

# PIP TRANSITIONAL FORM (TRS01)

## 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     1   /   1     5   /   1     3a  

A3. DATE OF THIS REPORT:       /       /              
M M D D Y Y Y Y

A4. FORM COMPLETED BY (INITIALS)         

**PROMPT: This form should be completed for participants who are considered no longer able to participate in regular CKiD study visits as a result of participant/family withdrawal, site withdrawal, transitioning to adult care/aged out or pregnancy. This form should also be completed for participants who have had or are scheduled to have transplants or dialysis treatment.**

B1. Reason for completing the TRS01 form.

- |   |   |              |
|---|---|--------------|
| Participant had kidney transplant .....                           | 2 | (Skip to C1) |
| Participant is <b>scheduled</b> to have kidney transplant .....   | 8 | (Skip to C1) |
| Participant began dialysis treatment .....                        | 3 | (Skip to C2) |
| Participant is <b>scheduled</b> to begin dialysis treatment ..... | 9 | (Skip to C2) |
| Participant's (child's or legal guardian's) decision to withdraw  | 4 |              |
| Site's decision to withdraw participant from regular study visits | 5 | (Skip to B3) |
| Participant transferred to adult care (i.e., aged out).....       | 7 | (Skip to B4) |
| Female participant becomes pregnant.....                          | 6 | (Skip to B4) |

B2. Reason for participant's decision to withdrawal 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 B2i and specify reason) |
| Participant/family has personal constraints.....                          | 2 | (Skip to B4)                   |
| Problem(s) with needle sticks.....  | 4 | (Skip to B4)                   |
| Family relocated outside of CKiD study area.....                          | 5 | (Skip to B4)                   |
| Other.....  | 3 |                                |

B2i. Specify: \_\_\_\_\_  
\_\_\_\_\_ (Skip to B4)

B3. 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 |
| Family does not return calls/unable to reach | 2 |
| Other  | 4 |

B3i. Specify: \_\_\_\_\_  
\_\_\_\_\_ (Skip to B4)

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B4. Date of last contact (i.e., the last time someone physically saw or spoke to participant or family about CKiD)? \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ (Skip to D1a)  
M M    D D    Y Y    Y Y

**SECTION C: TRANSPLANT/DIALYSIS TREATMENT**  
**NOTE: Complete Section C for participants who have had or are scheduled to have a transplant or dialysis treatment.**

C1. a. Scheduled or Actual Date of kidney transplant: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
M M    D D    Y Y    Y Y

b. Name of provider and address of institution where kidney transplant will be or was performed:  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

c. Were there clinical factors that prompted the scheduling or proceeding with the kidney transplant (e.g., increase in serum creatinine measurement)?  
 Yes..... 1 (if yes, then complete C1ci-vii)  
 No..... 2 (Skip to D1a)  
 Don't Know..... -8 (Skip to D1a)

Indicate the clinical factors that were important in deciding to proceed toward kidney transplantation from conservative management of CKD (Indicate all that may apply)

	<u>Yes</u>	<u>No</u>
i. Estimated GFR $\leq 15\text{ml}/\text{min}/1.73\text{m}^2$ .....	1	2
ii. Rapid decline in GFR, but estimated GFR $> 15\text{ml}/\text{min}/1.73\text{m}^2$ .....	1	2
iii. Poor Growth.....	1	2
iv. Patient/family desired pre-emptive transplantation.....	1	2
v. Need to accommodate the family/patient's school/work schedule.....	1	2
vi. Malnutrition.....	1	2
vii. Other factor, not given above.....	1	2 (skip to D1a)

1. Please specify the other clinical factors : \_\_\_\_\_  
(Skip to D1a)

C2. a. Date dialysis treatment begins or began: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
M M    D D    Y Y    Y Y

b. Name of provider and address of institution where dialysis treatment will be or was performed:  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

c. Were there clinical factors that prompted the scheduling or initiating dialysis treatment (e.g., increase in serum creatinine measurement)?  
 Yes..... 1 (if yes, then complete C2ci-xiii)  
 No..... 2 (Skip to d)  
 Don't Know..... -8 (Skip to d)



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Indicate the clinical factors that were important in deciding to initiating dialysis.  
(Indicate all that may apply)

	<u>Yes</u>	<u>No</u>
i. eGFR $\leq$ 15ml/min/1.73m <sup>2</sup> .....	1	2
ii. Rapid Decline in GFR, but eGFR > 15.....	1	2
iii. Poor Growth.....	1	2
iv. Urgent Need to Initiate.....	1	2
v. Hyperphosphatemia.....	1	2
vi. Hyperkalemia.....	1	2
vii. Pulmonary Edema.....	1	2
viii. Volume Overload.....	1	2
ix. Nephrotic Syndrome.....	1	2
x. Uncontrolled Hypertension.....	1	2
xi. Oligo/Anuria.....	1	2
xii. Malnutrition.....	1	2
xiii. Other factor, not given above.....	1	2

**(Skip to C2d)**

1. Please specify the other clinical factors: \_\_\_\_\_

d. Did the initiation of dialysis coincide with a precipitous event/hospitalization?

- Yes..... 1
- No..... 2 **(Skip to C2e)**
- Don't Know..... -8 **(Skip to C2e)**

1. Briefly describe the reason for the event/hospitalization.

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

e. Given that the patient will begin dialysis, what are the plans for kidney transplantation?

- None at this time..... 1
- Waiting for living related donor transplant..... 2
- Placed on donor waiting list, no living donor available..... 3

<b>SECTION D: REPOSITORY SAMPLES</b>
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D1. a. Did the participant request disposal of any specimen(s)? (If unable to contact, indicate "No.")

- Yes..... 1
- No..... 2 **(Skip to D2a)**
- Don't Know..... -8 **(Skip to D2a)**

b. Which specimens did the participant 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 |

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### SECTION D: OBTAIN MOST RECENT HEIGHT AND LAB VALUES PRIOR TO RRT

- D2a. 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
- D3. DATE LOCAL LAB SAMPLE DRAWN: \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
M M D D Y Y Y Y
- D4. Renal Panel Blood Results:
- a. Serum Creatinine |\_\_\_\_| . |\_\_\_\_| (mg/dL)
- b. Urea Nitrogen (BUN) |\_\_\_\_|\_\_\_\_|\_\_\_\_| (mg/dL)
- D5. 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 ...

### SECTION E: PARTICIPATION IN PHONE/IN-PERSON (PIP) FOLLOW-UP PROTOCOL

- E1. a. Did the participant/family consent to the Phone/In-Person (PIP) Follow-up Protocol?  
Yes..... 1 **(Go to E1ai)**  
No..... 2 **(Skip to E1b)**  
Family considering participation in PIP 3 **(END FORM and contact CCC)**
- E1ai. Date of consent? \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
M M D D Y Y Y Y **(END FORM, complete "Enrolled in Phone Follow-up" & download PIP forms from the CKiD website)**
- b. Has the participant/family been contacted to participate in the Phone/In-Person (PIP) Follow-up Protocol?  
Yes..... 1  
No..... 2 **(skip to E1d)**
- c. Please indicate the reason(s) the participant/family did not consent to the Phone/In-Person Follow-up Protocol. **(Circle "Yes" or "No" for EACH of the following.)**
- |   | Yes | No |                                     |
|---|-----|----|-------------------------------------|
| 1. Not interested in participating.....             | 1   | 2  |                                     |
| 2. Participant/family has personal constraints..... | 1   | 2  |                                     |
| 3. Family relocated outside of CKiD study area..... | 1   | 2  |                                     |
| 4. Other reason.....                                | 1   | 2  | <b>END FORM &amp; complete DSEN</b> |
- i. Please specify reason: \_\_\_\_\_

### Since family did not consent to PIP Follow-up Protocol, END FORM and complete DSEN.

- d. Please indicate the reason(s) the participant/family has not been contacted to participate in the Phone/In-Person Follow-up Protocol. **(Circle "Yes" or "No" for EACH of the following.)**
- |   | Yes | No |  |
|---|-----|----|--|
| 1. Family does not return calls/unable to reach.. | 1   | 2  |  |
| 2. Other reason.....                              | 1   | 2  | <b>(If no, END FORM &amp; complete DSEN)</b> |
- i..... Please specify reason: \_\_\_\_\_

### END FORM and complete DSEN