

State Statutes & Regulations on Dietary Treatment of Disorders Identified Through Newborn Screening

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TABLE OF CONTENTS

Introduction	5
Methodology	5
Summary	6
Medical Foods Products Descriptions	7
Abbreviations	9
Key Definitions	10
Summary Chart 1: State list of coverage types for dietary treatments of disorders identified through newborn screening	11
Summary Chart 2: States that provide PKU only coverage.....	13
STATE STATUTES AND REGULATIONS ON DIETARY TREATMENT OF DISORDERS IDENTIFIED THROUGH NEWBORN SCREENING	15
ALABAMA	15
ALASKA	16
ARIZONA	17
ARKANSAS	18
CALIFORNIA	19
COLORADO	20
CONNECTICUT	21
DELAWARE	22
DISTRICT OF COLUMBIA	23
FLORIDA	24
GEORGIA	25

HAWAII	26
IDAHO	27
ILLINOIS	28
INDIANA	29
IOWA	30
KANSAS	31
KENTUCKY	33
LOUISIANA	34
MAINE.....	35
MARYLAND.....	37
MASSACHUSETTS	38
MICHIGAN	40
MINNESOTA.....	41
MISSISSIPPI.....	43
MISSOURI	44
MONTANA.....	45
NEBRASKA.....	46
NEVADA	47
NEW HAMPSHIRE	48
NEW JERSEY.....	49
NEW MEXICO.....	52
NEW YORK	53
NORTH CAROLINA.....	54
NORTH DAKOTA	55

OHIO	56
OKLAHOMA	57
OREGON	58
PENNSYLVANIA	59
PUERTO RICO	60
RHODE ISLAND	61
SOUTH CAROLINA	62
TENNESSEE	64
TEXAS	65
UTAH	66
VERMONT	67
VIRGINIA	68
WASHINGTON	69
WEST VIRGINIA	70
WISCONSIN	71
WYOMING	72
References	73
Appendix A: State Newborn Screening Program Contact Information	75
Appendix B: State Title V CSHCN Director Contact Information	79

Introduction

Every state, the District of Columbia (DC), Puerto Rico, Guam, and the U.S. Virgin Islands¹ have Newborn Screening (NBS) Programs, which screen newborns for a variety of health conditions, including selected inborn errors of metabolism (IEMs) and other genetic disorders. Because state departments of public health choose the specific conditions for which they screen, both the conditions screened for and the cost of screening varies in each state. In some states, the hospital or birthing center bill separately for screening; in others, screening costs are folded into maternity charges. Medicaid and the Children's Health Insurance Program (CHIP) cover the cost of newborn screening for eligible newborns, and in many states employer-sponsored health plans are mandated by law to cover newborn screening. If there is no third party payer and the individual is not eligible for Medicaid, some states waive the fee. Other states do not charge for screening at all or use Title V Maternal and Child Health Block Grant funds to cover the cost. The [Baby's First Test website](http://www.babysfirsttest.org/newborn-screening/states)² provides a state-by-state list of conditions for which each state screens, the cost of screening, and how screening is paid for.

Individuals with genetic disorders identified through NBS programs often require Modified Low Protein Foods (MLPFs), medical foods, dietary supplements, or other dietary treatments as well as enteral feeding supplies. There is inconsistency among states in the terminology used to describe these dietary treatments, with some states being very specific and descriptive in their state mandated statutes and regulations, while others are more general and open to interpretation. For example, some states may describe coverage of formulas specifically, while other states may describe coverage of medical foods, generally, which includes formulas. These products are medically necessary components of treatment regimens to ensure the health and well-being of individuals with IEMs. However, because of the wide-ranging funding mechanisms across states, coverage for these categories of products and supplies also varies based on type of insurance coverage (e.g., public or private), type of health plan (e.g., individual, group, HMO), and any coverage and or related services that Title V or other state programs may fund.

The **State Statutes and Regulations on Dietary Treatment of Disorders Identified through Newborn Screening** chart that begins on page 14 provides information about state-specific legislation that mandates the coverage of medically necessary foods by employer-sponsored health insurance, Medicaid, and coverage and related services funded by other state programs such as the Women, Infants, and Children (WIC) supplemental nutrition program for pregnant, breast-feeding, and post-partum women, and children up to age 5³, Title V, or relief funds. It also details the covered services as well as any benefit limits or age and income restrictions.

Methodology

Building on a 2008 report of the same name by Alissa Johnson, Catalyst Center staff reviewed existing legislation and identified and updated the chart with new legislation, where applicable. The authors also included links to state-specific resources when we could not

¹ Not all of the US Territories have newborn screening programs

² <http://www.babysfirsttest.org/newborn-screening/states>

³ A special nutrition assistance program for Women, Infants, and Children for low-income women who are pregnant or breast-feeding and infants and children up to age 5 (<http://www.fns.usda.gov/wic/women-infants-and-children-wic>)

identify state statutes or regulations regarding coverage and financing of dietary treatments. We also reviewed documentation from several sources that collect information on genetic disorders and their treatment throughout the U.S. These sources included the American Partnership for Eosinophilic Disorders, the National Association of Insurance Commissioners, the National Organization for Rare Disorders, the National PKU Alliance, and Nutricia (see references section for a full list of sources). We also included information the Catalyst Center staff collected through structured interviews conducted with Title V representatives in 43 states, DC, and Puerto Rico.

Summary

The Medicaid program in every state, DC, and Puerto Rico provides some level of coverage for medical foods to treat metabolic and other conditions⁴. However, many states limit the conditions covered, the route of administration (oral or enteral), and age eligibility. Thirty-five states (Summary Chart 1) have legislative mandates for employer-sponsored insurance coverage of medical foods for IEMs, such as phenylketonuria (PKU), galactosemia (GALT), and maple syrup urine disease (MSUD). However, self-funded ERISA⁵ plans are generally exempt from state-mandated benefits; as a result, medical foods for individuals with self-funded health insurance may not be covered. In addition, if a state has chosen a benchmark plan that is exempt from state-mandated benefits to define the Essential Health Benefits for the Qualified Health Plans sold under its State Health Insurance Marketplace⁶, those plans are not required to include medically necessary foods as a covered benefit.

Thirty-four states provide coverage of medical foods through their Title V/CSHCN (Children with Special Health Care Needs) or other programs⁷. However, coverage for these medically necessary services varies significantly by state. Some states provide coverage only for specific disorders, typically PKU, MSUD, or GALT. For example, six states have legislation mandating coverage of medical foods required for children with PKU and five Medicaid programs, two WIC programs, and three Title V programs cover only those related to PKU. Additionally, some states mandate employer-sponsored coverage for formula only but do not cover other forms of medical foods, such as modular products, bars or MLPFs. WIC programs recognize that individuals with metabolic disorders are at nutritional risk. With

⁴ The term medical food, as defined in section 5(b) of the Orphan Drug Act (21 U.S.C. 360ee (b) (3)) is "a food which is formulated to be consumed or administered enterally under the supervision of a physician and which is intended for the specific dietary management of a disease or condition for which distinctive nutritional requirements, based on recognized scientific principles, are established by medical evaluation."

⁵ The Employee Retirement Income Security Act of 1974 (ERISA) sets minimum coverage and financing standards for employer-sponsored (also known as "private") health plans, including coverage offered by a company, typically a large employer, that chooses to pay employees' health care costs directly, instead of purchasing health insurance coverage. These "self-funded" plans are exempt under ERISA from state mandated benefit laws.

⁶ For background information on the Essential Health Benefit benchmark plans and a list of state choices for 2017, visit <https://www.cms.gov/ccio/resources/data-resources/ehb.html>

⁷ "Medical foods" is a broad term that encompasses a variety of products. See chart below for further information.

documentation of the metabolic condition and a prescription from a licensed health care provider, an infant (up to age 1) and child (up to age 5) can receive special infant formula or other special nutritional products, in all but three states.⁸

Tricare, the health insurance program for military personnel and their families, covers medically necessary medical foods for children with IEMs⁹ (regardless of the state of residence), but with significant limitations. Many services require cost sharing or are limited to specific conditions.¹⁰ In May 2016, the “[National Defense Authorization Act for Fiscal Year 2017](#)” (S. 2943)¹¹ was introduced in the United States Senate. Section 704 (“Coverage of Medically Necessary Food and Vitamins for Digestive and Inherited Metabolic Disorders under the Tricare Program”) specifies the provision of medically necessary food (defined in the Act as “low-protein modified food products or an amino acid preparation and specially formulated and processed product (as opposed to a naturally occurring foodstuff used in its natural state) for the partial or exclusive feeding of an individual by means of oral intake or enteral feeding by tube”) for individuals with inherited metabolic disorders, which would extend this benefit to adults.

In conclusion, coverage for medically necessary dietary treatments, medical foods, and supplies to treat metabolic conditions in newborns is highly dependent on the state in which a child is born and what type of health care coverage (public or private) they have.

Medical Foods Products Descriptions

Medical Foods Product ¹²	Description
Nutritionally complete formulas ¹³	Formula that includes all of the nutrients (carbohydrates, protein, fat, vitamins, minerals) needed and, thus, can be used as the sole source of nutrition.
Nutritionally incomplete formulas ¹⁴	Formula that includes specific nutrients (carbohydrates, protein, fat, vitamins, minerals), but may not be sufficient to comprise the sole source of nutrition.
Metabolic formulas ¹²	Formula used to treat metabolic conditions in patients over one year old.

⁸ Special Supplemental Nutrition Program for Women, Infants, and Children <http://www.fns.usda.gov/sites/default/files/wic/WICRegulations-7CFR246.pdf>

⁹ http://www.npkua.org/Portals/0/PDFs/advocacy/TRICARE_nutrition_alert_april2016.pdf?ver=2016-04-22-071508-757

¹⁰ Department of Defense. (2016). Tricare covered services. Department of Defense: Washington, DC.

¹¹ <http://www.armed-services.senate.gov/imo/media/doc/S2943%20-%20Committee-Passed%20NDAA.pdf>

¹² For more information on medical foods and FDA regulations, see:

<http://www.fda.gov/downloads/Food/ComplianceEnforcement/UCM073339.pdf>

¹³ <http://www.neocate.com/blog/understanding-food-labels-what-does-nutritionally-complete-mean/>

¹⁴ <http://www.findacode.com/hcpcs/b4155-enteral-formula-nutritionally-incompletemodular-nutrients-includes-hcpcs-code.html>

Oral rehydration products ¹⁵	Solutions that include added nutrients (often glucose or potassium) and are used to treat dehydration.
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¹⁵ http://apps.who.int/iris/bitstream/10665/95584/1/9789241506328_eng.pdf?ua=1

Abbreviations

Conditions and Disorders

AAD	<i>Amino Acid Disorders</i>	IVA	<i>Isovaleric Acidemia</i>
BIOT	<i>Biotinidase Deficiency</i>	MSUD	<i>Maple Syrup Urine Disease</i>
CRS	<i>Caudal Regression Syndrome</i>	MCAD	<i>Medium-Chain Acyl Co-A Dehydrogenase</i>
CCS	<i>Central Cord Syndrome</i>	MUT	<i>Methylmalonic Acidemia</i>
CAH	<i>Congenital Adrenal Hyperplasia</i>	OAD	<i>Organic Acid Disorders</i>
CH	<i>Congenital Hypothyroidism</i>	PKU	<i>Phenylketonuria</i>
CF	<i>Cystic Fibrosis</i>	PROP	<i>Propionic Acidemia</i>
EE	<i>Eosinophilic Esophagitis</i>	SBS	<i>Short Bowel Syndrome</i>
FAOD	<i>Fatty Acid Oxidation Disorders</i>	SCA	<i>Sickle Cell Anemia</i>
GALT	<i>Galactosemia</i>	SCD	<i>Sickle Cell Disease</i>
GA	<i>Glutaric Acidemia</i>	TYR	<i>Tyrosinemia</i>
HCY	<i>Homocystinuria</i>	UA	<i>Uric Acid</i>
IEM	<i>Inborn Error of Metabolism</i>		

Other Abbreviations

ACO	<i>Accountable Care Organization</i>
CSHCN	<i>Children with Special Health Care Needs</i>
DME	<i>Durable Medical Equipment</i>
EPSDT	<i>Early Periodic Screening, Diagnostic, and Treatment</i>
MLPF	<i>Modified Low Protein Food</i>
NBS	<i>Newborn Screening</i>
WIC	<i>Women, Infants, and Children</i>

Key Definitions

Enteral nutrition: A feeding method that delivers all or part of an individual's nutrient and/or calorie requirements using the gastrointestinal (GI) tract through typical oral feeding, liquid supplements, or feeding using a GI tube.¹⁶

Oral nutrition: Food that is consumed through the mouth³

Parenteral nutrition: A feeding method that delivers all or part of an individual's nutrient and/or calorie requirements directly into a vein.³

Medical foods: "Food which is formulated to be consumed or administered enterally under the supervision of a physician and which is intended for the specific dietary management of a disease or condition for which distinctive nutritional requirements, based on recognized scientific principles, are established by medical evaluation."¹⁷

Low-protein foods (or modified low-protein foods or low-protein modified food products): A type of medical food that is modified to be low in protein and formulated for consumption for individuals for whom a condition or disorder prevents typical food consumption. This does not include foods that are naturally low in protein, such as some fruits or vegetables.³

Metabolic formula: Term often used in place of medical food (see definition above).

Elemental formula (or amino acid-based elemental formula): Formula that is modified to include individual amino acids, replacing whole or partial milk or soy proteins, which can cause allergic reactions in some people. Elemental formula is nutritionally complete.¹⁸

Specialized formula: Formula that includes specific nutrients and/or is specially produced to meet the specific nutrition needs of individuals with certain conditions or disorders.⁴

Dietary supplement: A product that is intended to supplement the diet. A dietary supplement contains one or more dietary ingredients (including vitamins, minerals, herbs or other botanicals, amino acids, and other substances) or their components; is intended to be taken by mouth as a pill, capsule, tablet, or liquid; and is identified on the front label of the product as being a dietary supplement.

NIH Office of Dietary Supplements (<https://ods.od.nih.gov/HealthInformation/dictionary.aspx>)

Metabolic disorders (or inherited metabolic disorders or inborn errors of metabolism): Conditions or disorders that result from genetic defects inherited from one or both parents that interfere with an individual's ability to metabolize traditional foods.¹⁹

¹⁶ The Cleveland Clinic, 2011

¹⁷ FDA, 2016

¹⁸ http://www.eosinophilicesophagitis.org/eosinophilic_esophagitis_diets/eoe_elemental_formula_diet/

¹⁹ Mayo Clinic, 2016

Summary Chart 1: State list of coverage types for dietary treatments of disorders identified through newborn screening

	State Mandated Benefit	Medicaid	WIC	Title V or other Program
Alabama		X	X	X
Alaska	X	X	X	X
Arizona	X	X	X (limited)	X
Arkansas	X	X	X	
California	X	X		X
Colorado	X	X	X	
Connecticut	X	X	X	
Delaware	X	X	X	X
District of Columbia		X	X	X
Florida	X	X	X	
Georgia		X	X	X
Hawaii	X	X	X	
Idaho		X	X	X
Illinois	X	X	X (limited)	X
Indiana	X	X	X	X
Iowa		X	X	X
Kansas		X	X (case-by-case if not covered Title V/CSHCN)	X
Kentucky	X	X	X	X
Louisiana	X	X	X	X
Maine	X	X	X	X
Maryland	X	X	X	X
Massachusetts	X	X	X (limited)	X
Michigan		X	X	X
Minnesota	X	X	X	
Mississippi		X	X	
Missouri	X	X	X	X

Summary Chart 1: State list of coverage types for dietary treatments of disorders identified through newborn screening

	State Mandated Benefit	Medicaid	WIC	Title V or other Program
Montana	X	X	X	X
Nebraska		X	X	X
Nevada	X	X	X	X
New Hampshire	X	X	X	
New Jersey	X	X	X	X
New Mexico	X	X	X	
New York	X	X	X	
North Carolina		X	X	X
North Dakota	X	X	X	X
Ohio		X		
Oklahoma		X	X	X
Oregon	X	X	X	
Pennsylvania	X	X	X	X
Puerto Rico		X	X	X
Rhode Island	X	X	X	
South Carolina		X	X	
South Dakota	X	X	X	
Tennessee	X	X	X	
Texas	X	X	X	X
Utah	X	X	X	
Vermont	X	X	X (case-by-case)	X
Virginia		X	X	X
Washington	X	X	X	X
West Virginia		X	X	X
Wisconsin		X		
Wyoming	X	X	X	X
Total	35	52	49	34

Summary Chart 2: States that provide PKU only coverage

	State Mandated Benefit	Medicaid	WIC	Title V or other Program
Alabama				
Alaska	X	X		
Arizona				
Arkansas				
California	X			
Colorado				
Connecticut				
Delaware				
District of Columbia				
Florida		X (formula for PKU only)	X	
Georgia				
Hawaii				
Idaho				X
Illinois				
Indiana				
Iowa				
Kansas				
Kentucky				
Louisiana				
Maine				X
Maryland				
Massachusetts				
Michigan				
Minnesota	X			
Mississippi		X	X	
Missouri				
Montana				
Nebraska				

Summary Chart 2: States that provide PKU only coverage

	State Mandated Benefit	Medicaid	WIC	Title V or other Program
Nevada				
New Hampshire				
New Jersey				
New Mexico				
New York				
North Carolina				
North Dakota				
Ohio				
Oklahoma		X, other conditions on a case-by-case basis		
Oregon				
Pennsylvania				X
Puerto Rico				
Rhode Island		X		
South Carolina				
South Dakota	X			
Tennessee	X			
Texas				
Utah				
Vermont				
Virginia				
Washington	X			
West Virginia				
Wisconsin				
Wyoming				
Total	6	5	2	3

STATE STATUES AND REGULATIONS ON DIETARY TREATMENT OF DISORDERS IDENTIFIED THROUGH NEWBORN SCREENING

ALABAMA				
	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Children's Rehab Services (CRS-Title V); University of Alabama Sparks Clinic (UA)
		Medicaid	WIC	
Legislation	No legislative mandate		Chapter 12C, Administration of Women, Infants and Children Program (p. 207)	Alabama AC §22-20-3 (screening for infants < 28 days, includes PKU) Alabama Department of Public Health 420-10-1-.01 through 420-10-1.06 (list of disorders, definitions, reporting, fees)
Benefits Covered		Disorders covered: PKU, CH, GALT, CAH, hemoglobinathy, BD, CF, AAD, FAOD, OAD, and other heritable diseases	Yes	Disorders covered: Metabolic disorders (UA) Rare Disorders (CRS) Medical food: Metabolic foods (UA); Nutritional supplements/tube feeding/oral feeding (CRS) Other: Dieticians and care coordinators work together to find assistance for those ineligible for purchased services (CRS)
Limits		Coverage on a case-by-case basis. See age limits for children and adults at Nutritional Product Grid		

ALASKA

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Title V
		Medicaid	WIC	
Legislation	AS 21.42.380	AAC 43.924 (Nutrition services for pregnant women at high nutritional risk due to chronic or metabolic disease) AAC 43.454 (Nutrition services for Medicaid enrollees < 21, screened under EPSDT, and determined to be at high nutritional risk)	Alaska WIC Policy: With a physician's documentation of medical necessity, women and children with metabolic disorders can receive special formulas.	
Benefits Covered	Disorders covered: PKU Medical food: Formula only	Disorders covered: PKU		Medical food: Formula only
Limits	Annual cap: Limit set by each insurance company Other: Fraternal benefit societies exempt from mandate Limit on formula set by each insurance company			

ARIZONA

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Children's Rehabilitative Services (CRS); Title V
		Medicaid	WIC	
Legislation	20-1402	Chapter 300, Policy 320-H, Metabolic Medical Foods	Formula food packages for women, infants, and children with special dietary needs	CRS Metabolic Guidelines Arizona Title V
Benefits Covered	<p>Disorders covered: MSUD, HCY, GALT, and inherited metabolic disorders and diseases screened for under the newborn screening program Eosinophilic gastrointestinal disorder (ACOs)</p> <p>Medical food: Must cover at least 50% of cost (including formula) if plan covers prescriptions; ACOs must cover at least 75% of cost of amino acid-based formula</p> <p>Low protein food: Must cover at least 50% of cost</p>	<p>Disorders covered: AAD, BD, CF, hemoglobinopathy, HCY, hypothyroidism, PKU, MSUD, OAD, storage disease and other conditions with similar treatment requirements</p>	<p>Disorders covered: Includes inborn errors of metabolism</p>	<p>Disorders covered: Metabolic disorders and CF (CRS); CSHCN with genetic disorders (Title V)</p> <p>Medical food: Metabolic formula (Title V); Medical foods (Title V)</p> <p>Other: Nutrition services (CRS)</p>
Limits	<p>Annual cap: \$20,000 on formula for ACOs; \$5,000 on medical foods, formula, and low protein foods for all other plans</p>		Limited; Doctor must document medical necessity and provide a prescription	<p>Other: Uninsured or underinsured children and young adults (Title V)</p>

ARKANSAS

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Health Department
		Medicaid	WIC	
Legislation	23-79-701 (Definitions of terms) 23-79-702 (Tax credit) 23-79-703 (insurance coverage)	Hyperalimentation		23-79-129 (PKU screening)
Benefits Covered	Disorders covered: PKU, Galactosemia, organic acidemias, amino acid disorder Medical food: Formula Low protein food: Low protein food	Disorders covered: Inherited metabolic diseases including PKU, MSUD Medical food: Enteral for children younger than 21 Other: Nutritional therapy (other metabolic conditions)	Disorders covered: Inherited metabolic diseases including PKU, MSUD Medical food: Enteral for children younger than 21 Other: Nutritional therapy (other metabolic conditions)	
Limits	Other: Coverage kicks in after \$2,400 income tax credit		Access WIC first for children up to age 5 enrolled in Medicaid	Annual cap: Reimbursement to providers up to \$1,000 per person treated without insurance whose expenses exceed \$2,400

CALIFORNIA

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: PKU Genetically handicapped persons program (GHPP) ; California Children's Services (CCS-Title V)
		Medicaid	WIC	
Legislation	1374.56 § 10123.89			
Benefits Covered	Disorders covered: PKU Medical food: Formula Low protein food: Special food products that are part of a diet prescribed and managed by a physician/health care professional in consultation with a physician who specializes in treatment of metabolic disease			Disorders covered: CF, hemoglobinopathies, and certain metabolic disorders (GHPP); inborn errors of metabolism, CF and other lung disorders from metabolic & genetic defects (CCS) Medical food: GHPP Dietary supp: GHPP Other: Inpatient, outpatient, and home treatment services
Limits		Other: Medicaid coverage of enteral nutritional supplements and replacements if used as a therapy to prevent serious disability or death in patients with conditions that preclude use of regular food	No coverage	Age: Under 21 (CCS); Over 21 (GHPP)

COLORADO

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs:
		Medicaid	WIC	
Legislation	Section 10-16-104 (1)(c)(III), C.R.S			
Benefits Covered	<p>Disorders covered: All inborn errors of metabolism; inherited enzymatic disorders caused by single gene defects involved in metabolism of amino, organic and fatty acids, including but not limited to PKU, maternal PKU, MSUD, TYR, HCY, histidinemia, urea cycle disorders, hyperlysinemia, GAs, MMA and PROP</p> <p>Medical food: Formula; modular counterparts</p>	<p>Medical food: Formula for metabolic disorders</p>	<p>Medical food: Formula for metabolic disorders</p>	
Limits	<p>Age: Up to 21 for PKU (women of child-bearing age: up to age 35); no age limit for other metabolic diseases</p> <p>Other: Only applies to insurance plans that have a pharmacy benefit; Cost-sharing may apply</p>	<p>Age: Under 19</p> <p>Other: Pregnant women also covered</p>		

CONNECTICUT

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs:
		Medicaid	WIC	
Legislation	38a-492c (Individual plans) 38a-518c (Group plans)		19a-59c	19a-55-1 (Newborn Screening for PKU and other metabolic diseases)
Benefits Covered	Disorders covered: Inherited metabolic diseases and CF Medical food: Formula; amino acid modified preparations Low protein food: Low protein food	Disorders covered: PKU and other metabolic diseases, hypothyroidism, GALT, SCD, MSUD, HCY, BD, CAH and other inborn errors of metabolism as prescribed by the health department	Disorders covered: PKU and other metabolic diseases, hypothyroidism, GALT, SCD, MSUD, HCY, BD, CAH and other inborn errors of metabolism as prescribed by the health department	
Limits	Age: Formula up to age 12 Other: All inborn errors of metabolism covered	Other: CF not covered		

DELAWARE

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Specialty Formula Fund (Title V)
		Medicaid	WIC	
Legislation	18 Del. C. §3571D			
Benefits Covered	<p>Disorders covered: PKU and other inherited metabolic diseases caused by an inherited abnormality of biochemistry, including any diseases for which the state screens newborns</p> <p>Medical food: Medical food and formula; low protein modified formula</p> <p>Low protein food: Modified food products for the treatment of inherited metabolic diseases</p>	Medical food: Formula	Medical food: Formula	Medical food: Formula
Limits	<p>Age: For PKU: 21 (men), 35 (women)</p> <p>Other: Cost sharing may apply; coverage required if pharmacy services are covered</p>			Other: Health department covers costs of specialty formula to treat inherited metabolic disease not covered by insurance

DISTRICT OF COLUMBIA

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Health Services for Children with Special Needs (HSCSN)
		Medicaid	WIC	
Legislation	No legislative mandate			DCA §7-838 (Hospital & maternity center newborn screening for inborn errors of metabolism)
Benefits Covered		Disorders covered: GALT, HCY, hypothyroidism, MSUD, PKU, SCD, and other metabolic disorders identified by the committee of metabolic disorders	Disorders covered: GALT, HCY, hypothyroidism, MSUD, PKU, SCD, and other metabolic disorders identified by the committee of metabolic disorders	Disorders covered: Any diagnosis covered (HSCSN) Medical food: Enteral nutrition; medically-necessary medical foods (HSCSN)
Limits		Other: Medicaid covers enteral, but not oral; partially pays for treatment on a sliding scale if an infant's parents are indigent		Age: SSI recipients younger than 24 (HSCSN) Other: Medical foods covered on case-by-case basis (HSCSN)

FLORIDA

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs:
		Medicaid	WIC	
Legislation	627.42395 (Individual plans) 627.42395 (Group plans)	Category Lists for the HCPCS Codes for Enteral Formula		
Benefits Covered	Disorders covered: All inborn errors of metabolism Medical food: Enteral formula (for IEMs other than PKU) Low protein food: Low protein modified food products	Disorders covered: PKU and other metabolic disorders Medical food: Formula (for PKU only) Dietary supp: Dietary treatment as medically indicated	Disorders covered: PKU and other metabolic disorders Medical food: Formula (for PKU only) Other: Supplemental foods to eligible families	
Limits	Age: Up to age 24 (up to 14 for OAD and AAD) Annual cap: \$2,500 (for low protein foods to treat OAD and AAD) Other: Additional premium			

GEORGIA

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Children's Medical Services ; Newborn Screening Program (NBS)
		Medicaid	WIC	
Legislation	No legislative mandate	GC §31-12-6	Georgia WIC Program Medical Documentation Form for WIC Special Formulas and WIC Foods Georgia WIC Approved Formulas/Nutritionals	NBS
Benefits Covered		Disorders covered: Genetic conditions such as PKU, GALT, HCY, MSUD, hypothyroidism, CAH, and other inherited metabolic and genetic disorders	Disorders covered: Genetic conditions such as PKU, GALT, HCY, MSUD, hypothyroidism, CAH, and other inherited metabolic and genetic disorders	Disorders covered: Metabolic disorders (NBS) Medical food: Formula Low protein food: Low protein modified foods Dietary supp: Other: Specialized dieticians for assessment (NBS)
Limits		Other: Medicaid covers enteral, but not oral		Age: 21 and under

HAWAII

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs:
		Medicaid	WIC	
Legislation	431:10A-120	HRS §346-67 (Medicaid)		11-143 Testing of Newborn Infants for Metabolic and other Diseases
Benefits Covered	Disorders covered: Inborn error of metabolism caused by inherited abnormal biochemistry characterized by congenital or neonatal onset metabolic defect of amino acid, organic acid, carbohydrate or fat Medical food: Medical foods and formula Low protein food: Low protein food	Medical food: Medical foods Low protein food: Low protein food	Medical food: Medical foods Low protein food: Low protein food	
Limits	Other: Up to 80% of costs covered (formula and low-protein foods)			

IDAHO

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Children's Special Health Program and Genetic Services (CSHP-Title V)
		Medicaid	WIC	
Legislation	No legislative mandate	IDAPA §16.03.09 (Medicaid)	Yes	IC §39-910 – Dept of Public Health prescribes tests and maintains records of individuals diagnosed with PKU
Benefits Covered		Medical foods: Medical foods covered at no charge (Medicaid)		Disorders covered: PKU Medical food: Formula Other: Adults over 18 with PKU can purchase formula from CSHP at CSHP's cost
Limits		Other: Medicaid coverage of enteral, but not oral		Age: Enrollment in the PKU program is not restricted by age or insurance status, though services are limited for adults over 18 years of age

ILLINOIS

	Private Coverage	Public Coverage Medicaid, WIC, Health Department		Coverage/Related Services Funded by Other State Programs: UIC Specialized Care for Children
		Medicaid	WIC/Health Dept.	
Legislation	215 ILCS 5/356z.10 (Group, individual, and managed care health insurance policies)			IAC §661.50 (Newborn metabolic screening code) 410 ILCS 240/2 (Newborn Metabolic Screening Act)
Benefits Covered	Disorders covered: Amino & organic acid metabolism disorders, including PKU, and FAOs Eosinophilic disorders and SBS (amino acid-based elemental formulas) Medical food: Formula only; amino acid-based elemental formulas	Disorders covered: Amino & organic acid metabolism disorders, including PKU, FAOs, EE, SBS, hyperphenylalaninemia Medical food: Formula		Disorders covered: Inborn Errors of Metabolism (PKU, GALT) (UIC) Medical food: Medical food (UIC) Low protein food: Low protein food (UIC) Other: Formula if not covered by the Department of Health; also pay co-pays, and deductibles for child who is underinsured (UIC)
Limits	Other: Formula must be medically necessary and prescribed		Limited	Age: birth to 21 years (UIC) Other: Household income < 285% FPL (UIC)

INDIANA

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Newborn Screening Program (NBS); Children's Special Health Care Services (CSHCS-Title V)
		Medicaid	WIC	
Legislation	27-13-7-18		Indiana WIC Authorized Formulas	16-41-17 (Infant screening)
Benefits Covered	Disorders covered: Inherited metabolic diseases caused by inborn errors of amino or organic acids or urea cycle metabolism and treatable by dietary restriction of one or more amino acids Medical food: Formula only	Disorders covered: PKU, hypothyroidism, hemoglobinopathies, including SCA, GALT, MSUD, HCY, inborn errors of metabolism Medical food: Formula Other: Equipment and supplies	Disorders covered: PKU, hypothyroidism, hemoglobinopathies, including SCA, GALT, MSUD, HCY, inborn errors of metabolism Medical food: Formula	Disorders covered: Metabolic disorders, PKU (CSHCS)
Limits	Other: Enteral only; prescription required			Age: 21 and younger (CSHCS) Other: Income < 250% FPL (CSHCS)

IOWA

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Newborn Screening Program (NBS)
		Medicaid	WIC	
Legislation	No legislative mandate			IC §641- 4.3(136A) (Newborn screening program)
Benefits Covered		Dietary supp: Oral nutrition products Other: Enteral nutrition therapy	Dietary supp: Oral nutrition products Other: Enteral nutrition therapy	Other: NBS refers diagnosed infants to University of Iowa special medical formula program , which covers Inherited diseases of amino acid and organic acids
Limits		Other: Nutrition products are covered if provide ≥51% of daily calories to people with metabolic or digestive disorders	Other: Nutrition products are covered if provide ≥51% of daily calories to people with metabolic or digestive disorders	

KANSAS				
	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Educational, Screening, Testing, Follow-up Program (ESTF); Title V Services for Children with Special Health Care Needs
		Medicaid	WIC	
Legislation	No legislative mandate	KSA §65-180 KAR 28-4-514 (page 130) Financial assistance for individuals with PKU and MSUD		65-180 ESTF
Benefits Covered		Disorders covered: CH, GALT, PKU, MSUD and other genetic diseases being screened under the NBS program, MSUD and PKU Medical food: Medically necessary food (Health Department) Other: Necessary treatment products (Medicaid)		Disorders covered: PKU & other AAD (Title V) PKU, CH, GALT, MSUD, and certain other genetic diseases (ESTF) Medical food: Metabolic formula (Title V); medical food (ESTF) Low protein food: Low protein food (Title V) Other: Treatment products (ESTF)

KANSAS

(continued)

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Educational, Screening, Testing, Follow-up Program (ESTF); Title V Services for Children with Special Health Care Needs
		Medicaid	WIC	
Limits		Age: 18 and younger (Health Department) Annual cap: \$1,500 for food (Health Department) Other: Medicaid: Coverage on case-by-case basis; necessary treatment products must be medically necessary and not available through any other state agency	Coverage upon request if services are not covered by CSHCN program	Other: Income up to 185% FPL (all conditions identified through newborn screening have a sliding fee scale up to 385% FPL) (Title V) Health Dept: Income restriction of <300% FPL for food; reimburses 50-100% of products for those who don't qualify for Medicaid based on income, but have income <300% FPL; reimburses up to 50% for those with income >300% FPL when individual has exhausted all other sources of assistance

KENTUCKY

	Private Coverage	Public Coverage: Medicaid, WIC, Health Department		Coverage/Related Services Funded by Other State Programs: Metabolic Foods and Formula Program (MFFP)
		Medicaid	WIC	
Legislation	KAR 17:500 902 (State mandate) KRS 304.17A-258 (Benefits) KAR 17:150 806 (Benefits) KRS §205.560 (1c) (Conditions covered)	KAR 4:035 902 (Special foods) KAR 1:479 (DME, foods, formula)		
Benefits Covered	Disorders covered: All inborn errors of metabolism covered Medical food: Formula; amino acid modified preparations Low protein food: Low protein modified food products	Medical food: Special foods Dietary supp: Dietary supplements	Medical food: Amino acid modified preparation Low protein food: Low protein food	Disorders covered: Metabolic disorders (MFFP) Medical food: Medical foods (MFFP) Dietary supp: Dietary supplements (MFFP) Other: Individuals without private insurance and unable to use WIC, Medicaid or K-CHIP may qualify for assistance; Health Department provides assistance for treatment referred to as drugs when recipients are out of hospital and costs are not covered by a public or private health benefit plan
Limits	Annual cap: \$25,000 for formula; \$4,000 for low protein foods Other: Coverage required if prescription coverage provided; prescription required	Annual cap: \$25,000 (Medicaid – supplements and special foods) Other: Medicaid coverage by request		Other: MFFP supports are for Kentucky residents who do not qualify for other insurance, whose insurance coverage has been exhausted, or whose insurance has denied the benefit

LOUISIANA

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Newborn Screening Program (NBS), Title V
		Medicaid	WIC	
Legislation	R.S. 22:246 (Benefits) R.S. 22:469 (Self-insured plans)		LA Qualifying Medical Condition for Approved Special Formulas/WIC Eligible Nutritious	
Benefits Covered	Disorders covered: GA, IVA, MSUD, MMA, PKU, PROP, TYR, urea cycle defects Low protein food: Food formulated to have ≤ 1 gram of protein per serving (not naturally low in protein) Other: State employee benefits cover same service as private coverage	Disorders covered: PKU and other rare inborn errors of metabolism Medical food: Formula for inborn errors of metabolism	Disorders covered: Inborn errors of metabolism/metabolic disorders	Medical food: Formula for inborn errors of metabolism (NBS); Prescribed formula (Title V)
Limits	Annual cap: \$2,400 for formula and low protein foods			

MAINE

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: CSHCN Program
		Medicaid	WIC	
Legislation	Medical food coverage 24 §2320-D (individual & group plans) 24-A §2745-D (individual plans) 24-A §2837-D (group plans) 24-A §4238 (HMOs) Formula 24-A §2764 (individual plans) 24-A §2847-P (group plans) 24-A §4256 (HMOs)		Maine WIC	
Benefits Covered	Disorders covered: Inborn error of metabolism, or genetically determined biochemical disorder in which enzyme defect produces a metabolic block that may have pathogenic consequences at birth or later Medical food: Medical formula; metabolic formula; amino-acid based elemental formula Low protein food: Modified low-protein foods	Disorders covered: IEM, or genetically determined biochemical disorder in which enzyme defect produces a metabolic block that may have pathogenic consequences at birth or later	Disorders covered: IEM Medical food: Nutritional products	Disorders covered: Metabolic disorders (CSHCN); Pilot program for older children and adults with PKU and CF Medical food: Formulas (CSHCN); metabolic foods (pilot program)

MAINE

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: CSHCN Program
		Medicaid	WIC	
Limits	Age: Under 2 years for amino-acid based elemental formula Annual cap: \$3,000 on food products Other: Prescription required	Age: Under 18	Age: individuals with IEM can receive nutritional products regardless of age, whether oral or tube fed. Those older than 5 (adult or child) who are tube fed can receive any medically reasonable amount of nutritional product Other: PA is required for nutritional products that are NOT covered by WIC	Age: Up to 21 (CSHCN); Limited coverage for older children and adults through pilot program Annual cap: \$3,000 on uncovered medical costs (pilot program) Other: Income < 225% FPL (CSHCN)

MARYLAND

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Children's Medical Services Program (Title V)
		Medicaid	WIC	
Legislation	§ 15-807 , (Food coverage for individual, group, and nonprofit plans) § 15-843 , (Formula coverage for individual, group, and HMO plans) § 15-817 (Screening) §19-705.5 (Definitions of terms)	COMAR 31.11.12.03 (Covered services) COMAR 10.11.03.04 (Rights and responsibilities of Medicaid applicants)		
Benefits Covered	Disorders covered: Inherited metabolic disease caused by an inherited abnormality, including diseases for which the state screens newborns Eosinophilic disorders (amino acid-based formulas) Medical food: Amino acid-based elemental formulas Low protein food: Low protein modified food products	Disorders covered: Inherited metabolic disease caused by an inherited abnormality, including diseases for which the state screens newborns Medical food: as prescribed by a provider qualified to treat metabolic disorders	Medical food: Medical foods (WIC)	Medical food: Formula Other: Medication to correct metabolic errors
Limits				

MASSACHUSETTS

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: MDPH Metabolic Food and Formula Program
		Medicaid	WIC	
Legislation	M.G.L. c. 175 § 47I (Individual and group plans) M.G.L. c. 176A § 8L (Individual and group hospital services plans) M.G.L. c. 176B § 4K (Group medical service agreements) M.G.L. c. 176G § 4D (HMO plans) 175:47C (Special formula coverage) 176A:8B ; (Non-profit hospital services corporations) 176B:4C (Medical service corporations) MGL 32A§17A (Coverage for state employees)	Guidelines for Medical Necessity Determination for Enteral Nutrition Products		

MASSACHUSETTS

(continued)

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: MDPH Metabolic Food and Formula Program
		Medicaid	WIC	
Benefits Covered	Disorders covered: PKU, TYR, HCY, MSUD, PROP, or MMA, maternal PKU, Crohn's disease, ulcerative colitis, gastroesophageal reflux, gastrointestinal motility, chronic intestinal pseudo-obstruction, inherited diseases of amino and organic acids Medical food: Formula; enteral formula	Disorders covered: Inherited disease of metabolism, including protein, fat, carbohydrate, vitamins, minerals and possibly fiber Civil service insurance: inherited diseases of amino and organic acids Medical food: Formula Low protein food: Low protein food		Medical food: Special foods; formula
Limits	Annual cap: \$2,500 for food (doesn't apply to formula or low protein foods); \$5,000 for low protein modified foods to treat inherited diseases of amino acids and organic acids Other: Formula for infants, children, and pregnant women with PKU	Annual cap: \$5,000 (Medicaid) Other: Medicaid coverage on a case-by-case basis;	Limited coverage Other: WIC participants who carry MassHealth insurance will receive metabolic formulas through MassHealth upon prior authorization	Other: Coverage for foods for uninsured, underinsured, or Medicaid enrollees

MICHIGAN

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Title V CSHCN program; Children with Special Needs (CSN) Fund
		Medicaid	WIC	
Legislation	No legislative mandate	Act No. 246 Public Acts of 2008 section 1202a (Children's Special Health Care Services)	MI-WIC POLICY	
Benefits Covered		Disorders covered: PKU, CF, and other specified metabolic disorders Medical food: Formula	Disorders covered: IEM Medical food: Formula	Disorders covered: MSUD, PKU and other inborn errors of Metabolism (CSHCN)
Limits		Age: 21 or older (CF) Other: Medicaid coverage on case-by-case basis	Other: Must coordinate nutrition care with the metabolic treatment center registered dietitian for WIC clients who do not receive a metabolic formula provided through the Children's Hospital of Michigan Metabolic Clinic	Other: There is no financial eligibility limit for CSHCN; CSN Fund provides support for MI CSHCN that is not available through any other funding source.

MINNESOTA

	Private Coverage	Public Coverage: Medicaid, WIC, Medical assistance for needy persons, Health Department		Coverage/Related Services Funded by Other State Programs
		Medicaid/Health Dept	WIC	
Legislation	62A.26 (PKU treatment) 62E.06 (Dietary treatment)	MSA §256B.0625 (Coverage of nutritional products) MAR 4615.0760 (Health Department) MAR 9505.0325 (Definitions of terms)	Inborn Errors of Metabolism	
Benefits Covered	Disorders covered: PKU only Milk protein allergies, allergic enterocolitis, EE, and SBS (insurance agreement) Medical food: Amino acid-based formula (insurance agreement ¹) Dietary supp: Special dietary treatment per doctor recommendation	Disorders covered: Medicaid: PKU, hyperlysinemia, MSUD, or any other childhood or adulthood disease, conditions or disorders identified by the health commissioner Health Department: hemoglobinopathy, PKU, GALT, hypothyroidism and CAH Medical food: Parenteral and enteral nutrition products	Disorders covered: IEM Medical food: Infant formulas and WIC-eligible medical foods specifically formulated for IEM	

MINNESOTA

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	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs
		Medicaid/Health Dept	WIC	
Limits	Other: Copays may apply for insurance agreement ¹	Other: Parenteral nutrition subject to limits similar to pharmacy services; for conditions other than PKU, MSUD, Hyperlysinemia w/tube, Medicaid coverage on case-by-case basis		

MISSISSIPPI

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs:
		Medicaid	WIC	
Legislation	No legislative mandate			
Benefits Covered				
Limits		Other: Case-by-case basis; PKU only	Other: PKU only	

MISSOURI

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Dept of Health & Senior Services
		Medicaid/ Health Dept.	WIC	
Legislation	376.1219	MRS §191.331		Metabolic Formula Program
Benefits Covered	Disorders covered: PKU and any other inherited disease of amino or organic acid Medical food: Formula Low protein food: Low protein modified foods	Disorders covered: Inherited diseases of amino and organic acids (Medicaid) immunoglobulinE and non-immunoglobulin E mediated allergies to multiple food proteins, food protein, induced enterocolitis syndrome, eosinophilic disorders and impaired absorption (Health Department) Medical food: Formula (Medicaid); Amino-acid based elemental formula (Health Department)	Disorders covered: PKU, MSUD	Disorders covered: PKU, MSUD, glutaric acidemia; homocystinuria; methylmalonic acidemia; citrullinemia; argininosuccinic acidemia; isovaleric acidemia: 3-hydroxy-3-methylglutaryl CoA lyase deficiency (HMG); 3-methylcrotonyl CoA carboxylase deficiency (3MCC), propionic acidemia, long-chain 3 hydroxyacyl CoA dehydrogenase deficiency (LCHAD), very-long-chain acyl-CoA dehydrogenase deficiency (VLCAD), ornithine transcarbamylase deficiency (OTC) and tyrosinemia (type I, II and III). Medical food: Metabolic formula
Limits	Age: Younger than 6 Annual cap: \$5,000 Other: Deductible, coinsurance or copayments may not exceed 50% of cost of food and formula	Age: 18 years and under Other: Health department provides formula only if all other sources have been exhausted		Age: 0 – 5; pays 100% at any income at any Other: Provides financial assistance for the purchase of metabolic formula 6 – 18; pays 100% for income < 300% FPL; pays 75% for income < 400% FPL; pays 60% for income < 500% FPL; pays 50% for income > 500% FPL 19 and older; pays 100% for income up to 185% FPL

MONTANA				
	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Handicapped Children's Services Program (HCSP); Healthy Montana Kids (HMK)
		Medicaid	WIC	
Legislation	MCA 33-22-131		Inborn Errors of Metabolism	ARM 37.57.110 (HCSP)
Benefits Covered	Disorders covered: Inborn errors of metabolism that involve amino acid, carbohydrate, and fat metabolism for which medical standards of diagnosis, monitoring and treatment exist Medical food: Medical foods Dietary supp: Nutritional management	Disorders covered: Inborn errors of metabolism that involve amino acid, carbohydrate, and fat metabolism for which medical standards of diagnosis, monitoring and treatment exist	Disorders covered: PKU, MSUD, homocystinurea, tyrosinemia, GALT Medical food: Infant formulas and WIC-eligible medical foods specifically formulated for IEM	Disorders covered: Metabolic disorders (HCSP); inborn errors of metabolism (HMK) Medical food: Medical foods (HCSP; HMK) Dietary supp: Prescriptive supplements (HCSP)
Limits	Annual cap: Caps may apply Other: Durational limits, deductibles, coinsurance and copayments may apply			Age: Under 19 (HCSP); 18 or under (HMK) Annual cap: \$2,000 (HCSP) Other: Family income at or below 250% FPL (HMK)

NEBRASKA

	Private Coverage	Public Coverage: Medicaid, Department of Health & Human Services		Coverage/Related Services Funded by Other State Programs: Elemental Formula Reimbursement Program (EFRP)
		Medicaid, Dept of Health & Human Services	WIC	
Legislation	No legislative mandate	NRS §71-520 (Food Supplement and Treatment Services Program)	Chapter 71 Section 2227 WIC program 246.16(m); 246.10 (c) 1-3 (Special formula & Medical/Nutritional Products)	Chapter 71 Section 519 Newborn Screening
Benefits Covered		Disorders covered: PKU, primary hypothyroidism, BD, GALT, hemoglobinopathies, MCAD (Medicaid) Inherited metabolic disease (health department) Medical food: Formula; food supplements	Special formula for infants (up to age 1) with medical conditions, including metabolic disorders and inborn errors of metabolism Nutritionals for children age 1 up to age 5 with metabolic disorders and inborn errors of metabolism	Disorders covered: Immunoglobulin E and non-Immunoglobulin E mediated allergies to multiple food proteins, food-protein-induced enterocolitis syndrome, eosinophilic disorders, or impaired absorption of nutrients caused by disorders affecting the absorptive surface, functional length, and motility of the gastrointestinal tract (EFRP) Medical food: Amino acid-based elemental formulas (EFRP)
Limits		Other: No fees for formula; Scale fee for food supplements, but up to \$2,000/year of food supplements can be provided without fees		Annual cap: \$12,000 (EFRP) Other: 50% of out of pocket costs reimbursed (EFRP)

NEVADA

	Private Coverage	Public Coverage: Medicaid		Coverage/Related Services Funded by Other State Programs: Maternal and Child Health Services (MCH)
		Medicaid	WIC	
Legislation	NV Rev Stat § 689A.0423 (2015) (Individual plans) NV Rev Stat § 689B.0353 (2015) (Group plans) NV Rev Stat § 695B.1923 (2015) (Non-profit corporations for hospital, medical, and dental services) NV Rev Stat § 695C.1723 (2015) (HMOs)	Medical Foods for Inborn Errors of Metabolism (S9435) Appendix B, Page 40	Draft POLICY #17-01 Refers individuals eligible for WIC for nutritional education and food supplements	NAC 442.784i (MCH) 71-519 (Screening)
Benefits Covered	Disorders covered: Inherited metabolic diseases characterized by deficient metabolism or malabsorption caused by an inherited abnormality of body chemistry as a result of a congenital or neonatal defect of amino or organic acid, fat, or carbohydrate Medical food: Enteral formula Other: Special food products	Disorders covered: Inborn errors of metabolism Dietary supp: Dietary supplements	Dietary supp: Dietary supplements	Disorders covered: PKU, primary hypothyroidism, BD, GALT, hemoglobinopathies, MCAD, and such other metabolic diseases as the Department of Health and Human Services may from time to time specify (MCH)
Limits	Annual cap: \$2,500 for food Other: Prescription required for food products	Age: Under 21 Annual Cap: \$2,500.00 per year unless proof of medical necessity exceeds that amount. Other: Medicaid coverage of enteral, but not oral		Annual cap: \$2,000 (MCH)

NEW HAMPSHIRE

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs:
		Medicaid	WIC	
Legislation	RSA 415:6-c (Coverage for non-prescription enteral formula) RSA 420-A: 17 (Health services corporations) RSA 420-B: 8-ff (HMOs)	New Hampshire Health Families Member Handbook	NH WIC Program	
Benefits Covered	Disorders covered: Inherited diseases of amino or organic acids Medical food: Enteral formula Low protein food: Modified low protein foods Other: Food products	Disorders covered: Inherited diseases of amino or organic acids Medical food: Enteral	Disorders covered: IEM and metabolic disorders Medical food: Special formulas	
Limits	Annual cap: \$1,800 for low protein food Other: Physician must issue order that enteral formula or food product is medically necessary and is least restrictive and most cost effective means	Other: Medicaid coverage of enteral, but not oral	Other: WIC coordinates with NH Medicaid for the provision of special formulas to individuals enrolled in both WIC and Medicaid Medical necessity must be reviewed every year	

NEW JERSEY

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: State Health Benefits Program (SHBP)
		Medicaid	WIC	
Legislation	Prescription Coverage NJ Rev Stat § 17B:26-2.1v (2015) (individual plans) NJ Rev Stat § 17B:27-46.1z (2015) (group plans) NJ Rev Stat § 17:48-6z (2015) (service corporations) NJ Rev Stat § 17:48A-7y (2015) (medical service corporations) NJ Rev Stat § 17:48E-35.24 (2015) (health service corporations) NJ Rev Stat § 17B:27A-7 (2015) (High Deductible Health Plans) NJ Rev Stat § 17B:27A-19 (2015) (Small employer health benefit plans) Treatment of inherited metabolic diseases NJ Rev Stat § 17:48-6s (2015) (hospital service corporation) NJ Rev Stat § 17:48A-7q (2015) (medical service corporation)		Yes	

NEW JERSEY

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: State Health Benefits Program (SHBP)
		Medicaid	WIC	
Legislation (continued)	NJ Rev Stat § 17:48E-35.16 (2015) (health service corporation) NJ Rev Stat § 17B:26-2.1o (2015) (individual plans) NJ Rev Stat § 17B:27-46.1r (2015) (group plans) NJ Rev Stat § 17B:27A-7.4 (2015) (individual health benefits plans) NJ Rev Stat § 17B:27A-19.6 (2015) (small employer plans) NJ Rev Stat § 26:2J-4.17 (2015) (HMOs) 52:14-17.29c (State Health Benefits Program)			

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NEW JERSEY

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: State Health Benefits Program (SHBP)
		Medicaid	WIC	
Benefits Covered	Disorders covered: Inherited metabolic disease of abnormal body chemistry for which the state screens newborns Multiple food protein intolerance (for non-standard formula) Medical food: Non-standard infant formulas			Disorders covered: Inherited metabolic diseases (SHBP) Medical food: Medical foods (SHBP) Low protein food: Low protein modified food products (SHBP)
Limits	Other: Non-standard formula must be covered if policy covers prescription drugs	Other: Medicaid coverage at 3 specialty clinics		

NEW MEXICO

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Children's Medical Services –Title V
		Medicaid	WIC	
Legislation	NMSA 59A-22-41.1 (Medical diets) NMSA 59A-46-43.2 (HMOs) NMSA 59A-47-38 (Non-profit health care plans)	NMAC 7.30.3.1 (Medicaid)	New Mexico WIC Medical Request for Formula/Food	
Benefits Covered	Disorders covered: Genetic inborn errors of metabolism of amino acid, fat and carbohydrate for which treatment standards exist, including nutritional management and medical foods Medical food: Medical foods	Disorders covered: CH, GALT, hyperphenylalanemia, PKU, BD, disorders of amino acid and carbohydrate transport and metabolism, lipidoses, CAH, hypothyroidism, hemoglobinopathies and other disorders	Disorders Covered: Metabolic diseases	Disorders covered: Adults with CF or those at risk of having a child with special needs
Limits	Annual cap: May apply if they apply for other illnesses Other: Durational limits may apply if they apply for other illnesses	Other: Oral coverage on case-by-case basis	Other: Healthcare provider must document the medical necessity for special formula/medical foods	Age: Under 21 (those at increased risk of physical or developmental conditions)

NEW YORK

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs:
		Medicaid	WIC	
Legislation	Formula coverage §3216(i)(21) (for individual plans) §3221(k)(11) (group plans) §4303(y) (HMOs)		NYS WIC Medical Documentation	
Benefits Covered	Disorders covered: All inborn errors of metabolism; specific diseases for which enteral formulas have been proven effective Medical food: Formula; enteral formula when medically necessary Low protein food: Low protein foods	Disorders covered: All inborn errors of metabolism; specific diseases for which enteral formulas have been proven effective	Disorders covered: Metabolic disorders such as but not limited to GALT and IEM Medicaid food: Supplemental formula and medical food	
Limits	Annual cap: \$2,500 on low protein foods	Other: Medicaid coverage on case-by-case basis		

NORTH CAROLINA

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Newborn Screening Program (NBS); Title V/CSHCN program
		Medicaid	WIC	
Legislation	No legislative mandate	NC Division of Medical Assistance Dietary Evaluation and Counseling	NC WIC Program Manual	NCGS §130A-125 (Newborn screening) NCAC 43H .0314 (Newborn screening and testing)
Benefits Covered		Disorders covered: IEM (PKU, GALT, etc.)	Disorders covered: Metabolic disorders Medical Food: Metabolic formulas	Other: Treatment products or medications (NBS)
Limits		Age: up to age 21 Other: Medicaid coverage on case-by-case basis		Other: When not otherwise available (NBS)

NORTH DAKOTA

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Title V-Children's Special Health Services: Metabolic Food Program (MFP), Russell-Silver Syndrome Program (RSS)
		Medicaid	WIC	
Legislation	26.1-36-09.7 (Insurance companies, HMOs, nonprofit health service corporations) 54-52.1-04.11 (Self-insured plans)	Chapter 75-03-35	North Dakota WIC	
Benefits Covered	Disorders covered: PKU, MSUD Medical food: Part of prescription drug coverage Low protein food: Part of prescription drug coverage	Disorders covered: PKU, MSUD Medical food: Medical foods Low protein food: Low protein modified foods	Disorders covered: IEM and metabolic disorders Medical food: special formula or WIC-eligible nutritionals	Disorders covered: PKU, MSUD (MFP) Medical food: Medical foods (MFP), (RSS) Other: Growth hormone treatment (RSS)
Limits	Annual cap: \$3,000 for low protein modified foods and medical foods	Age: Males: Under 22; Females: Under 45 (older patients can purchase medical foods regardless of income)		Age: Under 18 (RSS) Annual cap: \$50,000 every 2 years (RSS)

OHIO				
	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Newborn Screening Program (NBS)
		Medicaid	WIC	
Legislation	No legislative mandate			ORC §3701.502 (Newborn screening)
Benefits Covered		Disorders covered: PKU, specified genetic disorders Medical food: Formula only		Disorders covered: Inborn errors of metabolism (NBS) Medical food: Metabolic formula (NBS)
Limits			No coverage	

OKLAHOMA

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: SSI Disabled Children's Program (SSI-DCP)
		Medicaid	WIC	
Legislation	No legislative mandate		Oklahoma State Department of Health WIC Service	
Benefits Covered		Disorders covered: PKU	Disorders covered: IEM and metabolic disorders Medical food: Special formulas for qualifying medical conditions	Disorders covered: Metabolic disorders (SSI- DCP) Medical food: Non-specialized formula (SSI- DCP)
Limits		Other: For conditions other than PKU, Medicaid coverage on case-by-case basis		Other: Children receiving SSI (SSI-DCP)

OREGON

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs:
		Medicaid	WIC	
Legislation	ORS 743A.070 (Formula) § 743A.188 (Individual and group plans)		WIC Policy Update 2016-05 Qualifying Conditions for Issuance of WIC-Approved Medical Formulas and Nutritionals	
Benefits Covered	Disorders covered: Inborn errors of metabolism that involve amino acid, carbohydrate and fat metabolism for which medically standard methods of diagnosis, treatment, and monitoring exist Medical food: Enteral formula Low protein food: Low protein food	Disorders covered: IEM that involve amino acid, carbohydrate and fat metabolism for which medically standard methods of diagnosis, treatment, and monitoring exist Medical food: Medically necessary formulas and foods are covered when prescribed by a physician. May require prior authorization	Disorders covered: Inborn errors of metabolism and metabolic disorders Medical food: Special medical formula or nutritional formula plus special food packages	
Limits				

PENNSYLVANIA

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Bureau of Family Health (BFH)/Newborn Screening Program
		Medicaid	WIC	
Legislation	2-14 Act 158 (Medical Foods insurance coverage Act) 40 § 3904 (Medical foods coverage) 40 P.S. § 3906 (Cost sharing)			
Benefits Covered	Disorders covered: PKU, branch-chained ketonuria, GALT and HCY Food protein allergies, food protein-induced enterocolitis syndrome, eosinophilic disorders and SBS (for elemental formula) Medical food: Formula; medically necessary amino acid-based elemental formula (oral and enteral) Dietary supp: Nutritional supplements		Disorders covered: Children and pregnant women at nutritional risk due to medical problems (WIC)	Disorders covered: PKU Medical food: Metabolic formula Other: BFH has agreement with PA Department of Aging (PDA) to use PDA administrative/claims processing system to provide medical formula to CSHCN
Limits	Age: 18 and under Other: Copay and coinsurance may apply in the same way as other covered services, but exempt from deductibles	Other: Medicaid coverage on case-by-case basis		

PUERTO RICO

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Title V
		Medicaid	WIC	
Legislation	No legislative mandate			
Benefits Covered	Dietary supp: Nutritional supplements	Disorders covered: GALT, CF Low protein food: Some Dietary supp: Nutritional supplements	Medical food: Enteral formula	Disorders covered: GALT, CF Medical food: Enteral formula
Limits		Other: Medicaid coverage on case-by-case basis for low protein food.		

RHODE ISLAND

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs:
		Medicaid	WIC	
Legislation	27-20-56 (individual and group plans) RIGL §27-20-56 (Individual and group plans) 27-18-70 (Accident & sickness plans) RIGL §27-19-60 (nonprofit hospital service corporations) RIGL §27-41-74 (HMOs)	RIGL §40-6-3.12	Rhode Island WIC Program	23-13-14 (Newborn screening)
Benefits Covered	Disorders covered: Crohn's disease, ulcerative colitis, gastroesophageal reflux, chronic intestinal pseudo-obstruction, and inherited diseases of amino and organic acids Medical food: Enteral formula Low protein food: Low protein modified foods Other: Mandated coverage of newborn screening fee	Disorders covered: IEM such as PKU, TYR, HCY, MSUD, PROP and MMA	Disorders covered: IEM or gene mutations or deletions that alter metabolism Other: Special formula	
Limits	Annual cap: \$2,500 Other: Copays and/or deductible apply	Age: Neonates, infants, children Annual cap: \$2,500 Other: Coverage on case-by-case basis	Other: Medical necessity must be documented by a physician.	

SOUTH CAROLINA

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs:
		Medicaid	WIC	
Legislation	No legislative mandate		Yes	
Benefits Covered		Disorders covered: Unspecified inborn metabolic disorders in children and some parents of dependent children		
Limits		Other: Medicaid coverage of enteral, but not oral		

SOUTH DAKOTA

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs:
		Medicaid	WIC	
Legislation	58-17-62 (individual plans) 58-18-41 (Group plans) 58-38-23 (Nonprofit medical and surgical plans) 58-41-98 (HMOs) 67:16:42 (Nutritional therapy and supplements)		South Dakota WIC	34-24-17 – Newborn Screening Program
Benefits Covered	Disorders covered: PKU Medical food: Formula; amino acid-based formula Dietary supp: Dietary management	Dietary supp: Oral nutrition supplements Other: Nutrition therapy	Disorders covered: IEM and metabolic diseases Dietary supp: special formula and other supplemental foods Other: Nutrition therapy	
Limits		Other: Medicaid coverage of enteral, but not oral		

TENNESSEE

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs:
		Medicaid	WIC	
Legislation	Tenn. Code Ann. 56-7-2505		Tennessee WIC Qualifying conditions	Tenn. Code Ann 56-7-2301(b) (Newborn screening)
Benefits Covered	Disorders covered: PKU Medical food: Formula only		Disorders covered: IEM and metabolic disorders Medical Food: therapeutic products	
Limits		Age: Up to 21 (for metabolic disorders)	Other: TN Medicaid is payer for therapeutic products for individuals with IEM who are also eligible for WIC	

TEXAS				
	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Newborn Screening (NBS), CSHCN program
		Medicaid	WIC	
Legislation	TIC Section 1377.051 (Formula) TIC Chapter 1359 (Group plans and HMOs)		Texas WIC Medical Request for Formula/Food	TAC Health Services §38 (CSHCN) Health and Safety Code §33.031 et seq. (NBS)
Benefits Covered	Disorders covered: PKU, inborn errors of amino acid or urea organic acid metabolism Eosinophilic disorders (for elemental formulas) Medical food: Formula only; amino acid-based elemental formulas	Medical food: For inborn metabolic disorders only	Disorders covered: IEM and metabolic disorders Medical food: Special formula and foods	Disorders covered: Identified metabolic disorders or other conditions Other: Nutritional services and products
Limits	Other: Coverage must mirror prescription drug benefits	Other: Medicaid coverage on case-by-case basis		

UTAH

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs:
		Medicaid	WIC	
Legislation	31A-22-623 R590-76-4 (HMOs) R590-194 (Dietary products)	Utah Medicaid Provider Manual	Utah Medicaid Provider Manual	
Benefits Covered	Disorders covered: Inborn errors of amino acid or urea cycle metabolism caused by an inherited abnormality of body chemistry treatable by dietary restriction Dietary supp: Dietary products	Disorders covered: IEM Medical foods: covered when meet Orphan Act amendment definition, is for oral or tube feeding, and is used under medical supervision.	Disorders covered: IEM Medical foods: nutritional supplements	
Limits		Age: Children younger than 21 Other: coverage on case-by-case basis	Other: coverage on case-by-case basis	

VERMONT				
	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: CSHCN program
		Medicaid	WIC	
Legislation	8 V.S.A. § 4089e	Department of Vermont Health Access		
Benefits Covered	Disorders covered: Inherited metabolic disease caused by an abnormality of body chemistry for which the state screens newborns Medical food: Medically necessary medical foods Low protein food: Low protein modified food products	Disorders covered: Inherited metabolic disease caused by an abnormality of body chemistry for which the state screens newborns Medical Food: Low protein modified food products for treatment of an inherited metabolic disease, as required by Act 128 of the 1998 Legislative Session	Other: Health department may cover children with chronic diseases	CSHCN program reviews and processes eligible applications for medically necessary expenses that are not otherwise covered. Medical Food: Medically necessary formula and nutritional supplements
Limits	Annual cap: \$2,500 for low protein foods		Other: WIC coverage on case-by-case basis	Other: Title V functions as payer of last resort; must exhaust all other potential payers

VIRGINIA				
	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Department of Health
		Medicaid	WIC	
Legislation	No legislative mandate		Yes	12 VAC 5-71-10 (DOH)
Benefits Covered		Disorders covered: Core panel of heritable disorders and genetic disease consistent with recommendations of the American College of Medical Genetics Other: Tube feeding only		Medical food: Metabolic formula (DOH), and Dietary supplements (when funds are available) Low protein food: Low protein food (DOH) Other: Supplies (DOH)
Limits				Age: Under 21; assistance available for those over 21 if income <300% FPL (DOH) Annual cap: \$1,500 (for those with income > 300% FPL) Other: Must be financially eligible and eligible for CSHCN program (DOH); those not eligible for CSHCN program, may be eligible to purchase from DOH

WASHINGTON

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Specialty clinics
		Medicaid	WIC	
Legislation	48.20.520 (PKU) 48.21.300 (Group plans)	WAC 388-554- 300	WAC 388-554- 300	
Benefits Covered	Disorders covered: PKU only Eosinophilic gastrointestinal associated disorders (for elemental formulas) Medical food: Formula; medically necessary elemental formula	Medicaid food: oral or tube-delivered enteral nutrition products Other: equipment and related supplies	Medicaid food: oral or tube-delivered enteral nutrition products Other: equipment and related supplies	Disorders covered: Hemoglobin diseases, PKU, CAH, CH, and other disorders for which the state screens newborns (specialty clinics)
Limits			Age: WIC pays for first for children younger than 5 eligible for both WIC and WA Medicaid	

WEST VIRGINIA

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: Office of Maternal, Child, and Family Health (MCFH), Newborn Screening Program (NBS)
		Medicaid	WIC	
Legislation	No legislative mandate		West Virginia WIC	§16-22-3(c) (NBS)
Benefits Covered		Disorders covered: PKU, GALT Medical food: Formula only	Disorders covered: IEM and metabolic disorders Medical food: Metabolic formula and WIC-eligible nutritionals	Disorders covered: PKU, Tyrosinemia, and Organic Acidemia disorders (MCFH) Medical food: Metabolic formula (MCFH) Dietary supp: Metabolic supplements (MCFH)
Limits		Other: Medicaid must refer to the WV University Genetics Team	Other: Medical necessity must be documented by a health care professional. WIC must refer to the WV University Genetics Team	

WISCONSIN

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs:
		Medicaid	WIC	
Legislation	No legislative mandate	HFS 107.09		
Benefits Covered		Disorders covered: Those at nutritional risk due to severe health conditions, including metabolic disorders Medical food: Medically necessary, specially formulated nutritional supplements and replacement products, including enteral and parenteral products		
Limits			No coverage	

WYOMING

	Private Coverage	Public Coverage		Coverage/Related Services Funded by Other State Programs: CSHCN program
		Medicaid	WIC	
Legislation	26-20-401	Wyoming Medicaid Rules	Physician authorization & Medical Documentation	
Benefits Covered	Disorders covered: Inherited enzymatic disorders caused by single gene defects involved in the metabolism of amino, organic and fatty acids and includes PKU, maternal PKU, MSUD. Tyrosinemia, homocystinuria, histidinemia, urea cycle disorders, hyperlysinemia, glutaric acidemias, methylmalonic academia, propionic academia Other: Medical nutrition therapy	Disorders covered: IEM involving amino acid, carbohydrate, and fat metabolism with an accepted diagnosis and treatment	Medical food: Specialty formulas and medical foods	Medical Food: Metabolic formula
Limits			Other: Must be prescribed by a licensed healthcare professional	

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<http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/reportsrecommendations/reports/statelaws.pdf>

Appendix A: State Newborn Screening Program Contact Information²⁰

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Indiana	Bob Bowman	317-233-1231	bobb Bowman@isdh.in.gov

²⁰ Source: National Newborn Screening and Global Resource Center. (2016). *Newborn Screening Programs in the U.S.* Retrieved from http://genes-r-us.uthscsa.edu/sites/genes-r-us/files/state_contacts.pdf

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STATE	CONTACT	PHONE NUMBER	E-MAIL ADDRESS
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Appendix B: State Title V CSHCN Director Contact Information²¹

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²¹ Source: HRSA/Maternal Child Health. Retrieved August 11, 2016 from <https://mchb.tvিসdata.hrsa.gov/>

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