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 3 / 0 1 / 2 1

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

A4. FORM COMPLETED BY (INITIALS) ___ ___ ___

PROMPT:
This form should be completed for a participant who is:

- **Deceased**
- **Withdrawing from Phone/In-Person (PIP) Follow-up protocol (If dialysis or kidney transplant was initiated, please complete the TRS03 form prior to DSEN form.**
- **Refusing 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)**
- **Assigned a KID ID# AND written consent has been obtained; however, the participant *did not* complete V1a.**

This form should also be completed if TRS03 form prompts the completion of the DSEN form.

SECTION B

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

Participant's death..... 1 ◯ **(Skip to B5a)**

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 B2b)**

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 other than the measurements/results documented on the TRS03 form?

Yes..... 1 ◯ **(Skip to C1a)**
No..... 2 ◯ **(Skip to D1 and complete PCO)**

B2b. Indicate whether the decision to disenroll was the site or participant/family: (Choose only one response.)

Participant's (or legal authorized representative) decision to disenroll..... 1 ◯
Site's decision to disenroll participant..... 2 ◯ **(Skip to B4)**

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B3. Reason for participant's decision to disenroll from the CKiD study:
(Circle ***primary*** reason for withdrawal. Choose only one response.)

No longer willing to follow the protocol/interested in participating..... 1 **(Go to B3i and specify reason)**
Participant/family has personal constraints..... 2 **(Skip to B8)**
Problem(s) with needle sticks..... 3 **(Skip to B8)**
Family relocated outside of CKiD study area..... 4 **(Skip to B8)**
Other..... 5

B3i. Specify: _____
_____ **(Skip to B8)**

B4. Reason for clinical site's decision to withdraw the participant from the CKiD study:
Circle ***primary*** reason for site's withdrawal. (Choose only one response.)

Family is chronic "no show"..... 1 **(Skip to B8)**
Family does not return calls/unable to reach..... 2 **(Skip to B8)**
Decision due to participant's chronic psychosocial barriers and/or health decline…..... 3 **(Skip to B8)**
Other..... 4

B4i. Specify: _____
_____ **(Skip to B8)**

B5a. Date of participant's death: ___ ___ / ___ ___ / ___ ___ ___ ___
M M D D Y Y Y Y

5b. 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		

B6. Source of initial information about the cause of death **(Circle "Yes" or "No" for each):**

		Yes	No	
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 B7a)**

Specify source: _____
_____

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B7a. 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 …

B7b. Date of last completed study visit: ___ ___ / ___ ___ / ___ ___ ___ ___
M M D D Y Y Y Y

B8. 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 ☐ 2=cm
(round height to the nearest inch or centimeter)

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

SECTION E: REPOSITORY SAMPLES

E1. a. Did the family request disposal of any specimen(s)? (If unable to contact, indicate "No."

Yes..... 1
No..... 2 **(End Form)**
Don't Know..... -8 **(End Form)**

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

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