

**REMINDER: SITE MUST ASSIGN ID NUMBER** →

Enter "1" in the first box. The next 2 digits indicate the site's number, 01-49 (Midwest sites) and 50-99 (East Coast sites). The local ID # should be at least 3 digits. It can be the child's medical record number or some other commonly used number by the site.

**LOCAL ID# IS NOT KID#.**

Cohort: \_\_\_ Site: \_\_\_ Local ID#: \_\_\_\_\_

**(NOT KID#)**

Interviewer Initials \_\_\_\_\_

**Chronic Kidney Disease in Children (CKiD)  
REFUSAL FORM/NON-PARTICIPATION (REF)**

Form Version: 06 / 01 / 2 0 0 8

1. Date Form Completed: \_\_\_ / \_\_\_ / \_\_\_ [mm/dd/yyyy]

2. Year of birth: \_\_\_\_\_ [yyyy]

2a. Most Recent sGFR: \_\_\_\_\_ . \_\_\_\_\_

3. Gender:  1) Male  2) Female

3a. Primary Refer to Table 1 in the REF QxQ for details on each category.

Diagnosis:  1) Glomerulonephritis  3) Non-GN (Other); specify Diagnosis: \_\_\_\_\_  
 2) Non-GN (Urologic/Cystic/Hereditary)  4) Unknown

4. Which of the following best describes the ethnicity of the child? (More than one race may be selected.)  
 1) American Indian/Alaskan Native  
 2) Asian/Asian American  
 3) African American/Black  
 4) Caucasian/ White  
 5) Native Hawaiian/other Pacific Islander  
 6) Other; specify Race: \_\_\_\_\_

5. Is the child of Hispanic or Latino/a origin?  1) Yes  2) No

6. Was the child screened and family asked to participate in the CKiD study?  1) Yes  
 2) No **(Skip to Question 7)**

6a. Reason for Refusal: (More than one answer may be selected.)  
 1) No reason given **(Skip to Question 8)**  
 2) Parent is not interested  
 3) Child is not interested  
 4) Parent and/or child is unable to make scheduled appointment/too busy/time constraints  
 5) Child feeling too ill to participate  
 6) Parent and/or child concerned about data privacy/protection of personal medical information  
 7) Parent and/or child declined because too many IVs for GFR and blood draws are required  
 8) Parent and/or child did not want child's blood to be stored in CKiD national repository  
 9) Parent and/or child does not consider the CKiD study beneficial  
 10) Parent and/or child concerned about research processes in CKiD study  
 11) Parent and/or child prefers (additional) compensation  
 12) Other Reason family refused to participate; specify other reason: \_\_\_\_\_

**SKIP TO QUESTION 8**

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7. Please specify the reason(s) why the child was screened but family NOT recruited.  
(More than one answer may be selected.)

- 1) Patient too ill
- 2) Child has rapidly declining GFR
- 3) Family pending relocation
- 4) Family has language barrier
- 5) Family has problem complying with clinical visits  
(misses too many clinical visits)
- 12) Other Reason family NOT recruited to participate;  
specify other reason: \_\_\_\_\_

8. Was a KID # assigned and Eligibility form sent to CCC for data entry?

- 1) Yes
- 2) No (END)

8a. Record the KID # that assigned and sent to CCC for data entered:

\_\_\_\_\_

**KID # SHOULD NOT BE REUSED**