FOR PARENTS OR LEGAL GUARDIANS

Chronic Kidney Disease in Children (CKiD)

SECTION A: GENERAL INFORMATION

| A1. | PARTICIPANT ID: AFFIX ID LABEL OR ENTER NUMBER IF ID LABEL IS NOT AVAILABLE | | | |
|-----|---|--|--|--|
| | | _ - _ - | | |
| A2. | CKiD VISIT #: | | | |
| A3. | FORM VERSION: | <u>0</u> <u>8</u> / <u>0</u> <u>1</u> / <u>1</u> <u>3c</u> | | |
| A4. | TESTING DATE: | $\begin{array}{c ccccccccccccccccccccccccccccccccccc$ | | |
| A5. | INTERVIEWER'S INITIALS: | | | |
| A6. | INDICATE INDIVIDUAL TAKING THE HLA: | Mother | | |
| | | i. Specify | | |

This form is to be completed by a parent or legal guardian for each individual enrolled in CKiD. Only one parent/legal guardian needs to complete the form. The HLA is based on the Short Test of Functional Health Literacy Assessment (STOFHLA), which is a standardized tool. The HLA consists of two STOFHLA components: 1) numeracy and 2) reading comprehension. Please refer to the HLA01 Cheat Sheet for instructions on how to administer the HLA.

Please read the following introduction (and all of the bolded text) verbatim to the CKiD test respondent:

"Thank you for participating in this study. Please listen to each question carefully. As with all study information, your answers will be kept private. No one will know who completed this assessment, because there is only a code number at the top, not your name. <u>Please answer all</u> questions honestly. Your answers are for research purposes only."

SECTION B: NUMERACY ASSESSMENT

Numeracy assessment: Timed for 4 minutes

Supplies required: Stopwatch, 4 Numeracy Prompt Cards, a pen to record the test respondent's answers

| B0. | Numeracy Test Completion Status: | | | |
|-----|--|-----------------------|--|--|
| a. | Was the Numeracy section completed at the study visit? | | | |
| | Yes | 1 (Skip to B1) | | |
| | No | 2 | | |
| | | | | |
| b. | b. Reason why the Numeracy section was not completed: | | | |
| | Participant refused to take the test | 1 | | |
| | Participant unable to complete, vision <20/100 | 2 | | |
| | Participant unable to complete, states illiterate | 3 | | |
| | Participant unable to complete, no reason given | 4 | | |
| | Participant unable to complete, other reason | 5 (Skip to Section C) | | |
| | i. Specify | | | |

Numeracy Assessment Script

PLEASE READ THE FOLLOWING BOLDED TEXT VERBATIM TO THE CKID TEST RESPONDENT:

"One of our most important goals as health care providers is to make sure we take time to explain instructions about your care in a way that is clear and will not cause any confusion. Today you can help us measure how well we are doing our job, by going through this exercise.

Do you wear glasses? (IF YES...) Please put them on.

This card contains directions you may be given in a healthcare setting. Please read the information in the box and use it to answer the question that I will read to you. If you do not know the answer, please say 'I don't know'. I will be handing you a total of four (4) cards which you will read to yourself, and then I will ask you one question about the information you just read. You will have 4 minutes to answer all 4 questions."

HAND RESPONDENT THE NUMERACY PROMPT CARD (LAMINATED CARD) FOR EACH QUESTION. REMEMBER TO START THE TIMER WHEN THEY BEGIN READING PROMPT 1. INSTRUCT THE RESPONDENT TO SAY "DONE" OR "FINISHED" WHEN THEY FINISH READING EACH PROMPT.

WHEN THE RESPONDENT INDICATES THAT THEY READ A PROMPT CARD, READ THE QUESTION FOR THAT PROMPT AND RECORD THE RESPONSE VERBATIM IN THE SPACE PROVIDED.

BEGIN EACH NEW QUESTION WITH A NEW PROMPT: "Have a look at this one" or "Here is another direction you might be given." The questions for the prompts are listed below. Refrain from asking clarifying questions (i.e., "Are you sure?").

STOP THE TEST AT THE END OF 4 MINUTES AND REMOVE TEST MATERIALS FROM THE PARTICIPANT

| | QUESTION | RESPONSE |
|-----|--|--|
| B1. | PROMPT 1: If you take your first tablet at 7:00 am, when should you take the next one? | |
| | | Redirect to answer in clock format if needed. |
| B2. | PROMPT 2: If this were your score, would your blood sugar be normal today? | |
| | | Redirect to answer in yes/no format if needed. |
| B3. | PROMPT 3: When is your next appointment? | |
| | | Redirect to answer in date format if needed. |
| B4. | PROMPT 4: If you eat lunch at 12:00 noon, and you want to take this medicine before lunch, what time should you take it? | |
| | | Redirect to answer in clock format if needed. |

SECTION C: READING COMPREHENSION ASSESSMENT

Reading Comprehension assessment: Timed for 7 minutes

Supplies required: Stopwatch, Prompt Card "Section C Example", a pen for respondent to record answers.

The four pages of the reading comprehension assessment can be found on pages 6-9 of this form. After reading the Reading Comprehension script to the respondent, please hand these pages to the respondent. After 7 minutes have elapsed, remove the test pages from the respondent and place them back in the binder with the rest of this form.

| 20. | Reading Comprehension Test Completion Status: | | |
|-----|---|-----------------------|--|
| a. | Was the Reading Comprehension section completed at the study visit? | | |
| | Yes | 1 (Skip to Passage A) | |
| | No | 2 | |
| | | | |
| b. | . Reason why the Reading Comprehension section was not completed: | | |
| | Participant refused to take the test | 1 | |
| | Participant unable to complete, vision <20/100 | 2 | |
| | Participant unable to complete, states illiterate | 3 | |
| | Participant unable to complete, no reason given | 4 | |
| | Participant unable to complete, other reason | 5 (END Form) | |
| | i. Specify | | |

Reading Comprehension Script

PLEASE READ THE FOLLOWING BOLDED TEXT VERBATIM TO THE CKID TEST RESPONDENT:

"Do you wear glasses? (IF YES...) Please put them on.

I am going to show you some medical instructions that you might see around a hospital. There are words missing in these instructions, like in this example (HAND PARTICIPANT THE SECTION C EXAMPLE PROMPT CARD).

I want you to fill in the missing words. Just below the blank line, we've listed 4 possible words to complete the sentence. Choose the word that makes the most sense. Circle the letter in front of the word you choose.

So, in this example, "Your blood test was <u>blank</u>", the word "normal" is the only word that can complete the sentence so it makes sense. So, you would circle the letter "a" in front of the word "normal". Is that clear?

There are four pages, and the page numbers are shown at the bottom of each page. (TURN TO THE FIRST PAGE OF THE TEST AND SHOW THE PAGE NUMBER). Be careful not to skip any.

You will have 7 minutes to do this. Please complete as much as you can in that time.

HAND PARTICIPANT THE FOUR PAGES OF THE TEST ATTACHED TO THE FORM.

START A TIMER WHEN THE PARTICIPANT STARTS THE TEST. STOP THE TEST AT THE END OF 7 MINUTES AND REMOVE TEST MATERIALS FROM THE PARTICIPANT.

Ready? You can start."

| Passage A | | | | |
|--------------------------|---------------|--------------|-------------|----------------------------------|
| Your doctor has sent you | ı to have a _ | | _X-ray. | |
| - | a. | stomach | - | |
| | b. | diabetes | | |
| | c. | stitches | | |
| | d. | germs | | |
| Vou must have an | stomas | sh whon w | ou come for | |
| You must have an a. ast | | m when yo | ou come for | |
| | | | | a. is |
| b. em | | | | b. am |
| c. inc | | | | c. if |
| d. and | emia | | | d. it |
| The X-ray will | _ from 1 to 3 | | _ to do. | |
| a. take | | a. beds | | |
| b. view | | b. brains | | |
| c. talk | | c. hours | | |
| d. look | | d. diets | | |
| | | | | |
| THE DAY BEFORE T | HE X-RAY | | | |
| For supper have only a _ | snac | ck of fruit, | | _ and jelly, with coffee or tea. |
| | a. little | | a. toes | |
| | b. broth | | b. throat | |
| | c. attack | | c. toast | |
| | d. nausea | | d. thigh | |
| | | | J | |
| | | | | |
| | | | | |

PAGE 1

| After | , you must not _ | or drink | |
|---|---|--|--------------|
| a. minuteb. midnigc. duringd. before | rht, | a. easyb. atec. drankd. eat | |
| 1 | until after yo a. ill b. all c. each d. any | a. are b. has c. had d. was | _ the X-ray. |
| THE DAY OF | ΓHE X-RAY | | |
| b. w c. b | ppointment valk-in reakfast linic | | |
| Do nota. drive b. drind c. dress d. dose | b. breath c. water | | |
| 1 | , call the a. answers, c. exercises, c. tracts, d. questions, | a. Department b. Sprain c. Pharmacy d. Toothache | at 616-4500. |

PAGE 2

PASSAGE B

| I agree to give correct information to | if I can receive Medicaid. | | |
|--|-------------------------------|--|--|
| | a. hair | | |
| | b. salt | | |
| | c. see | | |
| | d. ache | | |
| I to provide the county infor | rmation to any | | |
| a. agree | a. hide | | |
| b. probe | b. risk | | |
| c. send | c. discharge | | |
| d. gain | d. prove | | |
| | | | |
| statements given in this | and hereby give permission to | | |
| a. emphyse | | | |
| b. applicati | | | |
| c. gallblade | der | | |
| d. relations | ship | | |
| | | | |
| the to get such j | | | |
| a. inflammation | a. investigate | | |
| b. religion | b. entertain | | |
| c. iron | c. understand | | |
| d. county | d. establish | | |
| Medicaid I must report any | in my circumstances | | |
| a. changes | | | |
| b. hormone | es | | |
| c. antacids | | | |
| d. charges | | | |
| within(10) days of become | ning of the change. | | |
| a. three | a. award | | |
| b. one | b. aware | | |
| c. five | c. away | | |
| d. ten | d. await | | |

| I un | derstand | if I DO NOT like | the | made on my |
|-------|-----------------|-----------------------------|--------------------|------------------|
| | | hus | a. marital | · |
| | b. t | this | b. occupation | n |
| | c. t | hat | c. adult | |
| | d. t | than | d. decision | |
| case | , I have the | to a fair hearin | ng. I can | a |
| | | a. bright | a. reques | t |
| | | b. left | b. refuse | |
| | | c. wrong | c. fail | |
| | | d. right | d. mend | |
| | | | | |
| hear | ring by writing | or the county | y where I applied. | |
| | | a. counting | | |
| | | b. reading | | |
| | | c. calling | | |
| | | d. smelling | | |
| If yo | ou | AFDC for any family | , | you will have to |
| 3 | a. wash | | a. member | |
| | b. want | | b. history | |
| | c. cover | | c. weight | |
| | d. tape | | d. seatbelt | |
| | | | | |
| | | a different application for | rm | , we will use |
| | a. relax | | a. Since | |
| | b. break | | b. Whether | |
| | c. inhale | | c. However | |
| | d. sign | | d. Because | |
| .1 | | | | |
| the _ | . 1 | on this form to determin | ~ | · |
| | a. lung | | a. hypoglyco | |
| | b. date | | b. eligibility | |
| | c. meal | | c. osteoporo | |
| | d. pelvic | | d. schizophi | |
| | | | | PAGE 4 |