

**REMINDER: SITE MUST ASSIGN ID NUMBER** → Enter "4" 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 4 digits.  
**LOCAL ID# IS NOT KID#.**

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

**(NOT KID#)**

Coordinator Initials \_\_\_\_\_

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

Form Version: 03 / 01 / 2025

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

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

3. Sex assigned at birth:  1) Male  2) Female

4. Kidney Replacement Therapy (KRT) Status:  1) KRT Naïve  2) Transplant  3) Dialysis (skip to 5)

4a. Most Recent eGFR: \_\_\_ . \_\_\_ (use U25eGFR)

5. Primary Refer to Table 1 at the bottom of page 2 for details of categories 1, 2 and 3.

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

6. Which of the following best describes the race of the patient? (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: \_\_\_\_\_  
 -8) Don't know/ Information not available

7. Is the patient of Hispanic or Latino/a origin?  1) Yes  2) No  -8) Don't know/Information not available

8. Was the patient screened and family/patients asked to participate in the CKiD study?  1) Yes  
 2) No **(Skip to Question 9)**

8a. Reason for Refusal: **(Select all that apply)**

- |  |   |
|--|---|
| <input type="checkbox"/> 1) No reason given <b>(Skip to Question 10)</b>   | <input type="checkbox"/> 9) Long travel time to site  |
| <input type="checkbox"/> 2) Parent/Guardian is not interested  | <input type="checkbox"/> 10) Study visits perceived as too long   |
| <input type="checkbox"/> 3) Patient is not interested  | <input type="checkbox"/> 11) Patient feeling too ill to participate   |
| <input type="checkbox"/> 4) Patient has medical anxiety/other medical condition  | <input type="checkbox"/> 12) Patient and/or parent/guardian did not want patient's data to be stored in national repository |
| <input type="checkbox"/> 5) Patient and/or parent/guardian does not consider the CKiD study beneficial                             | <input type="checkbox"/> 13) Patient and/or parent/guardian concerned about research processes in CKiD study                |
| <input type="checkbox"/> 6) Patient and/or parent/guardian is unable to make scheduled appointment/too busy/time constraints       | <input type="checkbox"/> 14) Patient and/or parent/guardian prefer (additional) compensation for participation              |
| <input type="checkbox"/> 7) Patient and/or parent/guardian declined because too many IVs for blood draws are required              | <input type="checkbox"/> 15) Patient doesn't want to participate in any research (i.e., distrust research)                  |
| <input type="checkbox"/> 8) Patient and/or parent/guardian concerned about data privacy/protection of personal medical information | <input type="checkbox"/> 16) Other Reason family refused to participate; specify other reason: _____                        |

**SKIP TO QUESTION 10**

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9. Please specify the reason(s) why the patient was screened but patient/family NOT recruited.

**(Select all that apply)**

- 1) Patient too ill
- 2) Patient has rapidly declining GFR
- 3) Patient/Family pending relocation
- 4) Patient/Family has language barrier
- 5) Patient/Family has problem complying with clinical visits (misses too many clinical visits)
- 6) Medical chart specifies that patient should not be approached for research
- 7) Nephrologist/health professional indicates that the patient is not a good candidate (i.e., not a good fit)
- 8) Other Reason family NOT recruited to participate; specify other reason: \_\_\_\_\_

10. Was a KID # assigned and Eligibility form sent to CCC for data entry?  1) Yes  
 2) No **(END Form)**

10a. Record the KID # that assigned and sent to CCC for data entered:

\_\_\_\_ - \_\_\_\_ - \_\_\_\_ - \_\_\_\_  
**KID # SHOULD NOT BE REUSED**

**Table 1. Primary diagnosis of Chronic Kidney Disease CLASSIFICATION**

**1) Glomerular CKD diagnosis**

- 15) Chronic glomerulonephritis
- 20) Congenital nephrotic syndrome
- 23) Denys-Drash syndrome
- 24) Diabetic nephropathy
- 12) Familial nephritis (Alport's)
- 10) Focal segmental glomerulosclerosis
- 11) Hemolytic uremic syndrome
- 19) Henoch Schonlein nephritis
- 17) Idiopathic crescentic glomerulonephritis
- 13) IgA Nephropathy (Berger's)
- 16) Membranoproliferative glomerulonephritis Type I
- 21) Membranoproliferative glomerulonephritis Type II
- 18) Membranous nephropathy
- 22) Sickle cell nephropathy
- 14) Systemic immunological disease (including SLE)
- 40) Glomerular Other: \_\_\_\_\_

**2) Non-Glomerular (Urologic/Cystic/Hereditary)**

- 51) Aplastic/hypoplastic/dysplastic kidneys
- 65) Branchio-oto-Renal Disease/Syndrome
- 62) Congenital Urologic Disease (Bilateral Hydronephrosis)
- 57) Medullary cystic disease/juvenile nephronophthisis
- 50) Obstructive uropathy
- 61) Oxalosis
- 60) Polycystic kidney disease (Autosomal dominant)
- 53) Polycystic kidney disease (Autosomal recessive)
- 55) Pyelonephritis/Interstitial nephritis
- 52) Reflux nephropathy
- 58) Syndrome of agenesis of abdominal musculature
- 63) Vactrel or Vater Syndrome

**3) Non-Glomerular (Other)**

- 54) Cystinosis
- 64) Perinatal Asphyxia
- 56) Renal infarct
- 59) Wilms' tumor
- 80) Non-Glomerular Other: \_\_\_\_\_