DISENROLLMENT FORM (DSEN)

CKiD Chronic Kidney Disease in Children Cohort Study

SECTION A: GENERAL INFORMATION

	A1.	PARTICIPANT I	D: ENTER N	NUMBER (ONLY IF L	_ABEL I	S NOT A	AVAILABLI
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|__| - |__| - |__|

A2. FORM VERSION: <u>0 3 / 0 1 / 2 1</u>

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/fami (Choose only one response.)	ly:	
	Participant's (or legal authorized representative) decision to disenroll	1	
	Site's decision to disenroll participant	2	(Skip to B4)



DISENROLLMENT FORM (DSEN)

B3.	Reason for participant's decision to disenroll from the CKiD stude (Circle <i>primary</i> reason for withdrawal. Choose only one response	-			
	·	o to E	33i and	specify reason)	
	participating2 (SI	kip to	. R8)		
		kip to			
		kip to	•		
	Other5	-	•		
	B3i. Specify:			(211 - 22)	
				(Skip to B8))
B4.	Reason for clinical site's decision to withdraw the participant from	n the	CKiD st	udy:	
	Circle <i>primary</i> reason for site's withdrawal. (Choose only one re	spon	se.)	•	
		kip to	•		
		kip to	B8)		
	Decision due to participant's chronic psychosocial	in to	D0\		
	barriers and/or health decline	kip to	о Бој		
	B4i. Specify:				
	opos)			(Skip to B8))
				`	•
B5a.	Date of participant's death: / / /	_			
	$\overline{M} \overline{M} \overline{D} \overline{D} \overline{Y} \overline{Y} \overline{Y} \overline{Y}$				
5b.	What was the cause of death?				
	Pericarditis (incl Cardia Tamponade). 01 Accidental, Treatment Related	15	Tubercul	osis	29
	Myocardial Infarction, Acute	16	Aids		30
	Cerebrovascular	17	Other Inf	ection	31
	Embolism	18	Hepatitis	B	32
	Gi Hemorrhage 05 Cardiac Arrhythmia	19	Other Vir	al Infection	33
	Hemorrhage (other than 03 or 05) 06 Cardiac Arrest, Cause Unknown	20	Gastro-Ir	ntestinal Hemorrhage.	34
	Pulmonary Infection	21	Seizures		35
	Septicemia	22	Drug Ove	erdose (Street Drugs)	36
	Viral Hepatitis	23	Drug Ove	erdose (Not 14 or 36)	37
	Infection (Other than 07, 08 or 09) 10 Ischemic Brain Damage/Anoxic Enecephalopathy	24	Unknowr	1	98
	Hyperkalemia	25	Other Ide	ntified Cause of Death	99
	Pancreatitis	26			
	Malignancy	27			
	Suicide	28			
B6.	Source of initial information about the cause of death (Circle "Yo	es" o	r "No" 1	for each):	
	()	Yes		,	
	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	(Chin to DZs)	
	f. Other source	1	2	(Skip to B7a)	
	Specify source:				_



В7а	Last CKiD Visit V1a = 10
B7b	Date of last completed study visit: / / /
	M M D D Y Y Y
B8	Date of Last PIP Interview: / / / N/A*1
	M M D D Y Y Y
	*N/A: Not applicable applies to individuals who have died and did not participate in the PIP protocol.
Se	ction C: OBTAIN MOST RECENT HEIGHT AND LAB VALUES PRIOR TO DISENROLLMENT
C1a.	Height Measurement: (round height to the nearest inch or centimeter) — — — — 1=in — 2=cm
b.	Date of last height measurement:
	\overline{M} \overline{M} \overline{D} \overline{D} \overline{Y} \overline{Y} \overline{Y} \overline{Y}
C2.	DATE LOCAL LAB SAMPLE DRAWN:
	$\overline{M} \overline{M} \overline{D} \overline{D} \overline{V} \overline{Y} \overline{Y} \overline{Y} \overline{Y}$
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
	Don't Know8 (End Form)
	b. Which specimens did the family want disposed?
	<u>Yes</u> <u>No</u> 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

Chronic Kidney Disease in Children