

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

Enter "2" 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: 09 / 01 / 2011

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

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

2a. Most Recent eGFR: \_\_\_ . \_\_\_ (updated Schwartz formula to estimate GFR = 0.413 \* Height (in cm)/SCr)

3. Gender:  1) Male  2) Female

3a. 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

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

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

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)
  - 6) 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**

**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: \_\_\_\_\_