CKP Newsletter

Volume XIII, Issue I

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Greetings from the CKiD team! The CKiD study is now in its 20th year! Long term studies are very important. They are the only way to find out trends in chronic kidney disease (CKD), how well different treatments work over time, and best practices to improve patient care. Because of your continued participation in the CKiD study, you have helped achieve these goals!

The National Institutes of Health (NIH) – part of the U.S. government – has funded the CKiD study for 20 years, and recently allowed us to apply for another 5 years of funding. Therefore, it is possible that the CKiD study may be extended until 2028! This would allow us to continue to improve the care of children and young adults with kidney disease. Your nephrologist and/or research coordinator should be able to give you an update in the summer.

Highlights of the CKiD Study over the last 20 years:

- Developed new and improved ways to measure kidney function.
- Improved the prediction of how long it will take kidney function to get worse depending upon kidney diagnosis, age, blood pressure (BP), and blood and urine results.
- Increased knowledge of how genes can affect kidney disease.
- Improved treatment guidelines to slow down progression of kidney disease.
- Found that ultrasounds of the heart and blood vessels in the neck (carotid arteries) can help detect heart disease at an early stage.
- Found out how CKD can affect school performance, muscle strength, emotions, and behavior.
- Gained understanding about risks that can result in worsening of kidney disease and established guidelines to help reduce those risk factors.
- Learned more about how bones and minerals can be affected by CKD.

Did You Know?

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Parents/guardians can now take part in a CKiD sub-study! Parents/guardians of CKiD participants will be invited to complete an online survey. The survey will include short videos about research and genomics (the study of a person's genes) and will ask for the opinion of parents/guardians on potential harms and benefits of receiving genomic research results, especially results that are uncertain. Ask your nephrologist or research coordinator about participating in this important sub-study.

Candy for Patients with Kidney Disease

BETTER OPTIONS:			-	
Candy:	Calories:	Phosphorus:	Potassium:	Sodium:
Butterscotch (5 pieces)	112	1 mg	1 mg	12 mg
Candy Corn (1/4 cup)	182	3 mg	2 mg	106 mg
Chocolate Covered Mint (1 small)	45	6 mg	10 mg	20 mg
Choc. Marshmallow fudge (0.7 oz)	84	13 mg	28 mg	21 mg
Gum Drops (10 small)	135	0 mg	2 mg	15 mg
Hard Candy (1 oz)	106	1 mg	1 mg	11 mg
Jelly Beans (10 large)	103	1 mg	10 mg	7 mg
Lollipop (1)	22	0 mg	0 mg	2 mg
Marshmallows, Mini (1 cup)	146	4 mg	2 mg	22 mg
Peanut Brittle (1 oz)	128	31 mg	59 mg	128 mg
Skittles (2.3 oz package)	263	1 mg	3 mg	10 mg
Taffy (0.5 oz piece)	15	0 mg	1 mg	13 mg
OTHER OPTIONS:				
Candy:	Calories:	Phosphorus:	Potassium:	Sodium:
Almond Joy (1.7 oz)	241	69 mg	120 mg	72 mg
Baby Ruth (2.1 oz)	289	91 mg	238 mg	136 mg
Butterfinger (2.16 oz)	293	79 mg	230 mg	121 mg
Cherry Nibs (1 oz)	106	88 mg	18 mg	67 mg
Choc Chips, Semi-Sweet (1 cup)	1351	371 mg	1032 mg	371 mg
Chocolate Covered:				
Almonds (1 oz)	161	97 mg	155 mg	17 mg
Peanuts (10 pieces)	208	85 mg	201 mg	16 mg
Crunch, Nestle (1.4 oz)	209	81 mg	138 mg	53 mg
Fifth Avenue (2 oz)	197	86 mg	187 mg	66 mg
Kit Kat (1.5 oz bar)	219	73 mg	126 mg	32 mg
M & M's (1.69 oz package)	236	72 mg	128 mg	29 mg
M & M's – Peanut (1.74 oz package)	253	93 mg	169 mg	24 mg
Milky Way (2.15 oz bar)	258	98 mg	147 mg	146 mg
Peanut Butter Cups (2)	270	120 mg	176 mg	158 mg
Turtles, Demet's (0.6 oz piece)	82	33 mg	52 mg	16 mg
Twix, Caramel (2 pieces)	283	68 mg	115 mg	109 mg
Twix, Peanut Butter (2)	265	95 mg	178 mg	136 mg
Strawberry Twizzlers (2.5 oz)	263	220 mg	45 mg	197 mg



Remember, eating smaller portions can help with a craving.

Adapted from Bowe's and Church's Food Values, Pennington

Here is a comparison of Snickers:

	Calories:	Phosphorus:	Potassium:	Sodium:		
King Size (113 g)	541	170 mg	294 mg	336 mg		
Regular Bar (57 g)	273	86 mg	148 mg	123 mg		
Fun Size (15 g)	71	23 mg	39 mg	33 mg		
Miniature (10 g)	48	15 mg	26 mg	22 mg		



Department of Nutrition Services (816) 234-3468 1/8/18 LO

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More Information = More Control

The CKiD study can provide you with more information about your health.



CKiD performs tests that are not usually done as part of routine care.

Ask your research coordinator or CKiD nephrologist about your CKiD study results such as:

- Iohexol glomerular filtration rate (iGFR) or estimated GFR (eGFR) results that measure kidney function. Iohexol GFR is the gold standard, and the CKiD eGFR is the most accurate estimation of kidney function.
- 24-hour Blood Pressure Monitor (ABPM) and/or Home BP results. These BP measurements may show findings that are not detected during routine clinic visits.
- Central Labs some CKiD lab work is not routinely done at clinic visits and can provide more information about your health. Some of these samples are frozen and shipped in batches, so results are not immediately available. Some examples are lipids and vitamin D.
- Assessments that measure how you think and learn (cognition), as well as your behavior and how you feel.

You can share these results with your health care professional, school counselor, etc.

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We're on the web!

https://statepi.jhsph.edu /ckid/participants-andfamilies/ facebook

Join the CKiD Facebook group called "<u>CKiD Families</u>". This Facebook group is for CKiD participants and their families. Check with your coordinator about how to join. Goals of the CKiD Facebook group include:

- Provide an online community for CKiD participants and their families,
- Allow CKiD participants to connect with others involved in the study, and
- Share the scientific work that CKiD is doing as well as CKiD milestones in a way that is easy to access

CKiD Sites Across North America

