has (name of participant) birth mother had recurrent Urinary Tract Infections (UTI)?						
	Yes 1						
	No 2						
	Don't Know8						
≣14.	In the past year, has (name of participant) birth father had recurrent Urinary Tract Infections (UTI)?						
	Yes 1						
	No 2						
	Don't Know8						
≣15.	In the past year, have any of (name of participant) siblings had recurrent Urinary Tract Infections (UTI)?						
	Yes 1						
	No 2						
	Don't Know8						
	N/A, participant does not have any siblings1						



SECTION F: PARTICIPANT'S DEVELOPMENTAL HISTORY

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

F1.	At th	ne last CKiD study visit, was (<i>name of participant</i>) older than 5 years of age? Yes
F2.	a.	Is (<i>name of participant</i>) currently older than 5 years of age? Yes
	b.	Is (name of participant) currently breast-fed? Yes
	C.	Was (name of participant) breast-fed? Yes
	d.	How old was (name of participant) when he/she was weaned from breast feeding? (Please circle "1" for years, "2" for months, "3" for weeks or "4" for days.) Age 1 = year(s)
F3.	ls (n	name of participant) currently bottle-fed? Yes
	a.	Was (name of participant) bottle-fed? Yes
	b.	How old was (name of participant) when he/she was weaned from bottle feeding? (Please circle "1" for years, "2" for months, "3" for weeks or "4" for days) Age 1 = year(s) 2 = months 3 = week(s) 4 = days
		Don't Know



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.		e past year, has (name of participant) had any wetness or leakage of urine (accidents) ng the day or night?				
		Yes 1				
		No				
		Don't Know				
	a.	In the past year, is (name of participant) wet during the day?				
		Yes 1				
		No 2				
		Don't Know8				
	b.	In the past year, is (name of participant) wet during the night?				
		Yes 1				
		No 2				
		Don't Know8				
	C.	In the past year, has <i>(name of participant)</i> catheterized the bladder (i.e., put a tube in the bladder)?				
		Yes 1				
		No				
		Don't Know8 → (Skip to F5)				
		i. In the past year, has (name of participant) catheterized through the urethra?				
		Yes 1				
		No 2				
		Don't Know8				
		ii. In the past year, has (name of participant) catheterized through a stoma?				
		Yes 1				
		No 2				
		Don't Know				



F5.	At th	e last CKiD study visit, was (name of participant) toilet trained?	
		Yes 1 \rightarrow (Skip to I	= 6
		No	_^
		Don't Know8 → (Skip to l	-6
	a.	Is (name of participant) currently toilet trained?	
		Yes 1	
		No	
		Don't Know8 → (Skip to)	F6
	b.	When was (name of participant) toilet trained?	
		Age years	
	C.	After toilet training, did bed-wetting occur?	
		Yes 1	
		No $2 \rightarrow$ (Skip to o	(k
		Don't Know8 \rightarrow (Skip to e	d)
		i. Does bed-wetting still occur?	
		Yes 1 → (Skip to i	ii)
		No 2	
		Don't Know8 \rightarrow (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 Know8	
		iii. Were medical reasons the cause of bed-wetting?	
		Yes 1	
		No 2	
		Don't Know8	



	d.	After toilet training, did bed-soiling occur?
		Yes 1
		No
		Don't Know8 \rightarrow (Skip to F6)
		i. Does bed-soiling still occur?
		Yes 1 → (Skip to iii)
		· · · · · · · · · · · · · · · · · · ·
		No 2
		Don't Know8 \rightarrow (Skip to F6)
		ii. At what age did bed-soiling stop?(Please circle "1" for years and "2" for months)
		Age 1 = years
		2 = months
		Don't Know8
		iii. Were medical reasons the cause of bed-soiling?
		Yes 1
		No 2
		Don't Know8
		Don't Miowillian in the state of the state o
F6.	At th	ne last CKiD study visit, was (<i>name of participant</i>) 4 years of age or older
		Yes 1 \rightarrow (Skip to F8)
		No 2
		Don't Know8
	a.	Is (name of participant) currently 4 years of age or older? Yes 1
		No
		Don't Know8 \rightarrow (Skip to F9)



F7.	During (<i>name of participant</i>) first 4 years, were any problems noted in the areas listed below? Indicate yes, no or don't know for each of the following.						
	IIIG	•	<u>virig.</u> <u>Vo</u>	<u>Don't</u>	t Know		
	a.	Eating 1	2		-8		
	b.	Excessive crying 1	2		-8		
	C.	Failure to thrive 1	2		-8		
	d.	Motor skills 1	2		-8		
	e.	Separating from parents 1	2		-8		
	f.	Sleeping too little 1	2		-8		
	g.	Sleeping too much 1	2		-8		
	h.	Temper tantrums 1	2		-8		
F8.	Wh	nich hand does (name of participant) primarily us	se to writ	te?			
	Pri	marily right		1			
	Pri	marily left		2			
	Ambidextrous (writes equally with both left and right hands) 3						
a docto	r or ng p Has	ipant is under 4 years old, please answer the health care professional has told you that the roblems. Is (name of participant) experienced any of the focle "Yes", "No" or "Don't Know" for EACH of the focle "Yes", "No" or "Don't Know" for EACH of the fock of	e partic llowing p	ipant I probler wing.)	nas had any of the		
			<u>Yes</u>	<u>No</u>	Don't Know		
	a.	Feeding problem	1	2	-8		
	b.	Eating disorder Underweight problem		2 2	-8 -8		
	c. d.	Overweight problem		2	-8		
	e.	Walking difficulty (per healthcare professional)	1	2	-8		
	f.	Unclear speech (per healthcare professional)	1	2	-8		
	g.	Sleep problem		2	-8		
	h.	Colic	1	2	-8		
TO BE C	ОМІ	PLETED BY CLINICAL SITE:					
DATE:		//	INITI	ALS:			
DAIL.		M / D D / Y Y Y		ALO.			
ADMINIS		ATION: 1 = Interviewer Assisted "2" or "3") 2 = Self-Administered					



3 = Both