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# FOOD COST OF CLASSIC KETOGENIC DIET IN PATIENTS WITH GLUT1

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## Children's Mercy Kansas City, Kansas City, Missouri, USA

### Background

Glucose Transporter Deficiency Syndrome (GLUT1) is a rare genetic metabolic disorder characterized by deficiency of a protein that is required for glucose to cross the blood-brain barrier.<sup>1</sup> The current gold standard treatment for GLUT1 is the ketogenic diet (KD). The KD is carefully tailored to individual patients and involves purchasing specific foods unique to the family member on the KD. The foods and supplements required on the KD are currently an out of pocket expense for the majority of families (minimal insurance coverage). A review of literature indicated the average cost of the specialty foods and supplements to families is unknown. The purpose of this study was to determine the estimated monthly cost of KD ingredients of foods and supplement consumed by orally fed patients with GLUT1.

### Method

This study involved a retrospective chart review of patients seen in the Epilepsy Center at Children's Mercy Hospital (CMH).

#### Inclusion criteria:

- Diagnoses of GLUT1.
- Age between 4-24
- Orally fed
- Following classic KD

#### Chart review:

- Current calorie consumption of meals and snacks
- Current ratio of the KD
- Number of meals and snacks consumed by patient

#### Calculations:

- Quantity of ingredients purchased for each patient
- Averaged cost from local grocery stores in the Kansas City metropolitan area
- Cost per gram of ingredients consumed per week by patients
- Cost of groceries purchased per month for patient
- Compared age and gender to USDA food plans<sup>2</sup>
- Calculated cost of supplements patients consume per month

Table 1. Estimated Food Cost per Glut 1 Patient

Age	Gender	Ratio	Calories Per day	Meals Per day	Snacks Per day	Cost (\$) of ingredients meal/snack /week	Purchased cost (\$) groceries/month	Cost (\$) Calorie
4	M	2.5:1	1600	3	2	27.37	170.65	0.002
5	F	2.75:1	975	3	2	14.59	107.50	0.002
6	M	2.25:1	1353	3	2	23.55	151.53	0.002
6	F	2.25:1	1905	3	3	31.77	195.38	0.002
7	F	3:1	1235	3	2	57.79	258.63*	0.007*
7	F	2:1	1715	3	2	33.17	173.69	0.003
8	F	2:1	1865	3	3	78.03	381.01*	0.006*
10	F	3.5:1	1985	3	2	24.15	165.34	0.002
10	M	3:1	2250	3	2	28.52	108.08	0.002
24	F	3.25:1	3000	5		25.71	143.88	0.001

\* patients using commercial ketogenic formula for recipes and oral supplementation.

### Results

Ten patients with GLUT1 were identified on the KD at CMH.

- Monthly cost of foods averaged between \$143-185 per patient.
- USDA estimated average monthly cost food plan for a child within a family of four was between \$42-82.<sup>2</sup>
- Average cost did not differ with age, gender, calories nor ratio.
- Cost of ingredients reflected on the types of foods the patient consumed.
- Micronutrient supplement costs ranged between \$0.22-2.22 per day per patient.

Includes any out of pocket cost associated with supplements (i.e. multivitamins, calcium, vitamin D, phosphorus, sodium bicarbonate, potassium, carnitine)

Table 2. Average ketogenic food cost compared to the Official USDA Food Plans: Average cost of food at home<sup>2</sup>

Age	Individual monthly USDA cost of food Average for all food levels based a family of 4 <sup>2</sup>	Average ketogenic estimated cost per month per child (based on average for each age group in Table 1, supplements not included in cost)
4-5	\$42.00	\$143.23
6-8	\$69.00	\$184.54*
9-11	\$80.00	\$160.72
19-15	\$82-92	\$143.88

\* 2 patients in this age group use commercial ketogenic formula for recipes and oral supplementation and were removed from the calculation for average cost.

### Conclusion

The average cost of ingredients for GLUT1 patients on the KD is 1.75-3.5 times greater than the USDA average for age/gender for average cost food plan. The KD foods and supplements are currently an out of pocket expense for most families. Future research should include multiple sites representing additional regions of the United States. The data collected can provide information for potential future legislation or program development intended to support families' expenses related to the dietary treatment of their disease.

#### References:

1. Glut1 Deficiency Foundation (2019). *About the Ketogenic Diet*. <https://www.g1dfoundation.org/about-the-ketogenic-diet.html>
2. Official USDA Food Plans: Cost of Food at Home at Four Levels U.S. Average, January 2019 [www.cnpp.usda.gov](http://www.cnpp.usda.gov);
3. This Rare Day Blog (2016, February). *The Cost of Keto*. <http://www.thisrareday.com/blog/2016/2/8/the-cost-of-keto>