FOLLOW-UP MEDICAL HISTORY (F14)

Chronic Kidney Disease in Children (CKiD)

SECTION A: GENERAL INFORMATION

A1. PARTICIPANT ID: AFFIX ID LABEL OR ENTER NUMBER IF ID LABEL IS NOT AVAILABLE

|__| - |__|__| - |__|__|__|

A2. CKiD VISIT #: ___ ___

A3. FORM VERSION: 0 8 / 0 1 / 2 1

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

A5. SITE COORDINATOR'S INITIALS: ___ ___ ___

A6. Is this study visit an irregular (accelerated) visit?
Yes..... 1
No..... 2

A7. INDICATE PERSON COMPLETING THE FORM
Child/young adult..... 1
Parent or other adult..... 2
Both (Parent and Child/young adult) 3

For each question, fill in the answer or circle the number that best matches the respondent's answer. Circle -8 for "Don't Know" responses. If a participant declines to answer a question, document -7 to the right of the response choice(s). For missing data, document -9 to the right of the response choice(s). Please document the reason for missing data (i.e., the question was accidentally skipped.)

Read each question and follow skip patterns as they appear on the form. Review the QxQ for detailed descriptions of questions.

INTRODUCTION TO PARTICIPANT/PARENT OR OTHER ADULT:

The following questions are about the participant's health history, including information about the current and past diseases that the participant may have had in life. Dates may be hard to remember. Please take as much time as you need so I can gather information that is as accurate as possible.

As with all study information, your responses will be kept strictly confidential, and the responses you provide will in no way affect the participant's clinical care. The first set of questions asks about the participant's kidney disease. Whenever the term "health care provider" is used, it means any doctor, nurse, physician assistant or nurse practitioner the child has ever seen. If you have trouble understanding anything, please feel free to ask for further clarification.

SECTION B: KIDNEY DISEASE

B1. In the past year, has *(name of participant)* been seen by a Urologist (adult or pediatric)?

Yes..... 1
No..... 2

PROMPT: IF ANY OF B2 – B3 = YES, THEN COMPLETE THE MEDICAL ABSTRACTION TRACKING FORM (MAT).

B2. In the past year, has (*name of participant*) had a urologic procedure, including surgery to treat his or her kidney problems?

Yes..... 1 → **(Complete MAT)**
No..... 2
Don't Know..... -8

B3. In the past year, has (*name of participant*) had a genetic test (i.e., Podocin or Nephrin) performed to help diagnose his or her kidney disease?

Yes..... 1 → **(Complete MAT)**
No..... 2
Don't Know..... -8

B4. In the past year, has a healthcare provider diagnosed (*name of participant*) with a kidney infection with a fever?

Yes..... 1
No..... 2 **(Skip to B5)**
Don't Know..... -8 **(Skip to B5)**

a. In the past year, how many times did he/she have a kidney infection with a fever?

___ ___ times
Don't Know..... -8

B5. Is participant a female?

Yes..... 1
No..... 2 **(Skip to C1)**

B6. In the past year, has (*name of participant*) started her menses (i.e. period)?

Yes..... 1
No..... 2 **(Skip to C1)**
Don't Know..... -8 **(Skip to C1)**

a. How old was she when she started her first period?

___ ___ years of age
Don't Know..... -8

SECTION C: GENERAL MEDICAL HISTORY

The next set of questions asks about diseases/illnesses that the participant had or developed in the past year.

In the past year, has a doctor or any other healthcare professional told you that (*name of participant*) had or has developed any of the following diseases/illnesses?

PROMPT: IF ANY OF C1 – C4 = YES, THEN COMPLETE THE MEDICAL ABSTRACTION TRACKING FORM (MAT).

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

	Yes	No	Don't Know
C1. GENERAL / METABOLIC DISEASE			
a. Diabetes Mellitus (Sugar Diabetes, High Blood Sugar)	1	2	-8
b. Sickle Cell Disease	1	2	-8
c. Auto-immune Disease (Lupus, Rheumotid Arthritis)	1	2	-8
C2. CARDIOVASCULAR DISEASE			
a. Heart Failure (Congestive heart failure)	1	2	-8
b. Stroke	1	2	-8
c. Left Ventricular Hypertrophy (LVH)/ Thickened Heart Muscle	1	2	-8
C3. LUNG DISEASE			
a. Asthma	1	2	-8
b. Chronic Lung Disease	1	2	-8
c. Bronchopulmonary Dysplasia (BPD)	1	2	-8
C4. GENITOURINARY DISEASE			
a. Urinary Tract Infections	1	2	-8
b. Blood in urine	1	2	-8
c. Protein in urine	1	2	-8
d. Passage of kidney stones	1	2	-8
e. Recurrent pain on urinating	1	2	-8
C5. GASTROINTESTINAL DISEASE			
a. Gastroenteritis (stomach flu, food poisoning)	1	2	-8
b. Gastroesophageal Reflux (GERD)	1	2	-8
c. Gastrointestinal Ulcer	1	2	-8
d. Gastrointestinal Bleeding	1	2	-8
e. Liver Inflammation Non-Infectious	1	2	-8
f. Fatty Liver	1	2	-8
g. Irritable Bowel	1	2	-8
h. Encopresis (constipation)	1	2	-8

C6. In the past year, has a doctor or healthcare professional told you that (*name of participant*) has hypertension (high blood pressure) or that (*name of participant*) should take medicine to lower blood pressure?

Yes..... 1 → Complete MAT
No..... 2 **(Skip to C7)**
Don't Know..... -8 **(Skip to C7)**

a. What is the status of (*name of participant's*) high blood pressure (i.e., hypertension)?

Taking medicine but BP still high (Continued problem) 1
No longer has high blood pressure (Resolved problem) 2
Taking medicine and BP no longer high (Controlled w/ meds) 3

b. Was the hypertension diagnosed within the past year?

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

C7. In the past year, has a doctor or healthcare professional told you that (*name of participant*) has hepatitis?

Yes..... 1 → Complete MAT
No..... 2 **(Skip to C8)**
Don't Know..... -8 **(Skip to C8)**

a. Which of the following types of hepatitis does (name of participant) have?

	Yes	No	Don't Know
Type A	1	2	-8
Type B	1	2	-8
Type C	1	2	-8
Other type	1	2 **(Skip to C7b)**	-8 **(Skip to C7b)**

Specify: _____

b. Was the hepatitis diagnosed within the past year?

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

C8. In the past year, has a doctor or healthcare professional told you that (*name of participant*) has any other infection(s)?

Yes..... 1 → Complete MAT
No..... 2 **(Skip to C9)**
Don't Know..... -8 **(Skip to C9)**
Specify: _____

a. Was the infection diagnosed within the past year?

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

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

		Yes	No	Don't Know
C9.	CANCER			
a.	Leukemia	1	2	-8
b.	Lymphoma	1	2	-8
c.	Bone Cancer	1	2	-8
d.	Liver Cancer	1	2	-8
e.	Skin Cancer	1	2	-8
f.	Soft Tissue Sarcoma	1	2	-8
g.	Other	1	2 **(Skip to C10)**	-8 **(Skip to C10)**
	Specify:_____			
C10.	NEUROPSYCHIATRIC DISEASE			
a.	Attention Deficit Disorder (ADD)	1	2	-8
b.	Attention Deficit Hyperactivity Disorder (ADHD)	1	2	-8
c.	Depression	1	2	-8
d.	Learning Disability other than ADD or ADHD	1	2	-8
e.	Anxiety Disorder	1	2	-8
f.	Other	1	2 **(Skip to C11)**	-8 **(Skip to C11)**
	Specify:_____			

Please indicate whether (*name of participant*) has or has had any of the following problems.
(Please circle "Yes", "No" or "Don't Know" for EACH of the following.)

	Yes	No	Don't Know
C12. NEUROLOGICAL			
a. Seizures/Convulsions	1	2	-8
b. Speech Defects	1	2	-8
c. Accident Prone	1	2	-8
d. Bites Nails	1	2	-8
e. Sucks Thumb	1	2	-8
f. Grinds Teeth	1	2	-8
g. Twitches/Tics	1	2	-8
h. Bangs Head	1	2	-8
i. Rocks Back and Forth	1	2	-8
j. Bowel Movements in Bed/Pants	1	2	-8
C13. HEARING			
a. Ear Infections	1	2	-8
b. Hearing Problems	1	2	-8
c. Ear Tubes	1	2	-8
C14. VISION			
a. Vision Problems	1	2	-8
b. Wears Glasses/Contacts	1	2	-8
c. Color Blindness	1	2	-8

SECTION D: ORTHOPEDIC HISTORY

The next set of questions asks about any orthopedic injuries the participant may currently have or that the participant has had in the past year. Orthopedic injuries are injuries to the bones.

		Yes	No	Don't Know
D1.	In the past year, has a doctor or any other health professional told you that (name of participant) has had any broken bones?	1	2 **(Skip to D2)**	-8 **(Skip to D2)**

a. Please indicate which of the following bones (name of participant) has broken.
(Please circle "Yes", "No" or "Don't Know" for EACH of the following.)

	Yes	No	Don't Know
1. Back.....	1	2	-8
2. Shoulder.....	1	2	-8
3. Arm/Elbow.....	1	2	-8
4. Wrist/Hand.....	1	2	-8
5. Hip.....	1	2	-8
6. Knee.....	1	2	-8
7. Ankle.....	1	2	-8
8. Foot.....	1	2	-8
9. Leg.....	1	2	-8
10. Fingers.....	1	2	-8
11. Toes.....	1	2	-8
12. Ribs.....	1	2	-8
13. Collar Bone.....	1	2	-8

D2. Does (*name of participant*) have any bone disease in the hips?

Yes..... 1 → **(Complete MAT)**
No..... 2 **(Skip to F1)**
Don't Know..... -8 **(Skip to F1)**

a. Was the bone disease diagnosed within the past year?

Yes..... 1 → **(Complete MAT)**
No..... 2
Don't Know..... -8

DELETED SECTION E

SECTION F: HEALTHCARE UTILIZATION

These questions ask about all the places the participant may have received care in the past year.

F1. In the past year, where has (*name of participant*) gone to receive medical care? **(Please circle "Yes" or "No" for EACH of the following places.)**

Did (name of participant) go to…

		Yes	No	
a.	A clinic or health care center (not a part of a hospital building)	1	2	
b.	A private doctor's office (not a part of a clinic or hospital)	1	2	
c.	Hospital Outpatient Department	1	2	
d.	The emergency room	1	2	**(Skip to e)**
	1. How many times has (name of participant) received care at the emergency room in the past year? ___ ___			
e.	Some other place	1	2	**(Skip to F2)**
	1. Please specify: _____			

These questions ask about the participant's use of health care. In this set of questions, the term "health care provider" means any doctor, nurse practitioner, or physician assistant you may go to for medical care.

F2. In the past year, how many times did (*name of participant*) see a health care provider, not including this CKiD study visit or the visit at which you were screened for eligibility into the study? Include well child visits, sick visits and ER visits. **Do not include** times when (name of participant) was hospitalized overnight.

___ ___ times

Don't Know..... -8

F3. In the past year, when you or (*name of participant*) went for medical care, did he/she usually (more than half of the time) see the same health care provider or group of providers for his/her medical appointments?

Yes..... 1

No..... 2

Don't Know..... -8

FOLLOW-UP MEDICAL HISTORY (F14)

The next questions ask about hospitalizations. Being hospitalized includes staying overnight or being admitted for a procedure that was done in one day. Please include all medical and psychiatric hospitalizations in the past year. This does not include being treated in the emergency room and then released the same day.

F4. In the past year, has (*name of participant*) been hospitalized (apart from when he or she was born)? Do not include overnight stays in the emergency room.

Yes ..... 1 → **(Complete MAT)**
No ..... 2 **(Skip to F5)**
Don't Know ..... -8 **(Skip to F5)**

a. How many different times was (*name of participant*) hospitalized in the past year?
___ ___ times

Don't Know ..... -8

These questions ask some questions about care or social services that the participant may have received in the past year.

F5. In the past year, has (*name of participant*) been seen by a social worker or a case manager to help him/her obtain services?

Yes 1
No 2

F6. In the past year, has (*name of participant*) received care or services from a psychologist, psychiatrist, psychiatric nurse, counselor, or other mental health professional?

Yes 1
No 2

F7. In the past year, has an agency assisted (*name of participant*) with food, such as food stamps or WIC, meals on wheels, food pantries, or arranged to have groceries delivered to your participant's parent/guardian's primary household (i.e., the home in which the participants lives at least half of the time or lived prior to living independently)?

Yes 1
No 2

F8. In the past year, has a social service agency helped you or (*name of participant*) find a place to live?

Yes 1
No 2

F9. In the past year, has (*name of participant*) received care from a dentist or dental hygienist?

Yes 1
No 2

F10. In the past year, has (*name of participant*) seen a nutritionist or a dietician?

Yes 1
No 2

SECTION G: HEALTH INSURANCE

These questions ask about the participant's health care coverage.

G1. Does (*name of participant*) currently have any kind of health insurance or health care coverage? This includes both private and public insurance programs (e.g., Medicaid, SCHIP or MCHIP), dental insurance, and programs that help pay for medications.

Yes ..... 1 **(Skip to G1b)**
No 2

G1a. How long has it been since (name of participant) last had ANY health insurance or coverage?

6 months or less ..... 1 **(skip to G16)**
More than 6 months, but no more than 1 yr ago..... 2 **(skip to G16)**
More than 1 year, but no more than 3 years ago..... 3 **(skip to G16)**
More than 3 years..... 4 **(skip to G16)**
Never had health insurance or coverage..... 5 **(skip to G16)**
Don't know..... -8 **(skip to G16)**

G1b. In the past year, was there any time when (name of participant) was not covered by ANY health insurance or coverage?

Yes 1
No ..... 2 **(Skip to G2)**

G1c. In the past year, about how long was (name of participant) without ANY health insurance or coverage?

__ __ 1 = months 2 = weeks 3 = days

G1d. In the past year, was (name of participant) not covered by ANY insurance or coverage?

Yes 1
No 2

FOLLOW-UP MEDICAL HISTORY (F14)

INSTRUCTIONS:	**ASK QUESTIONS G2 - G15. IF THE RESPONSE IS YES, CIRCLE "1" AND ASK QUESTION "A" (FAR RIGHT COLUMN) UNLESS THE BOX IS SHADED.**			
Does (*name of participant*) currently have...	YES	NO	**NA**	**A.** Do you or your family members pay for any of the insurance premium? YES NO
G2. *CALIFORNIA ONLY: Medi-CAL?	1	2	**99**	
G3. *MARYLAND ONLY: Medical Assistance?	1	2	**99**	
G4. ALL STATES EXCEPT CALIFORNIA and MARYLAND: Medicaid?	1	2	**99**	
G5. Private Health Insurance plan from employer or workplace?	1	2 **(Skip to G6)**		1 2
G6. Private Health Insurance plan purchased directly?	1	2 **(Skip to G7)**		1 2
G7. Private Health Insurance plan through a state or local government program or community program?	1	2 **(Skip to G8)**		1 2
G8. CHIP (Children's Health Insurance Program)?	1	2 **(Skip to G9)**		1 2
G9. Military Health Care/VA?	1	2 **(Skip to G10)**		1 2
G10. CHAMPUS or other veteran's health insurance?	1	2 **(Skip to G11)**		1 2
G11. Student Health Coverage?	1	2 **(Skip to G12)**		1 2
G12. State-Sponsored Health Plan?	1	2 **(Skip to G13)**		1 2
G13. Dental Insurance?	1	2		
G14. Vision Insurance?	1	2		
G15. Other types of health insurance? a. Specify _____ _____ _____	1	2 **(Skip to G16)**		

G16. Do any of these plans help pay for prescriptions/medications?

Yes 1
No 2
Not applicable / No Insurance..... -1

G17. In the past year, has (name of participant) been without needed prescription medication due to cost?

Yes 1
No 2
Not applicable / No Insurance..... -1
Don't Know..... -8

G18. Does the participant's health insurance plan(s) help pay for both doctor visits and hospital stays?

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

G19. In the past year, have you had difficulty filing insurance claims and/or getting reimbursed for medical care?

Yes 1
No 2
Did not file any claims / No insurance -1
Don't Know..... -8

G20. In the past year, how much of a problem was it to get care for (name of participant) that you or a doctor believed necessary?

A big problem 1
A small problem 2
No problem..... 3
My child had no visits in the last year -1
Don't Know..... -8

DELETED G21 – G25

SECTION H: RENAL REPLACEMENT THERAPY

Deleted H1

H2. In the past year, have you discussed renal replacement therapy (i.e., dialysis or transplantation) with your nephrologist or health care provider?

Yes 1
No ..... 2 **(END)**

a. Did you discuss renal replacement therapy **specifics** (i.e., modality, preference etc.) with your nephrologist?

Yes 1
No ..... 2 **(END)**

H3. Was dialysis discussed?

Yes 1
No ..... 2 **(skip to H5)**

H4. Which modality is preferred?

Hemodialysis 1
Peritoneal dialysis..... 2
No Preference..... 3

H5. Was transplantation discussed?

Yes 1
No ..... 2 **(END)**

H6. Which donor option(s) has/have been discussed?

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

	Yes	No	Don't Know
Living Donor.....	1	2	-8
Deceased Donor.....	1	2	-8

H7. Has child been listed for deceased donor transplantation?

Yes 1
No ..... 2 **(END)**

a. Date listed: ___ ___/ ___ ___/ ___ ___ ___ ___ ← **SITE SHOULD CONFIRM DATE**

M M / D D / Y Y Y Y

TO BE COMPLETED BY CLINICAL SITE:

DATE: ___ ___/ ___ ___/ ___ ___ ___ ___
M M / D D / Y Y Y Y

INITIALS: ___ ___ ___

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

1 = Interviewer Assisted
2 = Self-Administered
3 = Both

Was the date listed on DECEASE DONOR LIST CONFIRMED by site:
1 = YES
2 = NO