

Chronic Kidney Disease in Children Cohort Study (CKiD)
QUESTION BY QUESTION SPECIFICATIONS
DSEN: DISENROLLMENT FORM

This form is to be completed for each CKiD participant who has died, or refused to participate in the Phone/In-Person (PIP) Follow-up protocol, or were participating in the PIP protocol and decided to discontinue participation in PIP protocol. **This form should also be completed for participants for whom a KID ID# has been assigned AND written consent has been obtained. However, the participant *may or may not* have completed V1a.**

- A1. Record the participant's ID number or affix label in the space provided.
- A3. The form version is pre-printed. Be sure that you are using a current version and that all unused, outdated versions have been discarded. Use the form version dated 02/15/15.
- A4. Record the date in which the form is being completed – the month, day, and year.
- A5. Enter the initials of the person completing this form.

Example: K I D

SECTION B

- B2. Circle the **ONE CODE** that describes the reason for disenrolling the participant. If the participant died, circle (Code 1) and **skip to B3a**. If the participant was previously enrolled in the Phone/In-Person (PIP) Follow-up protocol, and is no longer interested in participating in the PIP protocol, then circle (Code 10), **skip to B7**. Also, if the participant was previously enrolled in PIP and the sites has decided to withdraw the participant/family (i.e., non-compliant family) or participation in PIP protocol has been discontinued, also circle (Code 10) and **skip to B7**. However, if the participant/family was never enrolled in PIP, then circle (Code 11), **skip to B2a**. If the child consented to study participation but did NOT complete V1a, then circle (Code 99), **END Form and complete PCO**.
- B2a. Record whether more recent height measurements and lab values are available. Compare the dates on the TRS01 form to determine if more recent measurement and lab values are available. If yes, **skip to C1a** and document the most recent height measurements and lab values. Otherwise, if no, **skip to D1 and complete PCO**.
- B3a. Record the date of the participant's death – the month, day, and year.
- B3b. Specify the cause of death by choosing one of the options provided. If the cause of death is unknown, circle "98" or not listed circle "99."

- B4. Specify the source of initial information about participant's death by circling "Yes" (Code 1) or "No" (Code 2) to each source in sub-answers a through f. If you select "Yes" to other source, specify the source in the provided space, otherwise **skip to B5a**.
- B5a. For sub-question "a", record whether the participant/family requested any of the collected specimens to be disposed by circling "Yes" (Code 1), "No" (Code 2) or "Don't Know" (Code -8). If "No" or "Don't Know" is selected, **skip to B6**. If the family is unable to be contacted, circle "No" and **skip to B6**.
- B5b. For sub-question "b", specify which of the collected specimens the participant/family wants to be disposed by circling "Yes" (Code 1) or "No" (Code 2) for each of the following: Serum, DNA samples, Urine, Nail clippings, and Hair Samples.
- B6. Record the last study visit the participant completed prior to disenrollment. Example: If the participant completed V1b, then record 15.
- B6a. Record the date of the last completed visit – the month, day, and year
- B7. Record the date of the last PIP Interview – the month, day, and year
If the participant died and did not participate in PIP, then circle N/A (Code -1).

The next set of question are used to obtain most recent height and lab values prior to transplantation, dialysis or lost to follow-up (either site or family's decision to withdraw) from the study.

- C1a. Record the child's most recent height and document whether the height was taken in inches or centimeters.
- C1b. Record the date the last height measurement was taken.
- C2. Record the date of the most recent local lab sample was drawn.
- C3a-b. Record the most recent serum creatinine and urea nitrogen (BUN).
- D1. Record the date of last contact. This date is the last date that someone physically saw or spoke to the participant or family about the CKiD study. **THIS DATE SHOULD NOT BE LEFT BLANK.**

**COMPLETE PARTICIPANT CLOSE-OUR FORM (PCO)
and
IMMEDIATELY CONTACT YOUR CCC**