

# CKiD Newsletter

Volume 1, Issue 9

Fall 2018

**CKiD has received continued funding! 20 TOTAL YEARS!**

**Thanks to you, it is the largest study of Chronic Kidney Disease in children and young adults IN THE WORLD!**



**THANK YOU**



Your participation in the CKiD study has resulted in a remarkable accomplishment – you are part of the largest study of Chronic Kidney Disease (CKD) in children and young adults ever! We will continue to obtain a lot of valuable information that is helping to answer important questions about how to improve the health of children and young adults with CKD. There have been over 1000 CKiD participants and each and every one of you have made an important contribution to the study!

**STUDY UPDATE:** The CKiD study has undergone some exciting changes! In 2016, we opened up enrollment again for younger participants and we have almost reached our goal of enrolling an additional 190 participants. In addition, in the past, if you had a kidney transplant or started dialysis, you were no longer eligible to continue with regular CKiD study visits. Now, we will start having regular study visits for interested participants who have had a kidney transplant or are on dialysis. These visits will include some tests that are not part of routine care and they will provide more information regarding your health.

To keep up with new technology, we have trialed 3 devices that will soon be used for all CKiD participants completing regular study visits:

- **The NIH toolbox** – a standardized iPad program used to show how you think and learn.
- **The QardioArm** – a Blood Pressure (BP) monitor that you take home. It uses blue tooth technology and it will take your BP periodically with the touch of a finger and an app loaded onto your phone or tablet.



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## Did You Know?

- If you are on dialysis or have had a transplant, talk to your nephrologist if you are interested in completing regular study visits including neurocognitive testing, echocardiograms, heart MRIs, and 24 hour blood pressure (BP) and activity monitoring. These visits will provide important new information that CKiD has not previously collected.
- 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 you for your help; there have been over 5,000 CKiD study visits.

# What have we learned so far from CKiD?



## Kidney Function

- The CKiD Study developed a simpler “bedside formula” to estimate glomerular filtration rate (GFR) in children with CKD (ages 1-16 years; GFR from 15-75 ml/min/1.73 m<sup>2</sup>). This formula is on an App that many doctors use today. Estimating the time until a child with CKD will halve their GFR (kidney function) or need dialysis or transplantation can be calculated at [www.ckdprognosis.com](http://www.ckdprognosis.com)
- Glomerular causes of CKD have Urine Protein/Creatinine Ratios (uPCR) on average 140% higher than Non-Glomerular causes of CKD.
- Race, lower GFR, & Glomerular causes of CKD can each impact the level of protein in the urine.



## Heart Health

- High blood pressure {or Hypertension (HTN)} is identified more often by the 24 hour ambulatory blood pressure monitor (ABPM) than by the BP (blood pressure) measured during a clinic visit.
- Of 366 CKiD participants with HTN, 38% had masked HTN. Masked HTN is a pattern of HTN in which HTN is not detected during the clinic BP, but detected only by ABPM.
- There is a strong association between HTN & Left Ventricular Hypertrophy (LVH). LVH is the enlargement and/or thickening of the walls of the heart’s main pumping chamber (left ventricle).
- Of 366 CKiD study participants with HTN:
  - 34% of participants with HTN had LVH
  - 20% of participants with masked HTN had LVH
- HTN is associated with a lower ability to think (IQ).
- African American children are at greater risk of HTN.
- A GFR of less than 30 ml/min/1.73 m<sup>2</sup> is shown to be linked to a greater risk of having increased lipid (*cholesterol, etc.*) levels in the blood.
- Increased levels of protein in the urine is shown to be linked to increased lipid levels in the blood.
- Of 340 participants, 45% had a low level of hemoglobin (anemia). 60% of those that had anemia were not yet receiving any therapy for anemia.
- African Americans with CKD have been shown to have lower hemoglobin levels and a higher rate of anemia than Caucasians, even though therapy was the same for both groups of participants.



## Growth, Cognition and Quality of Life

- Of 426 CKiD participants:
  - 17% were born with low birth weight (less than 5 pounds 8 ounces)
  - 14% were small for gestational age (birth weight below the 10<sup>th</sup> %ile)
  - 40% required admission to the neonatal intensive care immediately after birth
- Poor growth has been shown to negatively affect psychosocial (*personality*) development and quality of life in adults with CKD beginning in childhood.
- Children in the CKiD study consumed more sodium, phosphorus, protein, and calories than recommended.
- IQ, executive functions (EF), and academic achievement are all in the average range for CKiD participants as a group. EF are specific thinking skills that help people plan, organize and complete tasks. A higher percentage of kids with CKD are at risk for lower IQ, EF, and/or academic achievement than their peers who do not have CKD.
- In CKiD participants with mild-to-moderate CKD, the length of time of disease rather than estimated GFR was associated with impaired attention regulation (focus) and inhibitory control (resisting distractions, holding back a behavior/thought).
- Short height (less than 5th %ile for height) is found to be associated with poorer ratings of quality of life in the category of physical functioning (performing everyday tasks).



## Connect on Social Media



<https://www.childrensmercy.org/podcasts/?item=36670> Type this link into your browser to hear Dr. Warady talk about Lessons Learned in the CKiD study in the Children's Mercy Transformational Pediatrics Podcast.

**Facebook:** posts that you can copy and paste to your wall:

- Listen to @AngelicaHale! "Eat right, exercise, drink water and keep your kidneys healthy. Because whatever you're good at, there is only one you." #HeartYourKidneys <http://bit.ly/2kABohQ>
- Good health starts early, so kids listen up! Drink water instead of soda, exercise & tell mom to halt the salt! #HeartYourKidneys <http://bit.ly/2AAdvh7> (<http://bit.ly/2AAdvh7>)
- Did you know? Women may be more likely than men to develop kidney disease. #HeartYourkidneys <http://bit.ly/2kxAFOM>
- Kidneys are our body's little chemical factories and work 24/7 to sustain life. <http://bit.ly/2ju5Bgj> #HeartYourKidneys
- Facebook Frame for your profile pic: <https://www.facebook.com/profilepicframes> and look up "National Kidney Foundation" to find the Heart Your Kidneys profile frame.
- Ask your doctor a question, especially if you have high BP or diabetes: How are my kidneys, doc? <http://bit.ly/2km99m9> #HeartYourKidneys

**Twitter:** posts that you can copy and paste to your feed:

- Join @AngelicaHale and #HeartYourKidneys this month (and the other 11 months of the year)! <http://bit.ly/2AT59FC>

### Kids and Kidney Disease:

- What every child and teen should know about their kidneys. #HeartYourKidneys <http://bit.ly/2AAdvh7> [TWEET THIS]
- Kidney disease can affect anyone – from children to adults. #HeartYourKidneys <http://bit.ly/2AAdvh7> [TWEET THIS]
- Good health starts early, so kids listen up! Drink water instead of soda, exercise & tell mom to halt the salt! #HeartYourKidneys <http://bit.ly/2AAdvh7> [TWEET THIS]
- Children should learn about kidney health from an early age. But it's not something they'll learn in school. Test your child's knowledge with these tips! #HeartYourKidneys <http://bit.ly/2BeKqc7> [TWEET THIS]
- Kids: It's not hard to keep your kidneys healthy with a few easy steps. #HeartYourKidneys <http://bit.ly/2BeKqc7> [TWEET THIS]
- RT and share with a child or teen in your life. #HeartYourKidneys <http://bit.ly/2BeKqc7> [TWEET THIS]

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

# National Kidney News



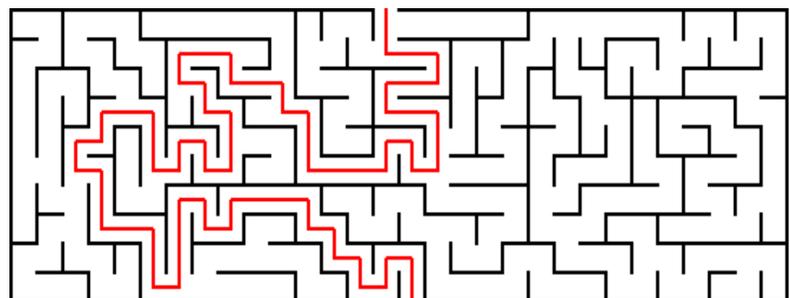
- March 8, 2018 was World Kidney Day
  - On March 8<sup>th</sup>, as night fell, iconic buildings and landmarks, throughout the U.S., turned Orange- the signature color for kidney disease. This included the Empire State Building!
- March is National Kidney Month
- In March 2018 –
  - The 5th Annual Kidney Patient Summit took place in Washington DC, where kidney advocates from across the country converged on Capitol Hill to urge their lawmakers to support legislative priorities that would improve the lives of millions of people with kidney disease.
  - The Summit gained more public attention at the outset this year with the help of our first-ever National Kidney Foundation (NKF) Kid Ambassador Angelica Hale, the 10 year-old singing Phenom and a kidney transplant recipient.
  - Angelica has taken her new role very seriously at the Summit, where she was interviewed by NBC, ABC, and FOX television affiliates in D.C.; led a Facebook Live Q&A with Congressman Bill Posey (FL) and Congresswoman Jaime Herrera-Beutler (WA); and performed a stellar rendition of "The Greatest Love of All" during the Tuesday evening Congressional Awards Reception chaired by former Secretary of Health and Human Services and Wisconsin Governor Tommy Thompson. Honored for their exemplary commitment to fighting kidney disease were Congressman G.K. Butterfield (NC), Congressman George Holding (NC), Congressman Markwayne Mullin (OK) and Congresswoman Linda Sanchez (CA).
- April is National Donate Life month
- April 23-27, 2018 was the **FIRST National Pediatric Transplant Week**

## Key to Word Search

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

## Key to True False Questions

1. False
2. True
3. False
4. True



# 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 dietitian's advice.



## Ice Cream in a Bag (Strawberry)

\*Makes: 1 bag \*Serving Size: 1 bag

### Ingredients:

- 1 Tbsp sugar
- ¼ tsp vanilla extract
- 1-2 Tbsp pureed strawberries or other renal-friendly fruit
- ½ cup soy milk
- ½ cup rock salt
- Ice cubes

### Directions:

1. Add sugar, vanilla, and fruit to a pint-sized Ziploc bag.
2. Seal bag tightly. Mix well by squeezing bag with fingers.
3. Open bag and add milk. Squeeze out extra air. Zip tightly and mix well.
4. Fill a gallon-sized bag halfway with ice cubes. Add rock salt.
5. Put pint-sized bag into gallon-sized bag. Seal well. Shake bag for 5-10 minutes or until liquid has changed to ice cream.

### Nutrition information (per serving):

135 calories; 4 g protein; 60 mg sodium; 65 mg phosphorus; 35 mg calcium

CMKC Department of Nutrition Services, Developed by Chef Educator R Finn, Analyzed by J. Tower RD 12/27/16

## Tortilla Garden Roll Ups

\*Makes: 4 roll ups \*Serving Size: 1 roll up

### Ingredients:

- 4 kidney friendly tortillas (uncooked or freshly made flour)
- 8 oz cream cheese
- ½ tsp garlic powder
- ½ tsp dried Italian seasoning
- ½ cup carrots, grated
- ½ cup cucumber, grated

### Directions:

1. Soften cream cheese. Mix in garlic powder and Italian seasoning.
2. Divide cream cheese filling among the tortillas.
3. Spread a thin layer of cream cheese mixture on each tortilla.
4. Add grated carrots and cucumbers.
5. Roll tortillas up like a jelly roll.
6. Cover. Refrigerate for at least 1 hour.

### Nutrition information (per serving):

295 calories; 6 g protein; 270 mg sodium; 210 mg potassium; 95 mg phosphorus, 65 mg calcium

CMKC Department of Nutrition Services, Chef Educator R Finn, 12/27/16, Analyzed by J. Tower, RD

## French Toast Sticks

\*Servings: 1 \*Serving size: 6 strips

### Ingredients:

- 2 egg whites
- 1 TBSP 2% milk
- ½ tsp cinnamon
- 1 tsp vanilla extract
- 2 slices white bread
- Maple syrup (optional)

### Directions:

1. Combine milk, egg whites, cinnamon, and vanilla extract in a bowl. Mix for 30 seconds.
2. Soak 1 slice of bread in mixture. Flip to soak the other side. Remove from liquid and place on a plate. Repeat 2<sup>nd</sup> slice.
3. Microwave for 1 minute.
4. Remove from microwave. Let cool for 15 seconds.
5. Cut each slice into 3 strips.
6. Add syrup, if desired.

### Nutrition information (per serving):

140 calories; 10 g protein; 265 mg sodium, 180 mg potassium; 55 mg phosphorus; 80 mg calcium.

CMKC Department of Nutrition Services, Chef Educator R Finn, 12/27/16, Analyzed by J. Tower, RD

## Queso Dip

\*Serves 8 • Serving size: ½ cup of sause

### Ingredients:

- ½ cup unsalted butter
- ½ cup cream cheese
- ½ cup Parmesan cheese, grated
- 1 tsp garlic powder
- ¾ cup unsweetened soy milk
- 2 Tbsp canned green chilies, chopped and drained
- 1 tsp ground cumin
- 1 tsp paprika
- Black pepper, to taste

### Directions:

1. Melt butter in medium sauce pan over medium heat.
2. Add cream cheese. Stir until smooth.
3. Add garlic powder, Parmesan cheese, soy milk, green chilies, cumin, and paprika. Stir until smooth. Do not overheat.
4. Season with black pepper.

### Nutrition information (per serving):

190 calories; 3 g protein, 165 mg sodium; 70 mg potassium; 65 mg phosphorus; 70 mg calcium.

CMKC Department of Nutrition Services, Chef Educator R Finn, 12/27/16, Analyzed by J. Tower, RD



# Kid's Corner!



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

## Word Search

GFR  
 PIP  
 CKID (twice)  
 HOME BP  
 KIDNEY  
 DIALYSIS  
 ACTIGRAPH  
 NIHTOOLBOX  
 TRANSPLANT  
 ECHOCARDIOGRAM



1. The NIH toolbox contains a hammer?
2. The Actigraph measures your activity?
3. If you had a kidney transplant, you will never be able to participate in regular study visits?
4. The CKiD study has taught us a lot already about kidney disease in children and young adults?

Help the water glass get to the kidney

