



Newsletter

Volume I, Issue 8

Fall 2017

Celebrations, and Thank You!

Since 2005, over 900 children and families have been a part of the CKiD study family. Your contributions have helped make the CKiD study known around the world as one of the best kidney studies ever. We thank you for your dedication and continued participation in this important study. Many of you have been a part of CKiD for 5 – 11 years now! Congratulations for reaching these awesome milestones! We appreciate you and value your continued participation.

We are also excited to announce that our doors are open for some new families to join the CKiD study. Enrollment is now open and we are expecting 190 new faces to become a part of our CKiD family. As of November, 86 new families have already agreed to join us.

During this period of enrollment, we are looking for children who have only had kidney problems for less than 5 years. This is a little different than when we enrolled children previously. Children joining the study before this year, had kidney problems for almost 8 years before they entered the study. Our new recruits will help provide us with



information about what life is like closer to the time that kidney problems begin. We wish to give a warm welcome to all the children and families who are new to the CKiD study, in addition to giving special thanks to our families who have been with us through the years. It is our pleasure to learn from you as we watch you grow. You are truly making a difference in the lives of other children with kidney problems today and in the years to come.

Inside This Issue:

Future Plans	2
Recipe File	3
Recent Study Advancement	4
Answers to Kids' Corner	4
Kids' Corner Insert	



Did You Know?

- Time spent participating in the CKiD study qualifies as volunteer hours. If you need volunteer hours just ask your study coordinator for details.
- The CKiD study has a website that families can use to access past newsletters, general study information, and publications. Check out the CKiD Family Corner: <https://statepi.jhsph.edu/ckid/family.html>
- Thanks to all of your help, there have been over 4,771 CKiD study visits.

Looking Towards the Future

CKiD has been a terrific study going for 14 years! As we plan about what the future years will bring to CKiD, we are continuously working to make sure that the study is staying up to date. Here is a sneak peek at some of the new elements which may be added to the CKiD Study in the near future.



Activity Monitor – (ActiGraph)

Currently during the CKiD visits, we ask you to complete a form relating how physically active you are in a typical week. Technology has now made it possible to go a step further and actually measure your activity with an ActiGraph monitor. The monitor is worn on the wrist and has a digital watch display. The monitor is worn for several days after a clinic visit and is then mailed back to us.

We know that staying physically active is important for your health. This is a way we can actually measure how active you are and study exactly how activity levels relate to your kidney health.

Some CKiD participants are testing out the monitors now and if the information gathered looks promising, you may see this monitor at an upcoming visit.

Exercises to See How You Think and Learn – NIH Toolbox

Every other year during your first 7 years in CKiD, you undergo some testing to show how you think and learn. This is typically done with a psychologist or someone trained to give standardized tests. Through the years we have changed and updated the tests. In line with keeping up with advances in technology, we are trialing the use of something called the NIH Toolbox App. This app makes it possible to complete tests that show how you think and learn on an iPad. It can be used for children as young as 3 years old. Now, we are not throwing out all of the paper and pencil tests, but this will certainly help shorten the overall time it takes to complete the tests and may actually be more fun.



Study Visits For CKiD Participants After Kidney Transplant or Starting Dialysis

Currently if a participant in the CKiD study has a kidney transplant or starts on dialysis, they can only stay in the study by participating in an annual interview (called the PIP or Continuing Review) without any study visits. As we plan for the future, we are considering allowing these participants to come back and complete study visits. These visits would be similar to the study visits you have taken part in, but will also include specific tests and questions geared towards their kidney health on dialysis or with a transplant.



Home Blood Pressure (Home BP)

Your heart health and kidney health are closely related. Keeping your blood pressure at a good level is not only beneficial to your heart, but is very important for the health of your kidney. High blood pressure can harm the delicate blood vessels of the kidney and overtime cause permanent kidney damage. We currently use a 24 hour monitor in the CKiD study to check how your blood pressure levels are during sleep and while you are awake. In order to look at your BP more closely, we are considering sending a different monitor home with you to periodically check your BP. The BP monitor called the QardioArm, works using blue tooth technology along with an app loaded on your phone or tablet. With the touch of a finger, your blood pressure is taken and recorded. No pencil or pen needed! Blood pressure measurement will be simple to do and easy to send the results to your physician.





Kidney Friendly Recipes



Eating well and exercising are extremely important for keeping your kidneys and the rest of your body healthy. Here are some kidney friendly recipes to try, but since everyone is different, make sure to always follow your kidney doctor's or nutritionist's advice.

Homemade Baked Stuffing

Serves 8 • Serving size: ½ cup

Ingredients:

- 1/4 cup Unsalted Butter
- 1/4 cup Onion
- Diced 1/4 cup Celery
- 8 slices White Bread cubed and dried out
- 1/2 teaspoon Black Pepper
- 2 teaspoon Poultry Seasoning
- 1/2 teaspoon Dried Rosemary
- 1/2 teaspoon Dried Sage
- 1/2 cup liquid Egg Substitute
- 1/4 cup Unsalted Chicken Stock

Directions:

1. Preheat oven to 350 F.
2. Melt butter in nonstick frying pan. Sauté onion and celery, until vegetables are soft.
3. Remove from heat.
4. Toss in cubed bread and seasonings.
5. Mix egg product and stock.
6. Pour into bread mixture and mix lightly.
7. Place stuffing in a greased baking dish.
8. Cover with foil, and bake for 30-40 minutes.
9. Remove foil, and bake an additional 10 minutes.

Calories: 131 Sodium (mg): 167 Potassium (mg): 69 Phosphorus (mg): 30

CMKC Department of Nutrition Services, R Finn, 10/15/14

Good Gravy

Serves 8 • Serving size: ¼ cup

Ingredients:

- 4 tablespoons unsalted butter
- 4 tablespoons all-purpose flour
- 2 cups no-salt chicken stock
- 1/4 teaspoon black pepper
- 1/4 teaspoon sugar

Directions:

1. In a medium saucepan melt butter.
2. Stir in flour and whisk for 1 minute.
3. Gradually add the stock, whisk continuously until gravy comes to a boil.
4. Reduce heat and simmer for 10 minutes until thickened.
5. Stir in pepper and sugar.
6. 1/8 teaspoon of dried herbs may be added for additional flavor: Rosemary, thyme, rubbed sage. If gravy thickens too much, thin with water to desired consistency.

Calories: 75 Sodium (mg): 33 Potassium (mg): 33 Phosphorus (mg): 24

CMKC Department of Nutrition Services, R Finn, 10/15/14

Mashed Potatoes (reduced potassium)

Servings: 4 • Serving size: ½ cup

Ingredients:

- 2 large potatoes, peeled and leached or use the double-boiling cook method (see notes)
- 1/2 teaspoon garlic powder
- 1/4 cup heavy whipping cream
- 1/4 cup unsalted butter
- 1/2 teaspoon black pepper

Notes on leaching potatoes: Peel and slice the potatoes into small pieces. Soak for at least 2-4 hours. Drain, then cover potatoes with water and bring to boil. Cook until potatoes are soft. Continue with the remaining directions in the recipe. Double-boiling cook method: Peel and dice potatoes. Place in a large pot of water and bring to a boil. Drain and boil again, cooking for 10 minutes or until potatoes are soft. Then drain and continue with the remaining directions in the recipe.

Directions

1. Drain potatoes.
2. Mash with a fork/potato masher or mixer.
3. Add cream, butter and pepper.
4. Mix until smooth.

Calories: 222 Sodium (mg): 11 Potassium (mg): 278 Phosphorus (mg): 45

CMKC Department of Nutrition Services, R Finn, 10/15/14

Yummy Pumpkin Cheesecake

Serves 8 • Serving size: 1/8 of pie

Ingredients:

- 1 9" graham cracker pie crust
- 1 egg white
- 16 ounces cream cheese, softened to room temperature
- 1/2 cup sugar or 1/2 cup Splenda™
- 1 teaspoon vanilla extract
- 1/2 cup liquid egg substitute
- 1/2 cup pumpkin puree
- 2 teaspoons pumpkin pie spice
- 1 cup frozen dessert topping (Cool Whip™)

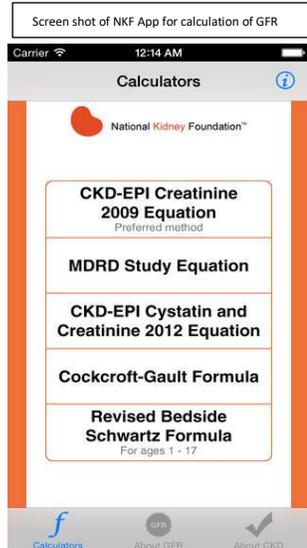
Directions:

1. Preheat oven to 350° Fahrenheit.
2. Brush graham cracker crust with egg white and bake for 5 minutes.
3. Remove from oven (this seals the crust).
4. In a food processor or mixer, combine cream cheese, sugar and vanilla. Beat until smooth and fluffy. Beat in egg substitute. Add pumpkin puree and pumpkin pie spice and blend until smooth.
5. Pour pumpkin mixture into pie shell and bake for 40-50 minutes, until center is almost set (it should be a little jiggly).
6. Cool pie to room temperature and then refrigerate.

Calories: 433 Sodium (mg): 392 Potassium (mg): 147 Phosphorus (mg): 93 Nutrition values reflect recipe made with sugar.

CMKC Department of Nutrition Services, R Finn, 10/15/14

Measuring How Well Your Kidney is Working (GFR)



In the CKiD study, many of you have participated in a test called the iohexol GFR (iGFR) test. GFR stands for glomerular filtration rate. GFR tells us about how well your kidney is filtering out waste products from your body. This is a reflection of how well your kidney is working. In the iGFR test, a small amount of iohexol is given through a needle stick. Iohexol is used because it is removed from the body by the kidney (and not the liver), and it is safe to give children with kidney problems. Blood samples are taken at 2 hours and 5 hours after the iohexol is given. We look at the blood samples to see how much iohexol is still in your system and make note of how much iohexol your kidney has removed or filtered out over time. The test takes 5 hours to complete, and involves several needle sticks.

The iGFR test information is very important to us. By studying the iGFR results, the CKiD study has developed a very simple way to quickly estimate (or give an approximation) of how well your kidney is working. Our estimate of kidney function (eGFR) is based on using your height and a lab test measuring the level of creatinine in your blood. These numbers are plugged into a simple mathematical formula to calculate your kidney function. We are excited to continue to perfect the formula by looking at our new and younger participants and their iGFR test results. The formula is not perfect for everyone, but it works very well for most children. Nephrologists around the country are now using the CKiD method to estimate kidney function. The National Kidney Foundation has even developed an app with the CKiD estimating formula (also known as the CKiD formula or the Revised Bedside Schwartz Formula). Other kidney function estimating formulas developed for adults are also included on the app. The formula most widely used for adults (18 years of age and older) is called CKD-Epi. So if you catch your nephrologist on their cell phone, they may be estimating your kidney function with the method that the CKiD study helped develop.

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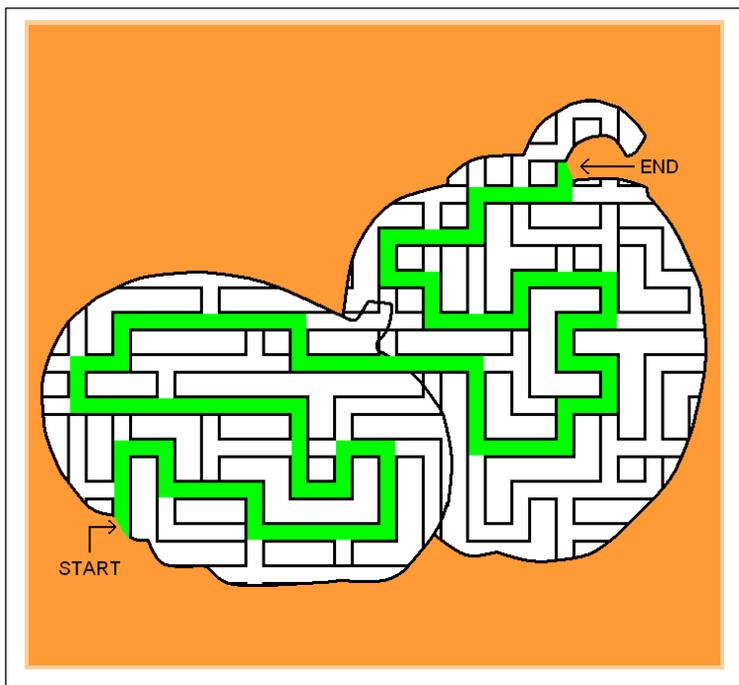
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We're on the web!
<https://statepi.jhsph.edu/ckid/family.html>



Name the Leaf animals: (Left to right and top to bottom)
 Squirrel, Donkey, Fox, Penguin, Mouse, Elephant, and Birds

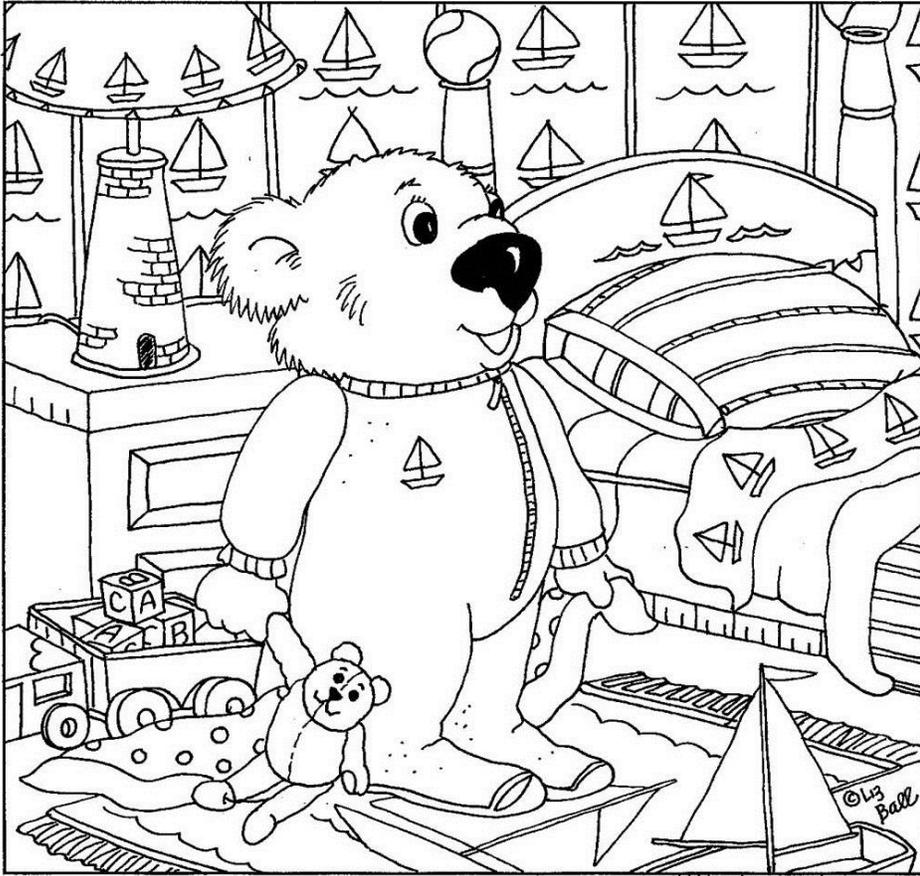




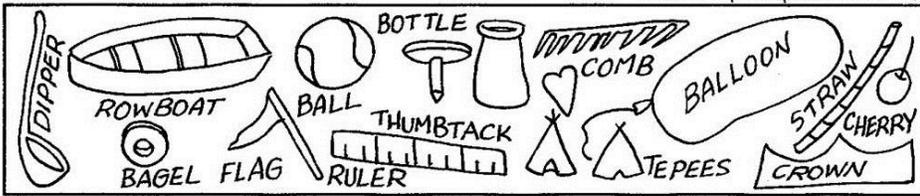
Kids' Corner!



Can you find the items at the bottom hidden in this picture?

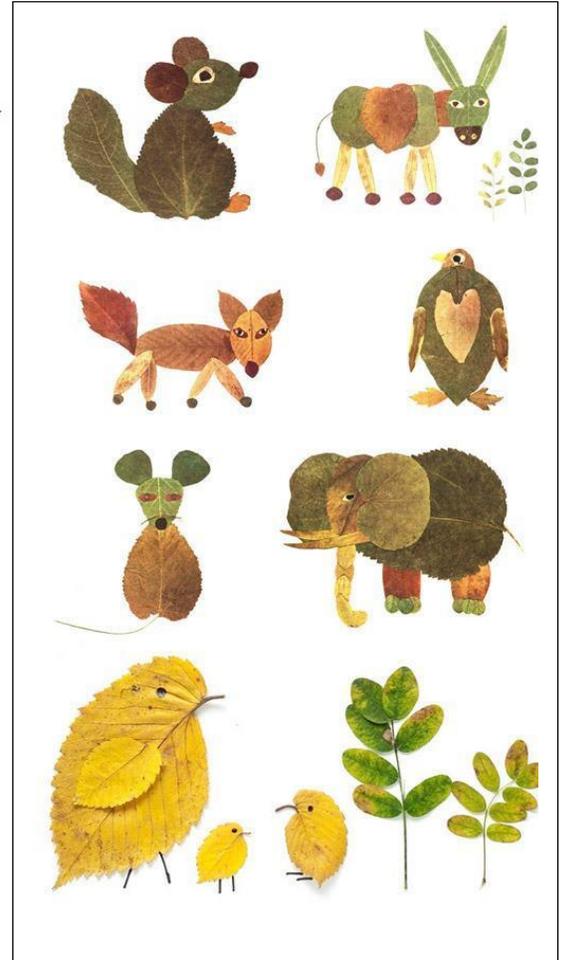


www.hiddenpicturepuzzles.com



Can you name the animals below?

Challenge: See what pictures you can create at home with leaves



Help Twiggy the caterpillar find the way through the pumpkin maze.

