The Catalyst Center School of Social Work Center for Innovation in Social Work & Health

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

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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 bills 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 provides a state-by-state list of conditions for which each state screens, the cost of screening, and how screening is paid for. Additional information about state newborn screening policies can be found on the NewSTEPs State Profiles page.

Individuals with genetic conditions 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 statemandated 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 10 provides information about state-specific legislation that mandates the coverage of medically necessary foods by employer-sponsored health insurance and Medicaid, and coverage and related services funded by other state programs such as Title V or relief funds. It also details the covered services as well as any benefit limits or age and income restrictions.

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¹ Not all of the US Territories have newborn screening programs.

National Programs and Regulations

Individuals under age 21 who are enrolled in Medicaid in any state are entitled to the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) benefit. Under EPSDT, Medicaid must cover all medically necessary services for children. Many state Medicaid programs cover metabolic formulas as an EPSDT benefit, but coverage differs state to state because each state can adopt their own definition of medical necessity. For more information about EPSDT and medical necessity, refer to sections 5 and 12 of the Catalyst Center's resource, Medicaid and CHIP: A Tutorial on Coverage for Children and Youth with Special Health Care Needs (CYSHCN).

The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) is available in every state and can assist with covering metabolic formulas for select individuals. To be eligible for WIC, a person must be an infant or child up to age 5, or an adult who is pregnant, postpartum, or breastfeeding, and have a family income below the standard set by the state's WIC agency.² Income eligibility standards range from 100 percent to 185 percent of the federal poverty level. For eligible individuals, the WIC program can provide nutritionally complete or incomplete metabolic formulas that are prescribed by a physician.³ If a person is enrolled in both WIC and Medicaid, Medicaid pays for medical foods first, but WIC will cover formulas if coverage is not available.⁴

Tricare, the health insurance program for military personnel and their families, covers medically necessary medical foods including specialized formulas and low protein modified foods, regardless of the state of residence.⁵

In addition to publicly funded programs, some private companies and organizations provide financial assistance for medical food coverage. The <u>nationwide directory on the Medical Home Portal</u>, a project of the Department of Pediatrics at the University of Utah Health that partners with state Maternal and Child Health programs, lists several of these programs under the "Nutrition, Metabolic" category.

² WIC Eligibility Requirements (2023): https://www.fns.usda.gov/wic/wic-eligibility-requirements

³ WIC Food Packages (2022): https://www.fns.usda.gov/wic/wic-food-packages-regulatory-requirements-wic-eligible-foods#WIC-ELIGIBLE%20NUTRITIONALS

⁴ U.S. Food and Nutrition Services (2015): https://www.fns.usda.gov/wic/medicaid-primary-payer-exempt-infant-formulas-and-medical-foods

⁵ Tricare Covered Services (2022): https://tricare.mil/CoveredServices/IsItCovered/NutritionalTherapy

Methodology

Building on a 2008 report of the same name by Alissa Johnson, and a Catalyst Center update to that report published in 2016, Catalyst Center staff again reviewed existing legislation and updated the chart with new legislation, where applicable. For Medicaid policy, the authors have linked to applicable state regulations and sections of the state's Medicaid provider manual, which outline coverage criteria for medical foods. We also reviewed documentation from several sources that collect information on genetic disorders and their treatment throughout the U.S. These sources included Baby's First Test, the National Coordinating Center for the Regional Genetics Networks Genetics Policy Hub, 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 for a full list of sources). We also included information collected through a review of Title V CYSHCN program websites. The 2016 version of this resource included information the Catalyst Center Staff collected through structured interviews conducted with Title V representatives in 43 states, DC, and Puerto Rico; in this update, we have aimed to verify this information and link to publicly available sources.

Summary

The Medicaid program in every state provides some level of coverage for medical foods to treat metabolic and other conditions.⁶ However, many states limit the conditions covered, the route of administration (oral or enteral), and age eligibility. Thirty-eight states and the District of Colombia 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 ERISA⁷ 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, a state may choose a benchmark plan that is exempt from state-mandated benefits to define the Essential

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⁶ 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."

⁷ 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.

Health Benefits for the Qualified Health Plans sold under its State Health Insurance Marketplace.⁸ In those cases, the plan is not required to include medically necessary foods as a covered benefit.

Twenty-nine states and DC provide coverage of medical foods through their Title V/CSHCN (Children with Special Health Care Needs) or other programs. However, coverage for these medically necessary services varies significantly by state. Some states provide coverage only for specific disorders, typically PKU, MSUD, or GALT. 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. Ultimately, 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 the type of health care coverage (public or private) they have.

Medical Foods Products Descriptions		
Nutritionally complete formulas ⁹	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 ¹⁰	Formula that includes specific nutrients (carbohydrates, protein, fat, vitamins, minerals), but may not be sufficient to comprise the sole source of nutrition.	
Metabolic formulas ¹¹	Formula used to treat metabolic conditions in patients over one year old.	
Oral rehydration products ¹²	Solutions that include added nutrients (often glucose or potassium) and are used to treat dehydration.	

 $\underline{\text{http://apps.who.int/iris/bitstream/handle/10665/95584/9789241506328}\underline{\text{eng.pdf;jsessionid=48E78C6F8A72851AF20C1803F5EAE186?sequence=1}}\\$

⁸ For background information on the Essential Health Benefit benchmark plans and a list of state choices for 2017, visit: https://www.cms.gov/cciio/resources/data-resources/ehb.html

⁹ Nutricia (2010): https://www.neocate.com/living-with-food-allergies-blog/understanding-food-labels-nutritionally-complete-mean/

¹⁰ HCPS Code: https://www.findacode.com/hcpcs/b4155-enteral-formula-nutritionally-incompletemodular-nutrients-includes-hcpcs-code.html

¹¹ FDA (2006): https://www.fda.gov/media/71685/download

¹² WHO (2013):

Abbreviations

Conditions

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

Other Abbreviations

IEM Inborn Error of Metabolism

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

Key Definitions¹³

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.

Oral nutrition: Food that is consumed through the mouth.

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

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." Metabolic formula is often used in place of medical foods.

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.

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.

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.

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. More terms related to dietary supplements can be found in the NIH Dictionary of Dietary Supplement Terms.

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.

¹³ CFR, Title 21: https://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfcfr/CFRSearch.cfm?fr=101.9&SearchTerm=medical%20foods%20program

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

	ALABAMA			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	No legislative mandate	Alabama Medicaid Pharmacy Forms and Criteria Nutritional Diagnosis Grid		
Benefits covered		Disorders covered: PKU, EE, CF, FAOD, GA, HCY, IEM, disorders of protein metabolism, IVA, MSUD, MUT, PROP, SBS, TYR		
Limits		Other: Coverage on a case- by-case basis		

	ALASKA			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	AS 21.42.380	Alaska Medicaid DMEPOS Provider Information 7 AAC 120.240		
Benefits covered	Disorders covered: PKU Medical food: Formula only	Formula is covered on a case-by-case basis. The prescribing provider must submit an Enteral Nutrition Certificate of Medical Necessity form.		
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	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	A.R.S § 20-2327 A.R.S § 20-1402.02	AHCCCS Medical Policy Manual AHCCCS Medical Policy Manual (AMPM) Section 310-GG: Nutritional Therapy, Metabolic Foods, and Total Parenteral Nutrition		
Benefits covered	Disorders covered: MSUD, HCY, GALT, and inherited metabolic disorders and diseases screened for under the newborn screening program; Eosinophilic gastrointestinal disorder (ACOs) 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 Low protein food: Must cover at least 50% of cost	Disorders covered: PKU, HCY, MSUD, GALT, Beta Keto-Thiolase Deficiency, Citrullinemia, GA, IVA, MUT, PROP, Argininosuccinic Acidemia, TYR, HMG CoA Lyase Deficiency, Very long chain acyl-CoA Dehydrogenase deficiency (VLCAD), and long Chain acyl-CoA dehydrogenase deficiency (LCHAD) Medical food: Metabolic formula and modified low protein foods		
Limits	Annual cap: \$20,000 on formula for ACOs; \$5,000 on medical foods, formula, and low protein foods for all other plans			

ARKANSAS			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs
Legislation	A.C.A. § 23-79-701 (definitions of terms) A.C.A. § 23-79-702 (tax credit) A.C.A. § 23-79-703 (insurance coverage)	Hyperalimentation - Provider Manual Section 2.242.120	
Benefits covered	Disorders covered: Multiple conditions Medical food: Formula and low protein food		
Limits	Other: Coverage kicks in after \$2,400 income tax credit	Other: Medicaid coverage on case-by-case basis.	

CALIFORNIA			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs
Legislation	California HSC § 1374.56	Medi-Cal Pharmacy Provider Manual Provider Manual	California Children's Services (CCS) Genetically Handicapped Persons Program (GHPP)
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: Inborn errors of metabolism Medical food: Formula	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: Formula, medical food Other: Inpatient, outpatient, and home treatment services
Limits		Other: Limited diagnoses covered for individuals age 22 and older	Age: Under 21 (CCS); Over 21 (GHPP)

	COLORADO			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	CRS 10-16-104 (1)(c)(III)	Durable Medical Equipment, Prosthetics, Orthotics, and Supplies - Enteral Nutrition Products Durable Medical Equipment HCPCS Codes - Enteral Formulas		
Benefits covered	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 Medical food: Formula; modular counterparts	Medical food: formula		
Limits	Age: Up to 21 for PKU (women of child-bearing age: up to age 35); no age limit for other metabolic diseases Other: Only applies to insurance plans that have a pharmacy benefit; Cost-sharing may apply	Other: Medicaid coverage on case-by-case basis		

CONNECTICUT			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs
Legislation	<u>Sec. 38a-492c</u> (Individual) <u>Sec. 38a-518c</u> (Group)	Connecticut Medicaid Provider Manuals Provider Manual Chapter 8 - Pharmacy HUSKY Health Provider Benefits and Prior Authorization Requirements Grid	CT Medical Home Initiative: may help with costs
Benefits covered	Disorders covered: Inherited metabolic diseases and CF Medical food: Formula; amino acid modified preparations Low protein food: Low protein food	Disorders covered: Inherited metabolic disease Medical food: medical food Low protein food: low protein food	
Limits	Age: Formula up to age 12	Age: Under 21	

	DELAWARE			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	18 Del. C. § 3571	Delaware Medicaid Policy Manuals Durable Medical Equipment Provider Specific Manual	Delaware Administrative Code 4103: Specialty Formula Fund	
Benefits covered	Disorders covered: PKU and other inherited metabolic diseases caused by an inherited abnormality of biochemistry, including any diseases for which the state screens newborns Medical food: Medical food and formula; low protein modified formula Low protein food: Modified food products for the treatment of inherited metabolic diseases	Disorders covered: birth defects, cerebral palsy, cystic fibrosis, metabolic diseases, or other medical conditions that prevent a person from obtaining sufficient nutrition from a normal diet Medical food: Formula	Medical food: Formula	
Limits	Other: Cost sharing may apply; coverage required if pharmacy services are covered		Other: Health department covers costs of specialty formula to treat inherited metabolic disease not covered by insurance	

	DISTRICT OF COLUMBIA			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	D.C. Law 24-168	DME/POS Billing Manual	Health Services for Children with Special Needs	
Benefits covered	Disorders covered: Inherited metabolic disorders and other conditions requiring medically necessary foods Medical food: Formula, low-protein modified food, amino acid preparation products		Other: Medical equipment and supplies	
Limits	Other: coverage shall not be more restrictive than or separate from coverage provided for any other illness, condition, or disorder		Age: SSI recipients younger than 26 Other: Medical foods covered on case-by- case basis	

	FLORIDA			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	Fla. Stat. § 627.42395	Florida Medicaid's Covered Services and HCBS Waivers, Durable Medical Equipment (DME), and Medical Supplies Enteral Nutritional Supplements - Download 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		
Limits	Age: Up to age 24 Annual cap: \$2,500 (for low protein foods to treat OAD and AAD) Other: Additional premium			

	GEORGIA			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	No legislative mandate	Policies and Procedures for Durable Medical Equipment Services Georgia Medicaid Provider Manuals	Children's Medical Services (CMS)	
Benefits covered		Disorders covered: All inherited metabolic disorders	Disorders covered: Metabolic disorders Benefits: Services and equipment not paid for by Medicaid or private insurance	
Limits		Age: Under 21	Age: Under 21	

	HAWAII			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	HRS § 432:1-609	DMEPOS Provider Manual Med-QUEST FFS Provider Manual		
Benefits covered	Disorders covered: IEM Medical food: Medical foods and formula Low protein food: Low protein food	Medical food: Prepared food formula		
Limits	Other: Up to 80% of costs covered (formula and low-protein foods)			

	IDAHO			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	No legislative mandate	Idaho Medicaid Provider Handbook Section 5.44, Nutritional Products	Children and Youth with Special Health Care Needs and Children's Special Health Program	
Benefits covered		Disorders covered: IEM. No prior authorization required for PKU. Medical food: Formula and medical foods	Disorders covered: PKU Medical food: Formula, medical food, and low protein food. Other: Adults over 18 with PKU can purchase formula from CSHP at CSHP's cost. The program also offers clinic visits, nutritional support, and phenylalanine testing.	
Limits			Age: Enrollment in the PKU program is not restricted by age or insurance status, though services are limited for adults 18 years of age and older. Maternal PKU participants receive the same services as a Pediatric PKU participant until six weeks postpartum. Other: \$250 maximum per month for low protein foods	

	ILLINOIS			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	215 ILCS 5/356z.10	Handbook for Providers of Medical Equipment and Supplies Sections 213.1 and 213.4 Medical Foods Frequently Asked Questions	PUBLIC HEALTH (410 ILCS 240/2 a-5.3) Newborn Metabolic Screening Act.	
Benefits covered	Disorders covered: Eosinophilic disorders and SBS (amino acid-based elemental formulas) Medical food: Formula only; amino acid-based elemental formulas	Disorders covered: PKU, MSUD, HCY Medical food: Formula and medical food	Disorders covered: Amino acid metabolism disorders, including PKU, OAD, and FAOD Medical food: Formula Other: The Department of Public Health will supply metabolic treatment formulas when the product is not available through other state agencies.	
Limits	Other: Formula must be medically necessary and prescribed	Age: Under 21		

	INDIANA			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	IC 27-8-24.1	405 IAC 5-24-9 Member Eligibility and Benefit Coverage: Food Supplements, Nutritional Supplements and Infant Formula	Section 410 IAC 3-3-2.5 Indiana Department of Health Metabolic Formula Program (MFP) Children's Special Health Care Services (CSHCS)	
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: Metabolic disorders Medical food: Formula Other: Equipment and supplies	Disorders covered: Metabolic disorders (MFP & CSHCS) Medical food: Formula	
Limits	Other: Enteral only; prescription required		Age: Under 21 (CSHCS) Other: Income < 250% FPL (CSHCS); must use all other coverage options before applying to MFP	

	IOWA			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	No legislative mandate	Medical Foods Enteral Products and Supplies	Iowa Newborn Screening Program Metabolic Food & Formula Program	
Benefits covered		Disorders covered: PKU, MSUD, HCY, Urea cycle disorders, OAD, histidinemia, TYR, von Gierke's disease, Pyruvate dehydrogenase deficiency, Lysinuric protein intolerance Medical food: formula and metabolic food	Disorders covered: IEM Medical food: Formula, medical food, low protein modified foods	
Limits				

	KANSAS			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	Kansas State Statute 40-2,196 - Applies to state employees health care commission only	Kansas State Statute 65.180	Title V Special Health Care Needs Metabolic Products Direct Assistance Program (Title V)	
	No legislative mandate for other private coverage		<u>Kansas Administrative Regulations 28-4-514</u> (Title V) <u>Kansas State Statute 65.180</u> Educational, Screening, Testing, and Follow-Up Program (ESTF)	
Benefits covered	Disorders covered: Food protein-induced enterocolitis syndrome, eosinophilic disorders, short bowel syndrome	Disorders covered: CH, GALT, PKU, MSUD, and other genetic diseases being screened under the NBS program	Disorders covered: PKU, MSUD, and other AAD (Title V); CH, GALT, PKU, MSUD, and other genetic diseases being screened under the NBS Program (ESTF)	
	Medical food: amino acid-based elemental formula	Other: Necessary treatment products	Medical food: Metabolic formula (Title V); Medical food (ESTF)	
			Low protein food: Low protein food (Title V)	
			Other: Treatment products (ESTF)	
Limits		Other: Coverage on case-by-case basis; necessary treatment products must be medically necessary and not available through any other state agency	Title V Other: Full coverage for individuals in households with income up to 185% FPL, sliding scale for households with income up to 385% FPL Monthly Cap: \$750 a month for formula (\$1,200 for PKU clients who are pregnant or nursing) Annual Cap: \$1,500 for low-protein food items	
			ESTF Other: 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 Annual Cap: \$1,500 for food	

	KENTUCKY			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	KRS 304.17A-258	KRS 205.560 907 KAR 1:479	Metabolic Foods and Formula Program 902 KAR 4:035	
Benefits covered	Disorders covered: All inborn errors of metabolism Medical food: Formula; amino acid modified preparations Low protein food: Low protein modified food products	Disorders covered: All inborn errors of metabolism Medical food: Therapeutic food, formulas, supplements, amino acid-based formula Low protein food: Low protein modified food products	Disorders covered: All inborn errors of metabolism Medical food: Formula Dietary supp: Dietary supplements Low protein food: Low protein modified food products 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		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	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	RS 22:246 RS 22:469	Louisiana Medicaid Program Manual Section 18.2.11: Enteral Nutrition Louisiana Medicaid Provider Manuals		
Benefits covered	Disorders covered: GA, IVA, MSUD, MMA, PKU, PROP, TYR, urea cycle defects Low protein food: Food especially formulated to have ≤1 gram of protein per serving (does not include natural foods that are naturally low in protein).	Disorders covered: Known or suspected IEMs served by the Office of Public Health Genetic Diseases program Medical food: Formula Other: Genetic Disease program must maintain a completed Request for Enteral Formula for Inborn Errors of Metabolism order form in the beneficiary's record which is signed and dated by the appropriate ordering provider		
Limits	Annual cap: Up to \$200/month, not to exceed \$2400/year for private insurance companies.			

	MAINE			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	Medical food 24 §2320-D (individual & group plans) 24-A §2745-D (individual plans) 24-A §2837-D (group plans) 24-A §4238 (HMOs) Amino Acid-Based Formula 24-A §2764 (individual plans) 24-A §2847-P (group plans) 24-A §4256 (HMOs)	MaineCare Benefits Manual: Chapter 2, Section 60		
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 lowprotein foods	Disorders covered: Inborn errors of metabolism or a qualifying medical condition where the most effective and appropriate form of caloric or nutritional intake is orally Medical food: Specially modified foods and formulas		
Limits	Age: Under 2 years for amino-acid based elemental formula Annual cap: \$3,000 on low-protein food products Other: Prescription required	Other: Coverage will be considered dependent on medical necessity determination		

MARYLAND			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs
Legislation	\$15–843 (Formula coverage for individual, group, HMO, and nonprofit plans) \$15–807 (Food coverage for individual, group, and nonprofit plans) \$19–705.5 (Food coverage for HMO plans) Summary document, last updated January 1, 2019 - Maryland's Mandated Benefits For Large Group Plans And Grandfathered Plans	COMAR 10.09.69.10 (Covered services under the Rare and Expensive Case Management program) COMAR 10.09.69.17 (Disorders covered)	Children's Medical Services Program
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: Medical food, amino acid-based elemental formulas Low protein food: Low protein modified food products	Disorders covered: Many metabolic conditions Medical food: nutritional supplements or enteral feeding when medically necessary Other: considered on a case-by-case basis	Medical food: Formula
Limits		Age: coverage is limited to ages 0 to 20 years for many conditions	Age: 0 to 21 years

MASSACHUSETTS			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs
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) 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)	MassHealth Guidelines for Medical Necessity Determination for Enteral Nutrition and Special Medical Formulas	
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 Low protein food: Low protein food	Disorders covered: inborn errors of metabolism that require food products to be modified to be low in protein, malabsorption syndromes or short-bowel syndromes such as or related to diabetes, celiac disease, cystic fibrosis, chronic pancreatitis, renal dialysis, draining abscess, or wounds Inherited disease of metabolism, including protein, fat, carbohydrate, vitamins, minerals, and possibly fiber Medical food: Formula Low protein food: Low protein food	
Limits	Annual cap: \$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		

MICHIGAN			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs
Legislation	No legislative mandate	Medicaid Provider Manual - Medical Supplier Section 2.13	Children's Special Health Care Services (CSHCS)
Benefits covered		Disorders covered: IEM identified by the International Classification of Diseases Medical food: Formula	Disorders covered: Many metabolic conditions
Limits			Other: There is no financial eligibility limit for CSHCS; families pay a sliding scale fee to participate in the program. This fee is waived if the client has Medicaid, MIChild, a court-appointed guardian, or lives in a foster home.

MINNESOTA			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs
Legislation	62A.26 62E.06 Insurance agreement to cover amino acid elemental formulas	256B.0625 Subd. 32 Enteral Nutrition Coverage Criteria MAR 9505.0325 (Definition of terms)	MAR 4615.0760
Benefits covered	Disorders covered: PKU only (legislation) Milk protein allergies, allergic enterocolitis, EE, and SBS (insurance agreement) Medical food: Amino acid-based formula (insurance agreement) Dietary supp: Special dietary treatment per doctor recommendation (legislation)	Disorders covered: PKU, hyperlysinemia, MSUD, or any other childhood or adulthood disease, conditions, or disorders identified by the health commissioner Medical food: Parenteral and enteral nutrition products	Disorders covered: hemoglobinopathy, PKU, GALT, hypothyroidism, and CAH Other: Assistance includes referral to appropriate agencies which have financial resources to pay for medically indicated treatment such as private health insurance companies, medical assistance, MinnesotaCare, and Services for Children with Disabilities
Limits	Other: Copays may apply for insurance agreement	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	Medicaid	Coverage/Related Services Funded by Other State Programs
Legislation	No legislative mandate	Mississippi Division of Medicaid Pharmacy Prior Authorization Enteral Nutrition Prior Authorization Form	
Benefits covered		Disorders covered: IEM Medical food: Formula	
Limits		Other: Case-by-case basis	

MISSOURI			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs
Legislation	MRS § 376.1219	State of Missouri MO HealthNet Manuals Durable Medical Equipment Manual	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) Medical food: Formula Dietary supp: Modified food supplements	Disorders covered: PKU, MSUD, GA, HCY, MUT, citrullinemia, argininosuccinic acidemia, IVA, 3-hydroxy-3-methylglutaryl CoA lyase deficiency (HMG), 3-methylcrotonyl CoA carboxylase deficiency (3MCC), PROP, long-chain 3 hydroxyacyl CoA dehydrogenase deficiency (LCHAD), very-long-chain acyl-CoA dehydrogenase deficiency (VLCAD), ornithine transcarbamylase deficiency (OTC), TYR (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: Under age 21 Other: Case-by-case basis	Age and income: Income eligibility and cost sharing table Other: Health department provides formula only if all other sources have been exhausted

MONTANA			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs
Legislation	MCA 33-22-131	Montana Healthcare Programs Notice Medical Food or Formula for Phenylketonuria (PKU) due to Inborn Errors of Metabolism (IEM)	Children's Special Health Services Financial Assistance Program Information
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: PKU and IEM Medical food: Formula and medical food	
Limits	Annual cap: Caps may apply Other: Durational limits, deductibles, coinsurance, and copayments may apply		Age: Under 22 Annual cap: \$2,000 Other: Funds are limited and applications are open until funds are exhausted

	NEBRASKA			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	No legislative mandate	DME, Medical Supplies, Orthotics & Prosthetics Handbook	Newborn Screening Metabolic Foods Program: 71- 519, 71-520 (NSMFP)	
			Elemental Formula Reimbursement Program: 68-158 (EFRP)	
Benefits covered		Medical food: Formula; food supplements	NSMFP Disorders covered: All conditions included in newborn screening	
			Medical food: Formula	
			Low protein food: pharmaceutically manufactured metabolic foods	
			EFRP 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	
			Medical food: Amino acid-based elemental formulas	
Limits			NSMFP Annual cap: \$2,000 for pharmaceutically manufactured metabolic foods EFRP	
			Annual cap: \$12,000 Other: 50% of out-of-pocket costs reimbursed	

	NEVADA			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	NRS 689A.0423 (Individual plans) NRS 698B.0353 (Group plans) NRS 695B.1923 (Non-profit corporations for hospital, medical, and dental services) NRS 695C.1723 (HMOs)	Medicaid Services Manual Chapter 1300 - DME, Disposable Supplies, and Supplements		
Benefits covered	Disorders covered: Inherited metabolic diseases characterized by deficient metabolism, or malabsorption originating from congenital defects or defects arising shortly after birth, of amino acid, organic acid, carbohydrate, or fat Medical food: enteral formula Low protein food: low protein food	Disorders covered: Inborn errors of metabolism Medical food: formula (cannot be administered orally) Low protein food: low protein food		
Limits	Annual cap: \$2,500 for food Other: Prescription required for food products	Annual cap: \$2,500 for food unless proof of medical necessity exceeds that amount		

	NEW HAMPSHIRE			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	RSA 415:6-c (Coverage for non-prescription enteral formula) RSA 420-A:17 (Health services corporations) RSA 420-B:8-ff (HMOs)	Code of Administrative Rules Chapter He-W 571.04(b)(3)		
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: Specialty formula and food products		
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			

		NEW JERSEY	
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs
Legislation	Prescription Coverage NJ Rev Stat § 17B:26-2.1v (individual plans) NJ Rev Stat § 17B:27-46.1z (group plans) NJ Rev Stat § 17:48-6z (service corporations) NJ Rev Stat § 17:48A-7y (medical service corporations) NJ Rev Stat § 17:48E-35.24 (health service corporations) NJ Rev Stat § 17B:27A-7 (high Deductible Health Plans) NJ Rev Stat § 17B:27A-19 (small employer health benefit plans) Treatment of inherited metabolic diseases NJ Rev Stat § 17:48-6s (hospital service corporation) NJ Rev Stat § 17:48A-7q (medical service corporation) NJ Rev Stat § 17:48E-35.16 (health service corporation) NJ Rev Stat § 17B:26-2.1o (individual plans) NJ Rev Stat § 17B:27-46.1r (group plans) NJ Rev Stat § 17B:27A-7.4 (individual health benefits plans) NJ Rev Stat § 17B:27A-19.6 (small employer plans) NJ Rev Stat § 26:2J-4.17 (HMOs) NJ Rev Stat § 52:14-17.29c (State Health Benefits Program)	N.J.A.C § 10:51-1.14	Catastrophic Illness in Children Relief Fund
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, medical food Low protein food: low protein food		Expenses due to a child's illness that were incurred prior to the child's 22nd birthday, and the expenses: 1. Exceed 10% of the family's income that year, plus 15% of any income over \$100,000; and 2. Are not covered by insurance, other State or Federal programs, or other sources such as fundraising.
Limits	Other: Non-standard formula must be covered if policy covers prescription drugs	Other: Case-by-case basis; must be prior authorized	Age: Under 22 years

	NEW MEXICO			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	NMSA 59A-22-41.1 (Benefits covered) NMSA 59A-46-43.2 (HMOs) NMSA 59A-47-38 (Non-profit health care plans)	Medical Assistance Division Managed Care Policy Manual Policy Manual - page 313 Medical Assistance Division Program Rules NMAC 8.324.5	Children's Medical Services	
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: IEM Medical food: Medical foods	Disorders covered: Genetic/metabolic conditions and CF	
Limits	Annual cap: May apply if they apply for other illnesses Other: Durational limits may apply if they apply for other illnesses	Age: Under 21	Age: Some services only available up to age 21	

	NEW YORK			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	ISC Section 3216(i)(21) (Individual plans) ISC Section 3221(k)(11) (Group plans) ISC Section 4303(y) (HMOs)	18 NY CRR 505.5 (g) Durable Medical Equipment, Prosthetics, Orthotics, and Supplies Procedure Codes and Coverage Guidelines Webinar on prior authorization for enteral therapy: Enteral Web Portal		
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 Medical food: formula		
Limits	Annual cap: \$2,500 on low protein foods			

	NORTH CAROLINA			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	No legislative mandate	NC Medicaid Clinical Coverage Policies NC Medicaid Clinical Coverage Policy No: 5A-3	G.S. 130A-125	
Benefits covered		Disorders covered: IEM diagnosed at birth and before 10 years of age Medical food: Formula	Other: Treatment products or medications	
Limits			Other: When not otherwise available	

	NORTH DAKOTA			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	26.1-36-09.7 (Insurance companies, HMOs, nonprofit health service corporations)	North Dakota Administrative Code - 75-03-35	North Dakota Health and Human Services Metabolic Food Program (MFP) Russell-Silver Syndrome Program (RSS)	
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: PKU, MSUD (MFP), Russell-Silver Syndrome (RSS) Medical food: Medical foods (MFP), (RSS) Low-protein food: if medically necessary (MFP) 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: Males: Under 22; Females: Under 45 (older patients can purchase medical foods regardless of income) (MFP), Under 18 (RSS) Annual cap: \$50,000 every 2 years (RSS)	

	OHIO			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	No legislative mandate	OAC Rule 5160-10-26	CMH Metabolic Formula Program	
Benefits covered		Disorders covered: Conditions in which the individual is able to ingest food but cannot derive sufficient energy and nutrients from ordinary food, even if the food is prepared in a liquefied, pureed, or blended form Medical food: Formula	Disorders covered: Inborn errors of metabolism Medical food: Metabolic formula	
Limits			Other: Must receive care at an approved Ohio Regional Comprehensive Genetics Center	

	OKLAHOMA			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	No legislative mandate	Oklahoma Health Care Authority Policies and Rules 317:30-5-72.1. Drug benefit	Children and Youth with Special Health Care Needs (CYSHCN) Supplemental Security Income - Disabled Children's Program (SSI-DCP)	
Benefits covered		Disorders covered: PKU, certain rare metabolic conditions when medically necessary and prior authorized Medical food: Nutritional formulas and amino acid bars	Disorders covered: PKU (CYSHCN) Medical food: Formula (CYSHCN), supplemental oral 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	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	ORS 743A.070 (nonprescription enteral elemental formula) ORS 743A.188 (medical foods)	Division 148 HOME ENTERAL/PARENTERAL NUTRITION AND IV SERVICES		
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: Recent registered dietician assessment shows sufficient caloric/protein intake is not obtainable through regular, liquefied, or pureed foods Other: Oral nutrition supplements		
Limits		Other: Medicaid coverage on case-by-case basis		

	PENNSYLVANIA			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	2014 Act 158	37 Pa.B. 2463: Medical Assistance Program Fee Schedule; Prior Authorization Requirements	50 Pa.B. 7109 Bureau of Family Health Metabolic Formula Program	
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: IEM Medical food: Formula	Disorders covered: PKU, MSUD Medical food: Metabolic formula	
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	Age: Up to age 21 and women 22 years of age or older who are either pursuing pregnancy or are pregnant Other: Bureau of Family Health covers the cost of formula when it is not available through private insurance or Medicaid	

	RHODE ISLAND			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	R.I. Gen. Laws § 27-18-70 (accident and sickness insurance policies) R.I. Gen. Laws § 27-19-61 (nonprofit hospital	Coverage Guidelines For Durable Medical Equipment		
	R.I. Gen. Laws § 27-20-56 (individual and group plans)			
-	R.I. Gen. Laws § 27-41-74 (HMOs)	District the second sec		
Benefits covered	Disorders covered: Crohn's disease, ulcerative colitis, gastroesophageal reflux, chronic intestinal pseudo-obstruction, and inherited diseases of amino and organic acids	Disorders covered: IEM such as (but not limited to) PKU, TYR, HCY, MSUD, PROP, and MMA Medical food: Formula		
	Medical food: Enteral formula			
	Low protein food: Low protein modified foods			
	Other: Mandated coverage of newborn screening fee			
Limits	Other: Copays and/or deductibles apply	Other: Coverage on case-by-case basis		

	SOUTH CAROLINA			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	No legislative mandate	Healthy Connections Medicaid Provider Manual List Durable Medical Equipment Services Provider Manual	Special Formula Program	
Benefits covered		Disorders covered: Unspecified inborn metabolic disorders in children and some parents of dependent children	Disorders covered: Children and youth with selected medical conditions who require nutritional supplements for adequate growth and development Medical food: Nutritional preparations recommended by licensed dieticians	
Limits		Other: Coverage on case-by-case basis; may only cover if feeding tube is placed	Age: Under 18 Other: Household income at or below 250% FPL; Determination of need for special formula related to physician diagnosed medical condition covered by Children's Rehabilitative Services program	

	SOUTH DAKOTA			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	58-17-62 (individual plans) 58-18-41 (Group plans) 58-38-23 (Nonprofit medical and surgical plans) 58-41-98 (HMOs)	South Dakota Administrative Rules 67:16:42 South Dakota Medicaid Provider Manuals Nutritional Therapy Services and Nutrition Supplements Billing and Policy Manual		
Benefits covered	Disorders covered: PKU Medical food: Formula; amino acid-based formula Dietary supp: Dietary management	Disorders covered: IEM Dietary supp: Oral nutrition supplement Other: Nutrition therapy		
Limits		Other: Medicaid coverage on case-by-case basis		

	TENNESSEE			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	Tenn. Code Ann. § 56-7-2505	TennCare Medicaid Rules TennCare Medicaid Rules Chapter 1200-13-13		
Benefits covered	Disorders covered: PKU Medical food: Formula only			
Limits		Age: Up to 21 (for metabolic disorders); coverage for adults 21 and older for PKU only		

	TEXAS			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	Tex. Ins. Code Chapter 1377 (Amino acid-based elemental formula) Tex. Ins. Code Chapter 1359 (Group plans and HMOs)	Texas Medicaid and Healthcare Partnership Provider Manuals Durable Medical Equipment, Medical Supplies, and Nutritional Products Handbook	Tex. Health & Safety Code § 33.031 Children with Special Health Care Needs Services Program (CSHCN) • Medical Nutrition Services: CSHCN Services Program Provider Manual Newborn Screening Benefits Program (NBS) • Newborn Screening Benefits Contractor Procedures Manual • Contractor Procedures Manual Supplement	
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	Disorders covered: Many metabolic disorders Medical food: Formula	Disorders covered: Inborn errors of metabolism (CSHCN); various conditions – see Manual Supplement (NBS) Medical food: Formula (CSHCN & NBS) Low protein food: Low protein food (CSHCN & NBS) Dietary supp: Nutritional supplements (CSHCN & NBS) Other: Medications and vitamins (NBS)	
Limits	Other: Coverage must mirror prescription drug benefits	Age: Under 21 Other: Medicaid coverage on case-by-case basis	Age: Under 21 (CSHCN); any age for CF (CSHCN); any age, but populations are listed in priority (NBS) (see Contractor Procedures Manual) Monthly cap: \$1,500 for supplements, \$300 for vitamins (NBS); \$200 for medical foods (CSHCN) Other: Income below 200% FPL (CSHCN); Income below 350% FPL (NBS)	

	UTAH			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	Utah Code § 31A-22-623 Utah Admin. Code R590-194 (coverage standards) Utah Admin. Code R590-126 (accident and health insurance policies) Utah Admin. Code R590-233 (individual and group plans) Utah Admin. Code R590-286 (short-term limited duration health insurance)	Utah Medicaid Provider Manuals Medical Supplies and Durable Medical Equipment Provider Manual - Section 8-9.4		
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, including formulas and low protein modified food products	Disorders covered: IEM Medical foods: Formula and medical foods		
Limits				

	VERMONT			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	Vt. Stat. Ann. tit. 8 § 4089e	Department of Vermont Health Access Drug Coverage Lists Metabolic Nutrition and Nutritional Products Medical Policy Metabolic Nutrition and Nutritional Products: Covered Products		
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: Formula Low protein food: Low protein modified food products		
Limits	Annual cap: \$2,500 for low protein foods		Other: Title V functions as payer of last resort; must exhaust all other potential payers	

	VIRGINIA			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	Va. Code Ann. § 38.2-3418.18	Virginia Medicaid Durable Medical Equipment and Supplies Manual Durable Medical Equipment and Supplies Manual Covered Services and Limitations	12 VAC 5-71-160 Metabolic Formula And Food Program	
Benefits covered	Disorders covered: Inherited metabolic disorders, defined as inherited enzymatic disorders caused by single gene defects involved in the metabolism of amino, organic, or fatty acids Medical food: Formula and enteral nutrition products	Disorders covered: Inherited diseases and metabolic disorders Medical food: Medical food and formula	Medical food: Metabolic formula Low protein food: Low protein food	
Limits	Other: coverage must be provided on the same terms and subject to the same conditions imposed on other medicines covered under the policy, contract, or plan	Age: Under 21	Other: Individuals under 21 who are financially eligible for CSHCN program and individuals over 21 who have a gross family income at or below 300% FPL may qualify to receive formula at no cost; those not eligible for CSHCN program or who have a gross family income above 300% FPL may be eligible to purchase through the program. Program expenditures limited to available funding.	

	WASHINGTON			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	RCW 48.20.520 (PKU) RCW 48.21.300 (PKU) RCW 48.43.176 (Eosinophilic gastrointestinal associated disorder)	WAC 182-554-300 Washington State Health Care Authority Provider Billing Guides and Fee Schedules Enteral Nutrition Billing Guide		
Benefits covered	Disorders covered: PKU, Eosinophilic gastrointestinal associated disorders (for elemental formulas) Medical food: Formula; medically necessary elemental formula	Disorders covered: Amino acid, fatty acid, and carbohydrate metabolic disorders, including PKU Medicaid food: Enteral nutrition products		
Limits		Age: Under 21. Those 21 and older can submit an exception to rule request for coverage		

	WEST VIRGINIA			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	W. Va. Code §33-25A-8q (HMOs) W. Va. Code §33-24-7q (hospital service corporations, medical service corporations) W. Va. Code §33-16-3bb (group plans) W. Va. Code §33-15-4q (accident and sickness insurance) W. Va. Code §33-25-8n (health care corporations)	West Virginia Bureau for Medical Services Manual: Chapter 506 Durable Medical Equipment, Prosthetics, Orthotics, and Supplies Appendix C - Non-Covered DMEPOS Supplies		
Benefits covered	Disorders covered: Immunoglobulin E and Nonimmunoglobulin E-medicated allergies to multiple food proteins; Severe food protein-induced enterocolitis syndrome; Eosinophilic disorders as evidenced by the results of a biopsy; and Impaired absorption of nutrients caused by disorders affecting the absorptive surface, function, length, and motility of the gastrointestinal tract (short bowel) Medical food: amino acid-based formula			
Limits	Age: Under 21	Other: Special metabolic formulas listed as a non-covered service. For children under 21, may be covered under EPSDT. WVU Genetics Outreach Clinics may be able to help obtain coverage.		

	WISCONSIN			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	No legislative mandate	DHS 107.10(2)(c) Enteral Nutrition Formula Procedure Codes	Wis. Stat. § 253.13(2) Newborn Screening Funding	
Benefits covered		Disorders covered: Metabolic disorders Medical food: Medically necessary, specially formulated nutritional supplements and replacement products, including enteral and parenteral products	Disorders covered: congenital disorders identified by newborn screening Medical food: special dietary treatment as prescribed by a physician	
Limits				

	WYOMING			
	Private Coverage	Medicaid	Coverage/Related Services Funded by Other State Programs	
Legislation	Wyo. Stat. § 26-20-401	Wyoming Medicaid Document Library Medical Supplies and Equipment Provider Manual	Children's Special Health Program Gap-Filling Financial Assistance	
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, and propionic acidemia Other: Medical nutrition therapy	Disorders covered: IEM Medical food: medical food and formula	Disorders covered: Endocrine/metabolic conditions	
Limits		Age: Under 21	Age: Under 19 Annual cap: \$40,000 Other: Below 200% FPL	

Appendix

State Title V CSHCN Program Websites

For up-to-date contact information for Title V CSHCN Programs, please visit https://mchb.tvisdata.hrsa.gov/. If your state does not appear to have a specific medical foods coverage program, consider contacting the CSHCN program to inquire.

Alabama	https://www.rehab.alabama.gov/services/crs
Alaska	https://health.alaska.gov/dph/wcfh/pages/special-needs/default.aspx
Arizona	https://www.azdhs.gov/prevention/womens-childrens-health/cyshcn/index.php
Arkansas	https://humanservices.arkansas.gov/divisions-shared-services/developmental-disabilities-services/service-for-children-with-dd-id-needs/title-v-children-with-special-health-needs/
California	https://www.cdph.ca.gov/Programs/CFH/DMCAH/Pages/CYSHCN.aspx#program-profile
Colorado	https://cdphe.colorado.gov/children-and-youth-with-special-health-care-needs
Connecticut	https://portal.ct.gov/dph/Family-Health/Children-and-Youth/ChildrenYouth-with-Special-Health-Care-Needs-and-Connecticuts-Medical-Home-Initiative
Delaware	https://dhss.delaware.gov/dph/chca/dphcshcn.html
District of Columbia	https://dchealth.dc.gov/service/children-and-youth-special-health-care-needs
Florida	https://www.floridahealth.gov/programs-and-services/childrens-health/cms-specialty-programs/title-5-program/index.html
Georgia	https://dph.georgia.gov/CMS
Hawaii	https://health.hawaii.gov/cshcn/
Idaho	https://healthandwelfare.idaho.gov/services-programs/about-childrens-special-health-program
Illinois	https://dscc.uic.edu/

Indiana	https://www.in.gov/health/cshcs/
Iowa	https://chsciowa.org/
Kansas	https://www.kdhe.ks.gov/747/Special-Health-Care-Needs
Kentucky	https://www.chfs.ky.gov/agencies/ccshcn/Pages/default.aspx
Louisiana	https://ldh.la.gov/page/ChildrenSpecialHealth
Maine	https://www.maine.gov/dhhs/mecdc/population-health/mch/cshn/
Maryland	https://health.maryland.gov/phpa/genetics/Pages/home.aspx
Massachusetts	https://www.mass.gov/orgs/division-for-children-youth-with-special-health-needs
Michigan	https://www.michigan.gov/mdhhs/assistance-programs/cshcs
Minnesota	https://www.health.state.mn.us/people/childrenyouth/cyshn/index.html
Mississippi	https://msdh.ms.gov/page/41,0,163.html
Missouri	https://health.mo.gov/living/families/shcn/cyshcn.php
Montana	https://dphhs.mt.gov/ecfsd/cshs/index
Nebraska	https://dhhs.ne.gov/Pages/Special-Health-Care-Needs.aspx
Nevada	https://dpbh.nv.gov/Programs/CYSHCN/CYSHCN-Home/
New Hampshire	https://www.dhhs.nh.gov/programs-services/disability-care/developmental-services/children-special-health-care-needs
New Jersey	https://www.nj.gov/health/fhs/specialneeds/
New Mexico	https://www.nmhealth.org/about/phd/fhb/cms/
New York	https://www.health.ny.gov/community/special_needs/

North Carolina	https://www.ncdhhs.gov/divisions/child-and-family-well-being/whole-child-health-section/best-practices/children-and-youth-special-health-care-needs
North Dakota	https://www.hhs.nd.gov/health/children/special-health-services
Ohio	https://odh.ohio.gov/about-us/offices-bureaus-and-departments/bmch/children-with-medical-handicaps
Oklahoma	https://oklahoma.gov/okdhs/services/health/children-with-special-health-care-needs.html
Oregon	https://www.ohsu.edu/occyshn
Pennsylvania	https://www.health.pa.gov/topics/programs/Special%20Kids%20Network/pages/special%20kids%20network.aspx
Puerto Rico	https://www.salud.pr.gov/CMS/38
Rhode Island	https://health.ri.gov/programs/detail.php?pgm_id=105
South Carolina	https://scdhec.gov/health/child-teen-health/services-children-special-health-care-needs
South Dakota	https://doh.sd.gov/family/childhood/cyshcn.aspx
Tennessee	https://www.tn.gov/health/health-program-areas/mch-cyshcn/cyshcn-section.html
Texas	https://www.hhs.texas.gov/services/disability/children-special-health-care-needs-program
Utah	https://health.utah.gov/cshcn/
Vermont	https://www.healthvermont.gov/family/children-special-health-needs
Virginia	https://www.vdh.virginia.gov/care-connection-for-children/
Washington	https://doh.wa.gov/you-and-your-family/infants-and-children/health-and-safety/children-and-youth-special-health-care-needs
West Virginia	https://www.wvdhhr.org/cshcn/about.asp
Wisconsin	https://www.dhs.wisconsin.gov/cyshcn/index.htm
Wyoming	https://health.wyo.gov/publichealth/mch/specialhealth/

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