

Welcome to CKiD!

Dear CKiD Participants and Families,

Welcome to this very important research study of children with chronic kidney disease (CKD). We hope that your experience with your CKiD visits has been good so far. We also hope that the results learned have helped with your child's understanding of and coping with their kidney disease. What we learn through CKiD will also help doctors. It will assist in their medical care of children with CKD in the future.

This is the first issue of the CKiD newsletter. This will be an annual resource for you and your families. We hope to give you updates on our study's progress. We will feature study results and other findings. We also hope to provide you with an added resource and support to help you care for your child. This newsletter has a nutrition section for you to enjoy. It offers healthy, kidney-friendly



CKiD Steering Committee, at the 2008 Training Meeting in New Orleans

recipes for the whole family. We would like to say thanks to your children, the participants who make CKiD possible! There is a page of the newsletter for them through the Kid's Corner. We hope that they enjoy the word-find puzzle. This will also add to their knowledge of kidney disease. They can also test their knowledge of their illness through the Kidney Quiz. You might enjoy taking the quiz yourself! Again, our thanks to all of you!

Sincerely,

Dr. Susan Furth & Dr. Brad Warady
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Recruitment Update

We are happy to announce that CKiD has met our initial goal. We enrolled 540 children across North America. This is one of the largest studies of children ever gathered in a study with mild to moderate chronic kidney disease. We are very proud! This is a great success for pediatric nephrol-

ogy research. Our next efforts will focus on close follow-up with the children. We hope you will complete CKiD return visits every year over the next 4 years.

Thanks to our study coordinators and principal investigators. We could not have done this without their tireless ef-

forts. Of course CKiD would never make it without you. Our study is all about your participation. Thank you for being a part of this study! We will to keep you informed about the results of the study over the next several years.

Study Results



What Have We Learned So Far?

Now that we enrolled 540 children with CKD into the CKiD study, we have met our initial goal. Next, we can start to analyze the large amount of data gathered. Here are some highlights of what we have learned so far:

Baseline Characteristics

The average age of children in the study is 11 years. There are more boys than girls in the group (62% boys). About two thirds of the kids have urologic problems causing their kidney disease, like reflux, obstruction, or dysplasia (kidneys did not develop normally). The rest of the group has a type of acquired glomerular kidney disease, like focal segmental glomerulosclerosis, or hemolytic uremic syndrome.

CKD Progression

We are happy to report so far that the average decline of kidney function seen in our study participants is very slow, about 1% per year. This is especially true in kids who have urological disease. Your continued involvement in CKiD is crucial to help us find out which risk factors cause kidney disease to progress faster in some children and slower in others. Answering this question will be our major goal over the next few years.

Anemia

Anemia is a common complication of CKD. We learned that around 1/3 of children enrolled in CKiD are anemic. Many also have iron deficiency, which can cause anemia. It is important for you and your doctor to know if your child is anemic. You also need to know if your child has adequate iron stores. Check

with your doctor to see if your child is anemic. If so, your child may need iron supplements or other medicine to increase their red blood cell count.

Blood Pressure

We have learned that many children in CKiD have high blood pressure at study visits. This is true even in children with who are taking blood pressure medicines. It is important for you to know what the blood pressure goals are for your child. Some kids who have a normal blood pressure during the clinic visit may have high blood pressure at other times in the day. You may want to discuss with your doctor if you should consider measuring many blood pressures over the day using an ABPM (ambulatory blood pressure monitor).

Recipe File

Kidney-Friendly Turkey Fajitas with Pico de Gallo



Ingredients:

1 lb boneless turkey breast
 1/4 teaspoon pepper
 2 cloves garlic, minced
 1 tsp chili powder
 2 tablespoons lime juice
 3 tablespoons chopped cilantro
 1 tablespoon oil
 1 cup chopped tomato
 1 tablespoon chopped red onion
 10 7-inch corn tortillas
 3 cups shredded lettuce
 1/2 cup light sour cream

Directions:

Sprinkle turkey with pepper, 1 clove minced garlic, chili powder, lime juice, 1 tablespoon cilantro, and oil. Turn to coat. Cover and marinate in refrigerator for at least three hours.

To make Pico de Gallo, combine tomato, 2 table spoons cilantro, onion, and 1 clove garlic in small bowl. Let stand one hour.

Broil turkey 6 inches from heat for 10 minutes each side. Cut into strips. While turkey cooks, wrap tortillas in aluminum foil and warm in oven at 300 degrees for 7-8 minutes. To serve, wrap turkey, pico de gallo, lettuce, and sour cream in warm tortillas. Serves ~ 10.

Nutrition Information: Calories 208, Carbohydrates 19, protein 13, fat 9, sodium 192, potassium 204, phosphorus 129.

Kid's Corner



Kidney Word Find

Can you find all of these words in the puzzle? Words can be spelled forwards, backwards, or diagonally.

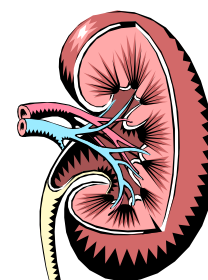
- Anemia
- Bone
- Calcitriol
- CKID
- EPO
- GFR
- Hypertension
- Iohexol
- Kidney
- Phosphorus
- Potassium
- Protein
- Sodium

N	O	I	S	N	E	T	R	E	P	Y	H
I	C	L	U	O	B	P	O	C	H	S	A
E	A	M	R	Y	D	J	K	X	O	V	R
T	L	A	N	E	M	I	A	T	S	I	F
O	C	Z	E	N	D	A	U	Q	P	S	E
R	I	G	T	D	U	O	C	M	H	P	A
P	T	M	U	I	S	S	A	T	O	P	K
O	R	S	C	K	F	B	N	H	R	F	G
R	I	O	H	E	X	O	L	E	U	G	A
F	O	Y	B	R	I	N	P	B	S	L	G
I	L	S	S	T	A	E	H	N	F	Y	X

QUIZ: How Much Do You Know About Your Kidneys?

How much do you know about your kidneys and Chronic Kidney Disease (CKD)? Take this quiz and find out! Turn to page 4 for the answers.

1. Which of the following are important jobs of your kidneys?
 - A. To keep your blood pressure normal
 - B. To clean and filter your blood
 - C. To support healthy bones
 - D. All of the above
2. T/F: Children with kidney problems are at a higher risk for heart disease when they are adults than other children.
3. Anemia is a frequent complication of CKD. What is anemia?
 - A. Low levels of an oxygen-transporting protein that lives in red blood cells
 - B. Too many white blood cells
 - C. Low blood pressure
4. T/F: Calcium and vitamin D are both important for building strong, healthy bones.
5. Usually a baby is born with how many kidneys?
 - A. 0
 - B. 1
 - C. 2
 - D. 3
6. Kids with CKD sometimes must limit phosphorus intake in their diet. Which of the following foods have the highest amount of phosphorus?
 - A. Potato chips
 - B. Low-fat yogurt
 - C. Apple juice
 - D. Bananas
7. T/F: Kids with CKD often develop low blood pressure.
8. If your doctor prescribes you a phosphate binder, when should you take it?
 - A. First thing in the morning
 - B. With meals
 - C. At night before you go to bed
 - D. When you remember
9. T/F: Kids with CKD are usually taller than other kids their age.
10. Who can get kidney disease?
 - A. Children
 - B. Teenagers
 - C. Adults
 - D. All of the above



26 million Americans have CKD, and another 20 million are at increased risk.



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What is CKiD?

The Chronic Kidney Disease in Children Study (CKiD) is an important national research study of children, 1 to 16 years, who have impaired kidney function. This study is funded by the National Institutes of Health: NIDDK, NINDS, NICHD, and NHLBI. Participants and their parents or guardians will attend 2 study visits in the first year, and annual visits thereafter for up to 8 years. The CKiD study will:

- Provide an accurate measure of your child's kidney function (glomerular filtration rate, GFR),
- Track your child's behavior and abilities to learn and think,
- Monitor your child's growth,
- Evaluate your child's heart and blood vessels and discuss risk factors for future heart disease, and
- Review your concerns about your child's social, physical, and emotional well-being.

Answers (from page 3)

N	O	I	S	N	E	T	R	E	P	Y	H
I	C	L	U	O	B	P	O	C	H	S	A
E	A	M	R	Y	D	J	K	X	O	V	R
T	L	A	N	E	M	I	A	T	S	I	F
O	C	Z	E	N	D	A	U	Q	P	S	E
R	I	G	T	D	U	O	C	M	H	P	A
P	T	M	U	I	S	S	A	T	O	P	K
O	R	S	C	K	F	B	N	H	R	F	G
R	I	O	H	E	X	O	L	E	U	G	A
F	O	Y	B	R	I	N	P	B	S	L	G
I	L	S	S	T	A	E	H	N	F	Y	X

QUIZ ANSWERS:

1. D. Your kidneys filter your blood of toxins, control your blood pressure, and make important hormones like vitamin D for strong bones and erythropoietin (or EPO) to help make red blood cells.
2. True. Young adults with CKD have much higher rates of cardiovascular disease (stroke, heart attack) compared to the normal population. It is important to monitor and modify heart disease risk factors (such as stop smoking, maintain a healthy body weight, exercise, and lower cholesterol) as children grow into young adults.
3. A. Anemia occurs when you have lower levels than normal of hemoglobin. Hemoglobin is a molecule inside red blood cells that carries oxygen to your tissues. People with anemia may feel weak or tired.
4. True. Your kidneys control the balance of calcium in your body. They also make activated vitamin D. Both calcium and vitamin D are important for strong and healthy bones.
5. C. Each person has two kidneys, though you can survive with only one (which is why many people can donate a kidney to somebody that needs one).
6. B. High levels of phosphorus are found in dairy products, dark soda, chocolate, and some meats/fish.
7. False. Kids with CKD may develop *high* blood pressure, also known as hypertension.
8. B. Phosphate binders should be taken *with* meals. This is so that the medicine can bind with the phosphorus in foods and prevent their absorption into the bloodstream.
9. False. Kids with CKD are often shorter than other kids their age. It is important for kids with CKD to maintain balanced diets with enough calories and protein to maximize their growth.
10. D. Anyone can get kidney disease at any age. When children get kidney disease it is often due to underlying urological disease, inherited causes, or infections. Older adults are more likely to get kidney disease from hypertension or diabetes.

We're on the web!
<http://www.statepi.jhsph.edu/ckid>