

GAMT Deficiency Treatment Cost Estimate

<i>Treatment costs of Creatine, Ornithine, and Sodium for a child diagnosed through newborn screening</i>						
Age (years)	⁴ Average body weight (kg)	^{1,5} Creatine cost	^{2,5} Ornithine cost	^{3,6} Sodium Benzoate cost	Total cost per day	Total cost per month
2	13	\$0.27	\$0.69	\$0.09	\$1.05	\$31.50
4	16	\$0.34	\$0.85	\$0.11	\$1.30	\$39.00
6	21	\$0.44	\$1.11	\$0.15	\$1.70	\$51.00
8	26	\$0.55	\$1.38	\$0.18	\$2.11	\$63.30
10	32	\$0.67	\$1.70	\$0.22	\$2.59	\$77.70
12	40	\$0.84	\$2.12	\$0.28	⁷ \$3.24	⁷ \$97.20
14	52	\$1.09	\$2.76	\$0.36	⁷ \$4.22	⁷ \$126.60
Total for GAMT Treatment Years 0-18						\$15,631

Health Care Costs				
Purpose of Visit	# of Visits/year	Years	⁹ Cost/visit	Total
Diagnosis & F/U Year 0-1	4	1	\$300	\$1200
Follow Up Years 2-10	2	9	\$300	\$5400
Follow Up Years 11-18	1	8	\$300	\$2400
HCP Care Years 0-18				\$9,000

⁸In 2003, the CDC estimated the average lifetime direct cost to the family of an individual with **mental retardation is \$1,014,000**. Indirect costs to family and society not included. The cost during years 0-18 for an infant diagnosed at birth with GAMT Deficiency, to **avoid mental retardation, is \$24,631**. This includes regular checkups with a specialist, and creatine, ornithine, and sodium benzoate supplementation.

- ¹**Cost of creatine** based on dosage of 600mg/kg body weight; (treatment range is 400-800mg)
- ²**Cost of ornithine** based on dosage of 600mg/kg body weight; (treatment range is 400-800mg)
- ³**Cost of sodium benzoate** based on dosage of 200mg/kg body weight; (treatment range is 100-200mg)
- ⁴Average body weight is for males and is from CDC growth chart: cdc.gov/growthcharts/data/set1clinical/cj411021.pdf
- ⁵Costs based on online supplier jomarlabs.com current cost to GAMT families for creatine monohydrate \$30.05/kilogram and l-ornithine HCL \$88.48/kilogram
- ⁶Cost based on South Valley Compounding Pharmacy cost of \$35.00/kilogram
- ⁷Supplement requirements tend to plateau between 40-52 kilograms body weight
- ⁸Estimated direct costs of mental retardation by CDC can be found at <https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5303a4.htm>
- ⁹Specialist visit cost based on University of Utah costs for a metabolic geneticist appointment.

This document was created through a collaboration between the Association for Creatine Deficiencies, Utah Public Health Lab, ARUP Laboratories, and University of Utah Hospital

LDT GAMT Deficiency Newborn Screening Implementation Cost Estimate

Additional Lab Instrument	N/A
Additional Lab Staff	N/A
Additional Specimen Collection Costs	N/A
¹ Guanidinoacetate Internal Standard -five year supply	\$50
¹ Creatine Internal Standard -five year supply	\$50
² Eight weeks of method validation (\$75/hour mass spec research scientist)	\$24,000
² Two week LIMS Implementation (\$60/hour health informaticist)	\$4,800
² Two hours per week of additional data review of GUAC & CRE (\$75/hour)	\$39,000
² Five hours per year contacting families regarding GAMT (\$60/hour)	\$1,500
^{2,3} DNA Sequencing of three patients per year (\$500/test)	\$7,500
Total cost years 1-5:	\$76,900
⁴ Infants Screened:	250,000
COST PER SCREEN years 1-5:	\$0.31
COST TO IDENTIFY 1 case in 250,000; years 1-5:	\$76,900
Total cost years 6-10:	\$48,100
⁴ Infants Screened:	250,000
COST PER SCREEN years 6-10:	\$0.19
COST TO IDENTIFY 1 case in 250,000; years 6-10:	\$48,100

- Estimates based on Utah's annual birth rate of 50,000
- ¹Internal Standards from Cambridge Isotopes
- ²All labor costs are based on actual Utah Public Health Lab costs and include indirect costs and overhead; frequency of DNA testing, data review, and contacting families was rounded up significantly to allow for fluctuations
- ³UPHL cost for sequencing; a nice-to-have, but not necessary for screening and referral
- ⁴GAMT Incidence rate based on Rare Genomes Project estimate; conservative compared to other estimates

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