

Medical History For Post-KRT

Chronic Kidney Disease in Children (CKiD)

SECTION A: GENERAL INFORMATION

Data entry person:

A2. CKiD VISIT #:

A3. FORM VERSION:

08/01/21

A4. DATE OF VISIT:

A5. INTERVIEWER'S INITIALS:

A6. INDICATE PERSON COMPLETING THE FORM

- Child/young adult
- Parent or other adult
- Both (Parent and Child/young adult)

For each question, select the number that best matches the respondent's answer. Select -8 for "Don't Know" responses. If a participant declines to answer a question, choose -7 to the right of the response choice(s). For missing data, choose -9 to the right of the response choice(s). Please document the reason for missing data (i.e., the question was accidentally skipped.)

Read each question and follow skip patterns as they appear on the form. Review the QxQ for detailed descriptions of questions.

INTRODUCTION TO PARTICIPANT/PARENT OR OTHER ADULT:

The following questions are about the participant's health history, including information about the current and past diseases that the participant may have had in the past year. Dates may be hard to remember. Please take as much time as you need so we can gather information that is as accurate as possible.

As with all study information, your responses will be kept strictly confidential, and the responses you provide will in no way affect the participant's clinical care. The first set of questions asks about the participant's kidney disease. Whenever the term "health care provider" is used, it means any doctor, nurse, physician assistant or nurse practitioner the participant has ever seen. If you have trouble understanding anything, please feel free to ask for further clarification.

SECTION B: KIDNEY DISEASE

B1. In the past year, has (name of participant) been seen by a Urologist (adult or pediatric)?

- Yes
 No

B2. In the past year, has (name of participant) had a urologic procedure, including surgery to treat his or her kidney problems?

- Yes
 No
 Don't know

B3. In the past year, has (name of participant) had a genetic test (i.e., Podocin or Nephryn) performed to help diagnose his or her kidney disease?

- Yes
 No
 Don't know

B4. In the past year, has a healthcare provider diagnosed (name of participant) with a kidney infection with a fever?

- Yes
 No
 Don't know

a. In the past year, how many times did he/she have a kidney infection with a fever?

_____ (times)

B5. Is participant a female?

- Yes
 No

B6. In the past year, has (name of participant) started her menses (i.e. period)?

- Yes
 No
 Don't know

a. How old was she when she started her first period?

_____ (years of age)

The next set of questions asks about diseases/illnesses that the participant had or developed in the past year.

In the past year, has a doctor or any other healthcare professional told you that (name of participant) had or has developed any of the following diseases/illnesses?

Please select "Yes", "No" or "Don't Know" for EACH of the following.

C1. GENERAL / METABOLIC DISEASE:

a. Diabetes Mellitus

(Sugar Diabetes, High Blood Sugar)

b. Auto-immune Disease

(Lupus, Rheumatoid Arthritis)

C2. CARDIOVASCULAR DISEASE:

- a. Heart Failure (Congestive heart failure) _____
- b. Stroke _____
- c. Left Ventricular Hypertrophy (LVH)/ Thickened Heart Muscle _____

C3. LUNG DISEASE:

- a. Asthma _____

C4. GENITOURINARY DISEASE:

- a. Urinary Tract Infections _____
- b. Blood in urine _____
- c. Protein in urine _____
- d. Passage of kidney stones _____

C5. GASTROINTESTINAL DISEASE:

- a. Gastroenteritis (stomach flu, food poisoning) _____
- b. Gastrointestinal Ulcer _____
- c. Gastrointestinal Bleeding _____

C6. In the past year, has a doctor or healthcare professional told you that (name of participant) has hypertension (high blood pressure) or that (name of participant) should take medicine to lower blood pressure?

- Yes
- No
- Don't know

a. What is the status of (name of participant's) high blood pressure (i.e., hypertension)?

- Taking medicine but BP still high (Continued problem)
- No longer has high blood pressure (Resolved problem)
- Taking medicine and BP no longer high (Controlled w/ meds)

b. Was the hypertension diagnosed within the past year?

- Yes
- No
- Don't know

C7. In the past year, has a doctor or healthcare professional told you that (name of participant) has hepatitis?

- Yes
- No
- Don't know

a. Which of the following types of hepatitis does (name of participant) have?

- Type A _____
- Type B _____
- Type C _____
- Other type _____

b. Was the hepatitis diagnosed within the past year?

- Yes
- No
- Don't know

C8. In the past year, has a doctor or healthcare professional told you that (name of participant) has any other infection(s)?

- Yes (Complete MAT)
 No
 Don't know

Specify: _____

a. Was the infection diagnosed within the past year?

- Yes
 No
 Don't know

Please indicate whether (name of participant) had or has developed any of the following problems in the past year.

(Please select "Yes", "No" or "Don't Know" for EACH of the following.)

C9. CANCER:

- a. Leukemia _____
b. Lymphoma _____
c. Bone Cancer _____
d. Liver Cancer _____
e. Skin Cancer _____
f. Soft Tissue Sarcoma _____
g. Other _____

C10. NEUROPSYCHIATRIC DISEASE:

- a. Attention Deficit Disorder (ADD) _____
b. Attention Deficit Hyperactivity Disorder (ADHD) _____
c. Depression _____
d. Learning Disability other than ADD or ADHD _____
e. Anxiety Disorder _____
f. Other _____

C11. NEUROLOGICAL:

- a. Seizures/Convulsions _____

C12. HEARING:

- b. Hearing Problems _____

SECTION D: ORTHOPEDIC HISTORY

The next set of questions asks about any orthopedic injuries the participant may currently have or that the participant has had in the past year. Orthopedic injuries are injuries to the bones.

D1. In the past year, has a doctor or any other health professional told you that (name of participant) has had any broken bones?

- Yes No Don't know

a. Please indicate which of the following bones (name of participant) has broken.

(Please select "Yes", "No" or "Don't Know" for EACH of the following.)

1. Back _____
2. Shoulder _____
3. Arm/Elbow _____
4. Wrist/Hand _____
5. Hip _____
6. Knee _____
7. Ankle _____

- 9. Leg _____
- 10. Fingers _____
- 11. Toes _____
- 12. Ribs _____
- 13. Collar Bone _____

D2. Does (name of participant) have any bone disease in the hips?

- Yes
- No
- Don't know

a. Was the bone disease diagnosed within the past year?

- Yes
- No
- Don't know

SECTION F: HEALTHCARE UTILIZATION

F1. In the past year, has (name of participant) been hospitalized (apart from when he or she was born)? Do not include overnight stays in the emergency room.

- Yes
- No
- Don't know

a. How many different times was (name of participant) hospitalized in the past year?

(times)

SECTION G: HEALTH INSURANCE

These questions ask about the participant's health care coverage.

G1. Does (name of participant) currently have any kind of health insurance or health care coverage? This includes both private and public insurance programs (e.g., Medicaid, SCHIP or MCHIP), dental insurance, and programs that help pay for medications.

- Yes
- No

G1a. How long has it been since (name of participant) last had ANY health insurance or coverage?

- 6 months or less
- More than 6 months, but no more than 1 year ago
- More than 1 year, but no more than 3 years ago
- More than 3 years
- Never had health insurance or coverage
- Don't know

G1b. In the past year, was there any time when (name of participant) was not covered by ANY health insurance or coverage?

- Yes
- No

G1c. In the past year, about how long was (name of participant) without ANY health insurance or coverage?

()

G1d. In the past year, was (name of participant) not covered by ANY insurance or coverage?

- Yes
 No

INSTRUCTIONS: ASK QUESTIONS G2 - G15. IF THE RESPONSE IS YES, SELECT "1" AND ASK QUESTION "A" (FAR RIGHT COLUMN) UNLESS THE BOX IS SHADED.

Does (name of participant) currently have... A. Do you or your family members pay for any of the insurance premium?

G2. *CALIFORNIA ONLY:

Medi-CAL? _____

G3. *MARYLAND ONLY:

Medical Assistance?

G4. ALL STATES EXCEPT CALIFORNIA and MARYLAND: Medicaid? _____

G5. Private Health Insurance plan from employer or workplace? _____

G6. Private Health Insurance plan purchased directly? _____

G7. Private Health Insurance plan through a state or local government program or community program? _____

G8. CHIP (Children's Health Insurance Program)? _____

G9. Military Health Care/VA? _____

G10. CHAMPUS or other veteran's health insurance? _____

G11. Student Health Coverage? _____

G12. State-Sponsored Health Plan? _____

G13. Dental Insurance? _____

G14. Vision Insurance? _____

G15. Other types of health insurance? _____

G16. Do any of these plans help pay for prescriptions/medications?

- Yes
 No
 Not applicable / No Insurance

G17. In the past year, has (name of participant) been without needed prescription medication due to cost?

- Yes
 No
 Not applicable / No Insurance
 Don't know

G18. Does the participant's health insurance plan(s) help pay for both doctor visits and hospital stays?

- Yes
 No
 Don't know

G19. In the past year, have you had difficulty filing insurance claims and/or getting reimbursed for medical care?

- Yes
- No
- Did not file any claims / No insurance
- Don't know

G20. In the past year, how much of a problem, if any, was it to get care for (name of participant) that you or a doctor believed necessary?

- A big problem
- A small problem
- No problem
- My child had not visits in the last year
- Don't know

TO BE COMPLETED BY CLINICAL SITE:

Date: _____ INITIALS: _____
ADMINISTRATION: _____ Was the date listed on DECEASE DONOR LIST CONFIRMED by site: _____

