

DISENROLLMENT FORM (DSEN)

CKiD Chronic Kidney Disease in Children Cohort Study

SECTION A: GENERAL INFORMATION

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

|_| - |_|_| - |_|_|_|

A2. FORM VERSION: 0 2 / 1 5 / 1 5

A3. DATE FORM COMPLETED: / /
M M D D Y Y Y Y

A4. FORM COMPLETED BY (INITIALS)

PROMPT:

This form should be completed for participants who are deceased or who have refused participation in the Phone/In-Person (PIP) Follow-up protocol (i.e., family or site's decision to withdraw/disenroll from the CKiD study and family refused/not invited to participate in the PIP protocol). This form should also be completed for children in which a KID ID# has been assigned AND written consent has been obtained; however, the participant *did not* complete V1a.

SECTION B

B2. Reason for Disenrollment (Circle ONLY one code):

Participant's death..... 1 **(Skip to B3a)**

Participant/Family **previously** enrolled in Phone/In-Person Protocol and is no longer interested in participating or site has decided to withdraw participant..... 10 **(Skip to B7)**

Participant/Family did not enroll in Phone/In-Person Follow-up Protocol (i.e., was not previously enrolled and not interested in participating in PIP) 11 **(Go to B2a)**

Disenrollment prior to completing V1a..... 99 **(END Form and complete PCO)**

B2a. Are more recent height measurements and lab values available than the measurements/results documented on the TRS01 form?

Yes..... 1 **(Skip to C1a)**

No..... 2 **(Skip to D1 and complete PCO)**

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B3a. Date of participant's death: ____ / ____ / ____
M M D D Y Y Y Y

3b. What was the cause of death ?

Pericarditis (incl Cardia Tamponade).....	01	Accidental, Treatment Related.....	15	Tuberculosis.....	29
Myocardial Infarction, Acute.....	02	Accidental, Not Treatment Related...	16	Aids.....	30
Cerebrovascular.....	03	Artherosclerotic Heart Disease.....	17	Other Infection.....	31
Embolism.....	04	Cardiomyopathy.....	18	Hepatitis B.....	32
Gi Hemorrhage.....	05	Cardiac Arrhythmia.....	19	Other Viral Infection.....	33
Hemorrhage (other than 03 or 05)	06	Cardiac Arrest, Cause Unknown....	20	Gastro-Intestinal Hemorrhage.	34
Pulmonary Infection.....	07	Valvular Heart Disease.....	21	Seizures.....	35
Septicemia.....	08	Pulmonary Edema Due to Exogenous Fluid.....	22	Drug Overdose (Street Drugs)	36
Viral Hepatitis.....	09	Cerebro-Vascular Accident Including Intracranial Hemorrhage.....	23	Drug Overdose (Not 14 or 36)	37
Infection (Other than 07, 08 or 09)....	10	Ischemic Brain Damage/Anoxic Enecephalopathy.....	24	Unknown.....	98
Hyperkalemia.....	11	Hemorrhage From Ruptured Vascular Aneurysm.....	25	Other Identified Cause of Death	99
Pancreatitis.....	12	Hemorrhage From Surgery.....	26		
Malignancy.....	13	Viral Infection.....	27		
Suicide.....	14	Viral Infection (Not 32 or 33)	28		

B4. Source of initial information about the cause of death (**Circle “Yes” or “No” for each**):

	<u>Yes</u>	<u>No</u>	
a. Report of family/friends.....	1	2	
b. Hospital.....	1	2	
c. Death certificate search.....	1	2	
e. Report from health care provider or social service provider.....	1	2	
f. Other source.....	1	2	(Skip to B5a)

Specify source: _____

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B5. a. Did the family request disposal of any specimen(s)? (If unable to contact, indicate "No.")

- Yes..... 1
- No..... **2 (Skip to B6a)**
- Don't Know..... **-8 (Skip to B6a)**

b. Which specimens did the family want disposed?

	Yes	No
1. Serum.....	1	2
2. DNA samples.....	1	2
3. Urine.....	1	2
4. Nail Clippings.....	1	2
5. Hair Samples.....	1	2

B6a. Last CKiD Visit ____ ____ ____ V1a = 10 V1b = 15 V2 = 20 V3 = 30
 V4 = 40 V5 = 50 V6 = 60 V7 = 70
 V8 = 80 V9 = 90 V10 = 100 V11 = 110 ...

B6b. Date of last completed study visit: ____ / ____ / ____
 M M D D Y Y Y Y

B7. Date of Last PIP Interview: ____ / ____ / ____ N/A*-1
 M M D D Y Y Y Y

***N/A: Not applicable applies to individuals who have died and did not participate in the PIP protocol.**

Section C: OBTAIN MOST RECENT HEIGHT AND LAB VALUES PRIOR TO DISENROLLMENT

C1a. Height Measurement: ____ ____ ____ 1=in
(round height to the nearest inch or centimeter) 2=cm

b. Date of last height measurement: ____ / ____ / ____
 M M D D Y Y Y Y

C2. DATE LOCAL LAB SAMPLE DRAWN: ____ / ____ / ____
 M M D D Y Y Y Y

C3. Renal Panel Blood Results:

- a. Serum Creatinine ____ | ____ | (mg/dL)
- b. Urea Nitrogen (BUN) ____ | ____ | (mg/dL)

D1. Date of last contact (i.e., the last time someone physically saw or spoke to participant or family about CKiD)? ____ / ____ / ____
 M M D D Y Y Y Y

COMPLETE PARTICIPANT CLOSE-OUT FORM (PCO), and SEND FORMS TO CCC