

What we have learned from CKiD so far:

- 14% of CKiD participants have blood pressure that is too high
⇒ Ask your doctor if your blood pressure is well controlled
- Almost 40% of CKiD participants are anemic
⇒ Ask your doctor about your red blood cell count
- Over 75% of CKiD participants have high levels of protein in their urine
⇒ Ask your doctor about protein in your urine and whether you should be on a medicine, like an ACE inhibitor or an ARB to decrease the protein

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Welcome to CKiD!

Dear CKiD Participants and Families,

We are glad that you are a part of this very important research study of children with chronic kidney disease (CKD). We hope that your experience with CKiD visits has been good so far. We also hope that the information collected by CKiD and shared with you has helped with your understanding of and coping with kidney disease. What we learn through CKiD will also help doctors. It will assist in their medical care of children with CKD now and in the future.

This is the second annual issue of the CKiD newsletter and we hope you enjoy it! We recently had our annual meeting and we're excited about all the progress CKiD has made. Check out the Study Update below for details!

Inside you will find an interview with the mother of one of our participants discussing the



CKiD Investigators, Study Coordinators, and Data Analysis and Laboratory Personnel at the 2009 Training Meeting in Las Vegas

CKiD experience. We have also found you another kidney friendly recipe for the whole family to enjoy!

We would like to say a special thank you to all of the participants who make CKiD possible! There is a page of the newsletter for them titled the Kid's Corner. We hope that they enjoy the word-scramble. They can also test their problem solving skills by making their way through the K maze.

Again, our thanks to all of

Sincerely,

Dr. Susan Furth & Dr. Brad Warady
Principal Investigators, East Coast and Mid-West Clinical Coordinating Center

Dr. Alvaro Muñoz and Dr. George Schwartz
Principal Investigators, Data Coordinating Center and Central Laboratory

Dr. Marva Moxey-Mims
National Institute of Diabetes and Digestive and Kidney Diseases

Study Update

In the past year CKiD has undergone some exciting changes! In February 2008 we met our initial recruitment goal of 540 participants and closed general enrollment. In order to make sure our study population was representative of the wider CKD population, we kept enrollment open for African American participants for an additional 12 months. By April 1, 2009 the CKiD Study had

met its additional goals and enrollment was officially closed. As of July 1, 2009 594 patients have enrolled into CKiD and 576 participants have completed at least one study visit. We are looking forward to following up with all of our current participants over the next several years!

We have been able to use information gained through study visits to develop an equation using blood tests to more pre-

cisely assess a patient's kidney function. We have also been able to reduce the number of blood draws associated with the iohexol GFR tests at your fifth visit and beyond.

Since our last newsletter, several new scholarly articles have been published using data collected in the CKiD Study. As always you can find links to all of these articles on Family Corner section of the CKiD website: <http://statepi.jhsph.edu/>

Participant Spotlight

An Interview with the mother of a CKiD participant



Q: How has your experience with CKiD been so far?

A: We have really enjoyed our time with CKiD. It's wonderful that we are able to do the visits in the PCRU (Pediatric Clinical Research Unit), which has a very positive and fun atmosphere for my son, and makes it less intimidating for him. We've really enjoyed getting to know all of the different people involved, and appreciate how accommodating and flexible everybody is with our schedules.

Q: What do you think is the most positive effect CKiD has had on your lives?

A: As a parent of a child with chronic kidney disease, we think that his medical care really benefits from knowing what his exact GFR is, and we appreciate that we, the parents, are informed as well as his primary nephrologist. We appreciate that he is getting such a comprehensive work-up on so many different levels, and also really like the detailed neurocognitive and behavioral testing, which we are also informed of. We are also very glad to do our part and hope that our involvement will benefit future children and families of children with chronic kidney disease.

Q: What advice would you offer to other parents of children with chronic kidney disease who are considering joining CKiD?

A: Just go in with an open mind, particularly if you have a very young child, and know that it's okay and to be expected if everything does not go exactly according to schedule. People are flexible and willing to work with you, but it is important for everybody to communicate well with each other. I also think that the visit is a lot less painful for your child than you might initially think. The roughest part is at the beginning when you are trying to get an IV, but these nurses are trained at getting IV's in small children and do it every day. The rest of the day really is pretty easy, you just have some questions and forms to go through, which you have plenty of time to do while you are waiting for the last couple of blood draws. He has a pretty good time in the afternoon playing with all of the toys here in the PCRU and watching movies.

Recipe File

Homemade Low Sodium Chicken Nuggets with Honey Mustard Dip



Ingredients:

- 1 tablespoon mustard
- 1/2 cup mayonnaise
- 1/3 cup honey
- 2 teaspoons Worcestershire sauce
- 1 egg,
- 2 tablespoons liquid non-dairy creamer
- 3 cups finely crushed low sodium cornflakes
- 1 pound boneless chicken breast, cut into 36 bite-sized pieces
- nonstick cooking spray



Directions:

1. Stir mustard, mayonnaise, honey and Worcestershire sauce together in a small bowl. Chill sauce until nuggets are cooked, then serve as a dipping sauce.
2. Preheat oven to 400° F.
3. Beat egg and combine egg with nondairy creamer in a small bowl. Crush cornflakes and pour crumbs into a large zip-lock bag.
4. Dip chicken pieces in egg mixture then shake in zip-lock bag to coat with cornflake crumbs.
5. Bake nuggets on a baking sheet sprayed with nonstick cooking spray for 15 minutes or until done.

• **Serving Size: 6 Nuggets and 2 Tbs Dip, Serves ~ 6.**

• **Nutrition Information:** Calories: 350, Protein: 18 g, Carbohydrate: 26g, Fat: 18 g, Cholesterol: 96 mg, Sodium: 232 mg, Potassium: 184 mg, Phosphorus: 152 mg, Calcium: 14 mg, Fiber: 0.4 g

Kid's Corner



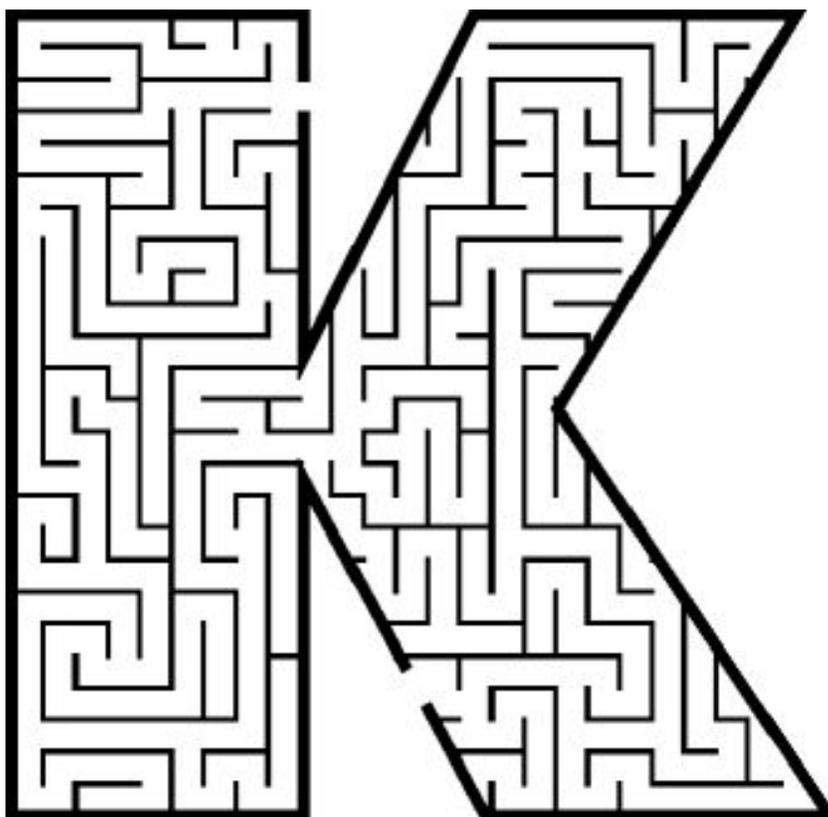
Kidney Word Scramble!

Can you unscramble the words below?

- | | | |
|---------------------|--------------------------|------------------------|
| 1. irepotn
----- | 5. prytneisohne
----- | 9. ialcucm
----- |
| 2. oben
----- | 6. hopshporus
----- | 10. opsitumas
----- |
| 3. oelixho
----- | 7. idekyn
----- | 11. naemai
----- |
| 4. ritlfe
----- | 8. ecainrinte
----- | 12. msudio
----- |

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

Puzzle: Can you navigate your way through the K maze?





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Recently Published CKiD Articles:

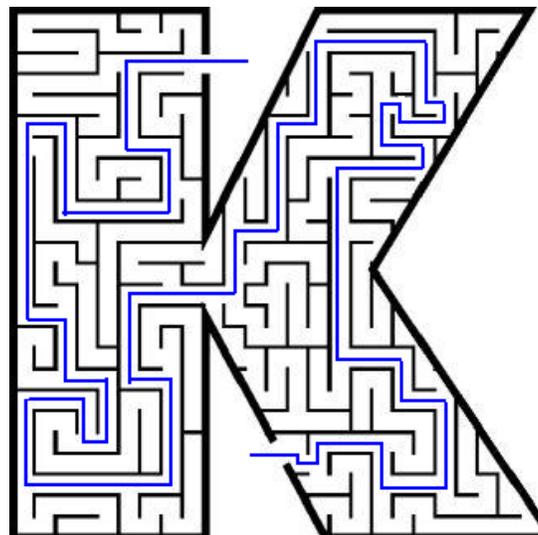
- **Schwartz GJ, Kwong T, Erway B, Warady B, Sokoll L, Dharnidharka V, Furth S, Muñoz A.** Validation of creatinine assays utilizing HPLC and IDMS traceable standards in sera of children. *Pediatr Nephrol* 2009;24(1): 113-119.
⇒ Compared the serum creatinine values of CKiD samples using two different tests and found them comparable in accuracy.
- **Schwartz GJ, Muñoz A, Schneider MF, Mak RH, Kaskel F, Warady BA, Furth SL.** New equations to estimate GFR in children with CKD. *J Am Soc Nephrol* 2009;20(3): 629-637.
⇒ Describes how the researchers used the results from CKiD to create a newer and more accurate estimating equation for GFR.
- **Fadowski JJ, Pierce CB, Cole SR, Moxley-Mims M, Warady BA, Furth SL.** Hemoglobin decline in children with chronic kidney disease: baseline results from the chronic kidney disease in children prospective cohort study. *Clin J Am Soc Nephrol* 2008;3(2): 457-462.
⇒ The authors found a linear decline in hemoglobin in people with a iohexol-determined GFR of 43 ml/min per 1.73 m², independent of age, race, gender and underlying diagnosis.
- **Flynn JT, Mitsnefes M, Pierce C, Cole SR, Parekh RS, Furth SL, Warady BA.** Blood pressure in children with chronic kidney disease: a report from the Chronic Kidney Disease in Children study. *Hypertension* 2008;52(4): 631-637.
⇒ The authors found that for systolic BP 14% of participants were hypertensive and 11% were pre-hypertensive. For diastolic BP 14% were hypertensive and 9% were pre-hypertensive.

[More articles will be going to press soon, check the website regularly for updates!](#)

Word Scramble

Answers (from page 3)

- | | | |
|------------|-----------------|---------------|
| 1. Calcium | 5. Hypertension | 9. Calcium |
| 2. Bone | 6. Phosphorus | 10. Potassium |
| 3. Iohexol | 7. Kidney | 11. Anemia |
| 4. Filter | 8. Creatinine | 12. Sodium |



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