



**Rules of
Department of Health and
Senior Services**

**Division 40—Division of Maternal, Child and
Family Health**

Chapter 7—Metabolic Formula Program

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**Title 19—DEPARTMENT OF
HEALTH AND SENIOR SERVICES
Division 40—Division of Maternal, Child
and Family Health
Chapter 7—Metabolic Formula Program**

19 CSR 40-7.010 Definitions

PURPOSE: This rule defines the terms used in this chapter.

(1) Client is a person who meets eligibility requirements as defined by 19 CSR 40-7.020 Program Eligibility, and is approved for participation in the phenylketonuria (PKU) program.

(2) Department is the Missouri Department of Health.

(3) Formula Distribution Program (FDP) is a program of the department through which low-protein formula, a special dietary product, is provided to individuals diagnosed as having PKU, maple syrup urine disease (MSUD) and other metabolic conditions as approved by the Newborn Screening Standing Committee. The Newborn Screening Standing Committee, a subcommittee of the Missouri Genetic Advisory Committee, makes recommendations on newborn screening issues.

(4) Maple syrup urine disease (MSUD) is a metabolic disorder due to a defect in the enzyme that is responsible for the metabolism of the essential branched-chain amino acids isoleucine, leucine and valine.

(5) Metabolic treatment center is a medical facility with the capacity to diagnosis metabolic conditions and to provide comprehensive medical management.

(6) Phenylketonuria (PKU) is a hereditary disorder of phenylalanine metabolism characterized by brain damage and mental retardation due to accumulation of toxic metabolic products.

(7) Resident is an individual being present in Missouri with the intention to abandon their previous domicile and to remain in Missouri permanently.

(8) This rule expires on June 30, 2002.

*AUTHORITY: sections 191.300–191.380, RSMo (1994 and Supp. 1995). * Emergency rule filed Aug. 19, 1996, effective Aug. 29, 1996, expired Feb. 24, 1997. Original rule filed Aug. 15, 1996, effective Jan. 30, 1997.*

**Original authority: 191.300–191.310, RSMo (1985); 191.315, RSMo (1985), amended 1993, 1995; 191.317–191.325, RSMo (1985); 191.331, RSMo (1965), amended 1985, 1992, 1993, 1995; 191.335, RSMo (1979); 191.340, RSMo (1979), amended 1985; 191.360–191.362, RSMo (1983); and 191.365–191.380, RSMo (1985).*

19 CSR 40-7.020 Program Eligibility

PURPOSE: The Department of Health (DOH) provides low-protein formula, a special dietary product, to individuals diagnosed as having phenylketonuria (PKU), maple syrup urine disease (MSUD) and other metabolic conditions as approved by the Newborn Screening Standing Committee. This rule establishes the criteria by which the Formula Distribution Program accepts clients for service.

(1) Conditions of eligibility for the Formula Distribution Program (FDP) include:

(A) A client must be diagnosed as having phenylketonuria (PKU), maple syrup urine disease (MSUD) or other metabolic condition as approved by the Newborn Screening Standing Committee. The diagnosis must be made by a physician who practices at a metabolic treatment center;

(B) A client must be a resident of Missouri and cannot reside in a state facility;

(C) A client must be financially eligible for FDP as defined by this rule;

(D) The physician treating the client must submit the following information to the department:

1. A letter requesting the client be put on the FDP;

2. The name and address of the client; and

3. A prescription, signed by the treating physician, stating the name of the low-protein formula, a special dietary product, the individual will be using; and

(E) Financial eligibility guidelines for enrollment in the FDP shall be based upon the Poverty Income Guidelines as established by the United States Department of Health and Human Services. Determination of individual client eligibility shall be based upon the following:

1. Total adjusted gross income shall not exceed one hundred and eighty-five percent (185%) of the federal poverty income guidelines for the family size as stated in subsection (1)(E) of this rule;

2. Size of family unit shall be the number of persons in the household, including the responsible party(ies) and dependents allowable by the Internal Revenue Service as federal income tax exemptions. If there is more than one (1) eligible FDP client in the household, the total family size shall be increased

by one (1) unit for each additional client. The family size may be increased by two (2) additional family members per affected child for the cost of low-protein formula, a special dietary product; and

3. Funding to eligible clients may be adjusted by the department based on available funding.

(2) This rule expires on June 30, 2002.

*AUTHORITY: sections 191.300–191.380, RSMo (1994 and Supp. 1995). * Original rule filed Aug. 15, 1996, effective Jan. 30, 1997.*

**Original authority: 191.300–191.310, RSMo (1985); 191.315, RSMo (1985), amended 1993, 1995; 191.317–191.325, RSMo (1985); 191.331, RSMo (1965), amended 1985, 1992, 1993, 1995; 191.335, RSMo (1979); 191.340, RSMo (1979), amended 1985; 191.360–191.362, RSMo (1983); and 191.365–191.380, RSMo (1985).*

19 CSR 40-7.030 Client Responsibilities

PURPOSE: This rule establishes how clients maintain program eligibility.

(1) The client or the client's parent(s) or legal guardian shall provide the department with accurate information concerning their financial status.

(2) The client or the client's parent(s) or legal guardian shall meet the following requirements:

(A) Complete a Formula Distribution Program (FDP) application and submit a copy of their most current 1040 tax form;

(B) Report any major changes in income, household composition, insurance, Medicaid coverage or address within ten (10) working days after the date the client or the client's parent(s) or legal guardian becomes aware of the change; and

(C) When the client is eligible, payments shall be made for such services through Medicaid or other insurance benefits available to the client to the fullest possible extent. The benefits available under the provisions of section 191.331, RSMo (1994) shall not replace those provided under other federal or state law or under other contractual or legal entitlements of the persons receiving them.

(3) To maintain eligibility, a client shall submit a new application prior to the end of the eligibility period. An eligibility period shall be the year following the anniversary date of original application or year following the date of the filing of a new 1040 tax form. Each new application submitted must meet the eligibility requirements.



(4) Sections (1)–(3) of this rule are mandatory. If these requirements are not met by the client or the client's parent(s) or legal guardian, the FDP may discontinue services.

(5) Any applicant determined ineligible for the FDP may reapply based on changes which may make them eligible.

(6) When an application is denied, the applicant shall be informed of the right to appeal.

(7) This rule expires on June 30, 2002.

*AUTHORITY: sections 191.300–191.380, RSMo (1994 and Supp. 1995). * Emergency rule filed Aug. 19, 1996, effective Aug. 29, 1996, expired Feb. 24, 1997. Original rule filed Aug. 15, 1996, effective Jan. 30, 1997.*

**Original authority: 191.300–191.310, RSMo (1985); 191.315, RSMo (1985), amended 1993, 1995; 191.317–191.325, RSMo (1985); 191.331, RSMo (1965), amended 1985, 1992, 1993, 1995; 191.335, RSMo (1979); 191.340, RSMo (1979), amended 1985; 191.360–191.362, RSMo (1983); and 191.365–191.380, RSMo (1985).*

19 CSR 40-7.040 Definitions

PURPOSE: This rule defines the terms used in this chapter.

(1) Client is a person who meets eligibility requirements as defined by 19 CSR 40-7.050 Program Eligibility, and is approved for participation in the Metabolic Formula Program (MFP).

(2) Department is the Missouri Department of Health and Senior Services.

(3) The Metabolic Formula Program is a program of the department through which low-protein formula, a special dietary product, is provided to individuals diagnosed as having phenylketonuria (PKU), maple syrup urine disease (MSUD) and other metabolic conditions as approved by the Newborn Screening Standing Committee. The Newborn Screening Standing Committee, a subcommittee of the Missouri Genetic Advisory Committee, makes recommendations on newborn screening issues.

(4) Maple syrup urine disease (MSUD) is a metabolic disorder due to a defect in the enzyme that is responsible for the metabolism of the essential branched-chain amino acids isoleucine, leucine and valine.

(5) Metabolic treatment center is a medical facility with the capacity to diagnose metabolic conditions and to provide comprehensive medical management.

(6) Phenylketonuria (PKU) is a hereditary disorder of phenylalanine metabolism characterized by brain damage and mental retardation due to accumulation of toxic metabolic products.

(7) Resident is an individual having a domicile in Missouri with the intention to live in Missouri on a permanent basis.

(8) Sliding fee scale is the tool utilized to determine the monthly premium to be paid for the MFP program services.

*AUTHORITY: section 191.315, RSMo 2000 and sections 191.331 and 191.332, RSMo Supp. 2007. * Emergency rule filed Sept. 7, 2007, effective Sept. 17, 2007, expired March 14, 2008. Original rule filed Nov. 1, 2007, effective May 30, 2008.*

**Original authority: 191.315, RSMo 1985, amended 1993, 1995; 191.331, RSMo 1965, amended 1985, 1992, 1993, 1995, 1997, 2007; and 191.332, RSMo 2001, amended 2005.*

19 CSR 40-7.050 Program Eligibility

PURPOSE: The Department of Health and Senior Services (DHSS) provides low-protein formula, a special dietary product, to individuals diagnosed as having phenylketonuria (PKU), maple syrup urine disease (MSUD) and other metabolic conditions as approved by the Newborn Screening Standing Committee, a subcommittee of the Missouri Genetic Advisory Committee which makes recommendations to the department on newborn screening issues. This rule establishes the criteria by which the Metabolic Formula Program accepts clients for service.

(1) Conditions of eligibility for the Metabolic Formula Program (MFP) include:

(A) An applicant must be diagnosed as having phenylketonuria (PKU), maple syrup urine disease (MSUD) or other metabolic conditions as approved by the Newborn Screening Standing Committee and recommended to the department. The diagnosis must be made by a physician who practices at a metabolic treatment center;

(B) An applicant must be a resident of Missouri and cannot reside in a state facility. Proof of residency will consist of submitting a copy of the previous month's utility bill with the applicant's home address clearly printed;

(C) The physician treating the applicant must submit the following information to the department:

1. A letter requesting the applicant be placed on the MFP;

2. The name and address of the applicant; and

3. A prescription, signed by the treating physician, stating the name of the low-protein formula, a special dietary product the individual will be using; and

(D) Financial eligibility guidelines for enrollment in the MFP shall be based upon the Poverty Income Guidelines as established by the United States Department of Health and Human Services. Determination of individual applicant eligibility shall be based upon the following:

1. Applicants five (5) years or under shall have no income qualification requirements;

2. Applicants six (6) through eighteen (18) years whose family income is below three hundred percent (300%) of the federal poverty level shall be eligible for enrollment in the MFP;

3. Applicants six (6) through eighteen (18) years whose family income is at three hundred percent (300%) of the federal poverty level or above shall be eligible based on a sliding fee scale for enrollment in the MFP;

4. Applicants nineteen (19) years and above whose income does not exceed one hundred eighty-five percent (185%) of the federal poverty level shall be eligible for enrollment in the MFP;

5. Size of family unit shall be the number of persons in the household, including the responsible party(ies) and dependents allowable by the Internal Revenue Service as federal income tax exemptions. The family size may be increased by two (2) additional family members per affected individual nineteen (19) years and above for the cost of low-protein formula; and

6. Funding to eligible applicants may be adjusted by the department based on available funding.

(2) A sliding fee scale shall be used to determine the amount of monthly premium and assistance to be provided by the department for those individuals six (6) through eighteen (18) years having no insurance, Medicaid or Medicare and whose adjusted gross income places the family at three hundred percent (300%) of the federal poverty level or above. The sliding fee scale shall be updated based on changes in the federal poverty guidelines. The adjusted gross income line from Internal Revenue Service recognized tax forms shall be the income used to determine financial eligibility with adjustments for child support received or paid. The table for establishing a sliding scale fee of premiums is provided below.



Table: Sliding Fee Scale for those Applicants Age 6 through 18 Years Based on Family Adjusted Gross Income

Adjusted Gross Income is:	Approximate Family Monthly Premium for Formula*
299% of poverty or below	0
300% - 399% of poverty	25%
400 - 499% of poverty	40%
500% of poverty and above	50%

*Based upon DHSS cost of formula and subject to available funding for the program.

(3) Approved applicants having no insurance coverage for metabolic formula, Medicaid benefits or other third party payor will have formula provided as prescribed by the person's genetic disease physician or a general physician in consultation with the genetic disease physician at the metabolic treatment center.

AUTHORITY: section 191.315, RSMo 2000 and sections 191.331 and 191.332, RSMo Supp. 2007. Emergency rule filed Sept. 7, 2007, effective Sept. 17, 2007, expired March 14, 2008. Original rule filed Nov. 1, 2007, effective May 30, 2008.*

**Original authority: 191.315, RSMo 1985, amended 1993, 1995; 191.331, RSMo 1965, amended 1985, 1992, 1993, 1995, 1997, 2007; and 191.332, RSMo 2001, amended 2005.*

19 CSR 40-7.060 Application Process

PURPOSE: This rule establishes how individuals apply for participation in the Metabolic Formula Program.

(1) Application for participation in the Metabolic Formula Program (MFP) shall be made on forms designated by the Department of Health and Senior Services. Application forms may be requested from the Department of Health and Senior Services, PO Box 570, Jefferson City, MO 65102-0570.

(2) The applicant, or if the applicant is a minor or incapacitated, the applicant's parent(s) or legal guardian, shall:

(A) Submit a copy of their most current federal 1040 tax form and complete a Metabolic Formula Program application that includes: the applicant's last name, first, middle initial; date of birth; gender; race; marital status; Social Security number; address (street, city, state, zip); county of residence; home telephone number; cell telephone number; work telephone number; responsible party (last, first, middle initial),

relationship and phone number; a copy of any applicable court appointed guardian/custodian document; dependents claimed on federal income tax filing (last, first, middle initial), relationship to the applicant and social security number of the dependents; alternate contact (last, first, middle initial), relationship to the applicant and phone number; MO HealthNet number (if applicable); amount of MO HealthNet spend down per month (if applicable); copy of the front and back on any third party payors (if applicable); other proof of income if the most recent federal income tax filing is not reflective of the current financial status; yearly amount of child support received; and yearly amount of child support paid.

(B) Submit a copy of the previous month's utility bill with the applicant's home address clearly printed as proof of residency.

(C) Report any major changes in income, household composition, insurance, MO HealthNet coverage or address within ten (10) working days after the date the applicant or the applicant's parent(s) or legal guardian becomes aware of the change.

(3) When the applicant is eligible, payments shall be made for such services through MO HealthNet or other insurance benefits available to the applicant to the fullest possible extent. The benefits available under the provisions of section 191.331, RSMo Supp. 2007 shall not replace those provided under other federal or state law or under other contractual or legal entitlements of the persons receiving them.

(4) The applicant is responsible for paying for any amount of debt incurred above the program amount paid by the department based on the established sliding fee scale in 19 CSR 40-7.050.

(5) The applicant or the applicant's parent(s) or legal guardian shall provide the department with complete and accurate information concerning their financial status.

(6) To maintain eligibility, an applicant shall submit a new application prior to the end of

the eligibility period. The eligibility period shall be the state fiscal year, July 1 through June 30. Each new application submitted must meet the eligibility requirements and the most recent federal 1040 tax form must be submitted with the application. Applications may be accepted any time during the fiscal year.

(7) If the applicant or the applicant's parent(s) or legal guardian does not meet the requirements of sections (1)–(3) of this rule, the MFP shall discontinue services. The applicant may retain eligibility for service coordination services if the applicant's income exceeds income eligibility guidelines.

(8) Any applicant determined ineligible for the MFP may reapply based on changes, which may make them eligible.

AUTHORITY: section 191.315, RSMo 2000 and sections 191.331 and 191.332, RSMo Supp. 2007. Emergency rule filed Sept. 7, 2007, effective Sept. 17, 2007, expired March 14, 2008. Original rule filed Nov. 1, 2007, effective May 30, 2008.*

**Original authority: 191.315, RSMo 1985, amended 1993, 1995; 191.331, RSMo 1965, amended 1985, 1992, 1993, 1995, 1997, 2007; and 191.332, RSMo 2001, amended 2005.*