CKiD Study Phone/In-Person Follow Up Interview Form

Follow-up Visit #: ____ ____ ____

Interviewer's Initials: ____ ____ ____

Form Version: _0_ _4_ / _1_ _5_ / _1_ _0_

Section A: Vital Status

A1. Date of Status Determination: ___ ___/ ___ ___/ ___ ___ ___ ___
M M D D Y Y Y Y

A2. Who reported the vital status of the participant?

Participant………………………. 1
Mother……………………………. 2
Father..................................... 3
Relative or Acquaintance………… 4
i. Please specify relationship: ________________________________
Other Method.......................... 5
i. Please specify **OTHER method**: ________________________________

A3. What is the vital status of the participant? Circle only one answer.

Alive……………………………... 1 (Skip to Section B)
Deceased*………………………. 2 **(Skip to Question A4)**
Unknown.................................... 3 **(Skip to Question A5)**
Contacted but refused interview… 4 **(END FORM HERE)**

A4. Date of Death ___ ___/ ___ ___/ ___ ___ ___ ___
M M D D Y Y Y Y

i. Cause of Death (Please use code from list provided): ___ ___ ___ **(END FORM HERE)**

A5. If vital status is unknown, what methods of contact were used to locate or reach the participant?
(Please circle "Yes", "No" or "Don't Know" for EACH of the following methods below)

	Yes	No	Don't Know
Home Number	1	2	-8
Work Number	1	2	-8
Family Contact	1	2	-8
Social Contact	1	2	-8
Other Method	1	2 **(Skip to A5i)**	-8 **(Skip to A5i)**

Specify other method used: ______________________

i. Date of first attempt to contact participant: ___ ___/ ___ ___/ ___ ___ ___ ___

ii. Number of times attempted to contact participant: ___

iii. Date of last attempt to contact participant: ___ ___/ ___ ___/ ___ ___ ___ ___

***Note: If patient death is known, do not contact family.**

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Section B: Renal Replacement Therapy

Transplantation:

B1. Has (*name of child*) ever had a kidney transplant?

Yes……………………………….…. 1
No……………………………….…. 2 **(Skip to B2)**

B1a. If yes, was it living related, living unrelated, or deceased donor?

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

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

B1b. Date of Transplant: ___ ___/ ___ ___/ ___ ___ ___ ___ (**Skip to B5**)
M M D D Y Y Y Y

B2. In the past year, have you discussed renal transplantation with your/your child's nephrologist or health care provider?

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

B3. 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

B4. Has (*name of child*) been listed for deceased donor transplantation?

Yes…………………………..…….. 1
No………………………………..…. 2 **(Skip to B5)**

a. Date Listed: ___ ___/ ___ ___ ___ ___
M M / Y Y Y Y

Dialysis:

B5. Has (*name of child*) ever been on dialysis?

Yes…………………………….....….. 1
No……………………..….…………. 2 **(Skip to B6)**
Don't Know……………..…………. -8 **(Skip to B6)**

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a. If yes, what type of dialysis did (*name of child*) use most recently:

Hemodialysis………………..…….. 1
Peritoneal Dialysis………..………. 2
Don't Know………………..……. -8

b. Date Dialysis was Initiated: ___ ___/ ___ ___/ ___ ___ ___ ___
M M D D Y Y Y Y

c. Is (*name of child*) currently on dialysis?

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

B6. In the past year, have you discussed dialysis with your/your child's nephrologist or health care provider?

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

B7. Which modality is preferred?

Hemodialysis………………..…….. 1
Peritoneal Dialysis………..………. 2
No Preference…………...………. 3

Section C: General History

C1. What is the current zip code of (*name of child*)'s **primary household** (i.e., the home in which the child lives at least half of the time)?

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

C2. Does (*name of child*) attend school outside of the home?

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

C3. 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

C4. Does (*name of child*) work outside of the home?

Yes……………………….....…….. 1
No…………………………………. 2 **(Skip to D1)**

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C5. During the past year, approximately how many days has (*name of child*) missed from work because of not feeling well?

___ ___ Days

Don't Know…...…………….……… -8

Section D: Medical History

D1. In the past year, has (*name of child*) had a urologic procedure, including surgery to treat his or her kidney problems?

Yes…………………….….….…….. 1

No………………………………….. 2

Don't Know……………….….…. -8

The next set of questions asks about diseases, other than kidney disease, that your child may currently have or that your child has had in the past year.

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

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

	Yes	No	Don't Know
D2. GENERAL / METABOLIC DISEASE			
a. Diabetes Mellitus (Sugar Diabetes, High Blood Sugar)	1	2	-8
D3. CARDIOVASCULAR DISEASE	1	2	-8
a. Hypertension (High blood pressure)	1	2 **(Skip to b)**	-8 **(Skip to b)**
1. If hypertensive, what is the status?			
Continued problem………... 1			
Resolved problem ……..… 2			
Controlled with medication… 3			
b. Heart Failure (Congestive heart failure)	1	2	-8
c. Stroke	1	2	-8
d. Left Ventricular Hypertrophy (LVH)	1	2	-8
D4. GENITOURINARY DISEASE			
a. Urinary Tract Infections	1	2	-8
b. Passage of kidney stones	1	2	-8
D5. NEUROLOGICAL			
a. Seizures/Convulsions	1	2	-8

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Section E: Overall Health and Nutrition

E1. In the past year, how would you rate (*name of child*) health compared to other people his/her age? Please circle one choice.

Very Good……………………….. 1
Good……………………………… 2
Fair……………………………….. 3
Poor………………………………. 4
Very Poor………………………… 5

E2. During the past week, how would you rate (*name of child*) appetite? Please circle one choice.

Very Good……………………….. 1
Good……………………………… 2
Fair……………………………….. 3
Poor………………………………. 4
Very Poor………………………… 5

Section F: Health Care Utilization

F1. In the past year, where has (*name of child*) gone to receive medical care?
(Please circle "Yes" "No" or "Don't Know" for EACH of the following places.)

Did (name of child) go to…

	Yes	No	Don't Know
a. A clinic or health care center	1	2	-8
b. A private doctor's office	1	2	-8
c. Hospital Outpatient Department	1	2	-8
d. The emergency room in a hospital	1	2 **(Skip to e)**	-8 **(Skip to e)**
1. How many times has (name of child) received care at the emergency room in the last year? ___ ___			
e. Some other place	1	2	-8

If yes, specify: ____________________________

F2. In the past year, how many times did (*name of child*) see a health care provider for well child visits and routine care?
Do not include times when (name of child) was hospitalized overnight or ER visits.

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

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F3. In the past year, how many times did (*name of child*) see a health care provider when he/she was sick or needed immediate care?

Do not include times when (name of child) was hospitalized overnight or ER visits.
___ ___ times
Don't Know………………………… -8

F4. In the past year, when (*name of child*) went for routine 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

F5. In the past year, has (*name of child*) been hospitalized overnight? Do not include overnight stays in the emergency room.

Yes…………………………………… 1
No…………………………………… 2 **(Skip to F6)**
Don't Know………………………… -8 **(Skip to F6)**

a. How many different times was (*name of child*) hospitalized in the past year?
___ ___ times
Don't Know……………………… -8

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

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

F7. In the past year, has (*name of child*) received care from a dentist or dental hygienist?

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

Participant ID: __ - ___ - ______

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Section G: Medications

Please provide the following information for each medication (*name of child*) is taking (Include both prescription and Over the Counter medicines and nutritional supplements that are taken regularly):

Name	Dosage	Frequency
G1.		
G2.		
G3.		
G4.		
G5.		
G6.		
G7.		
G8.		
G9.		
G10.		
G11.		

Section H: Symptom List

Symptom	**Number of DAYS** in past month *(Enter 0 if none.)*	Severity **Mild** Symptoms did not interfere with usual activities	**Moderate** Symptoms interfered somewhat with usual activities	**Severe** Symptoms were so bothersome that usual activities could not be performed
1. Nausea or upset stomach?	_____	**1**	**2**	**3**
2. Vomiting?	_____	**1**	**2**	**3**
3. Constipation	_____	**1**	**2**	**3**
4. Numbness and tingling in hands and feet?	_____	**1**	**2**	**3**
5. Blurred vision?	_____	**1**	**2**	**3**
6. Loss of appetite?	_____	**1**	**2**	**3**
7. Increased appetite?	_____	**1**	**2**	**3**
8. Weight increase?	_____	**1**	**2**	**3**
9. Swelling (excess fluid)?	_____	**1**	**2**	**3**
10. Tiring easily, weakness?	_____	**1**	**2**	**3**
11. Falling asleep during the day?	_____	**1**	**2**	**3**
12. Leg pain?	_____	**1**	**2**	**3**