

REMINDER: SITE MUST ASSIGN ID NUMBER →

Cohort: ___ Site: ___ Local ID#: _____

Enter "3" 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.

(NOT KID#)

Interviewer Initials _____

LOCAL ID# IS NOT KID#.

**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

REMINDER: SITE MUST ASSIGN ID NUMBER →

Enter "3" 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 _____

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: _____