**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#**.

**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 Diagnosis:
   - 1) Glomerulonephritis
   - 2) Non-GN (Urologic/Cystic/Hereditary)
   - 3) Non-GN (Other); specify Diagnosis: ___________
   - 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 “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 __ __ __

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

<table>
<thead>
<tr>
<th>1) Glomerular CKD diagnosis</th>
<th>2) Non-Glomerular (Urologic/Cystic/Hereditary)</th>
</tr>
</thead>
<tbody>
<tr>
<td>15) Chronic glomerulonephritis</td>
<td>51) Aplastic/hypoplastic/dysplastic kidneys</td>
</tr>
<tr>
<td>20) Congenital nephrotic syndrome</td>
<td>65) Branchio-oto-Renal Disease/Syndrome</td>
</tr>
<tr>
<td>23) Denys-Drash syndrome</td>
<td>62) Congenital Urologic Disease (Bilateral Hydronephrosis)</td>
</tr>
<tr>
<td>24) Diabetic nephropathy</td>
<td>57) Medullary cystic disease/juvenile nephronphthisis</td>
</tr>
<tr>
<td>12) Familial nephritis (Alport’s)</td>
<td>50) Obstructive uropathy</td>
</tr>
<tr>
<td>10) Focal segmental glomerulosclerosis</td>
<td>61) Oxalosis</td>
</tr>
<tr>
<td>11) Hemolytic uremic syndrome</td>
<td>60) Polycystic kidney disease (Autosomal dominant)</td>
</tr>
<tr>
<td>19) Henoch Schonlein nephritis</td>
<td>53) Polycystic kidney disease (Autosomal recessive)</td>
</tr>
<tr>
<td>17) Idiopathic crescentic glomerulonephritis</td>
<td>55) Pyelonephritis/Interstitial nephritis</td>
</tr>
<tr>
<td>13) IgA Nephropathy (Berger’s)</td>
<td>52) Reflux nephropathy</td>
</tr>
<tr>
<td>16) Membranoproliferative glomerulonephritis Type I</td>
<td>58) Syndrome of agenesia of abdominal musculature</td>
</tr>
<tr>
<td>21) Membranoproliferative glomerulonephritis Type II</td>
<td>63) Vactrel or Vater Syndrome</td>
</tr>
<tr>
<td>18) Membranous nephropathy</td>
<td></td>
</tr>
<tr>
<td>22) Sickle cell nephropathy</td>
<td></td>
</tr>
<tr>
<td>14) Systemic immunological disease (including SLE)</td>
<td></td>
</tr>
<tr>
<td>40) Glomerular Other: ___________________________</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3) Non-Glomerular (Other)</th>
</tr>
</thead>
<tbody>
<tr>
<td>54) Cystinosis</td>
</tr>
<tr>
<td>64) Perinatal Asphyxia</td>
</tr>
<tr>
<td>56) Renal infarct</td>
</tr>
<tr>
<td>59) Wilms’ tumor</td>
</tr>
<tr>
<td>80) Non-Glomerular Other: ___________________________</td>
</tr>
</tbody>
</table>