
PKU (PHENYLKETONURIA) COVERAGE OF TESTING AND TREATMENT

Policy

VCHCP covers the testing for and treatment of phenylketonuria (PKU) for members of any age when deemed medically necessary to avert the development of serious physical or mental disabilities or to promote normal development or function because of PKU. VCHCP also covers special enteral formulas and specially formulated food, when such products are used in place of normal products and to the extent that their cost exceeds the cost of a normal diet (see below).

Coverage of Special Formulas

Coverage includes special formulas and diet powders for use in the dietary management of members with PKU. Their restriction in phenylalanine content differentiates these metabolites from other products. These enteral products are available in liquid form or in a diet powder intended to be mixed with semisolid food, water or other appropriate beverages. Certain PKU formulas are on the Plan's Drug Formulary. The names of these products can be obtained by contacting the Customer Service Department (805-981-5050 option 1). Other PKU formulas and diet powders are covered if prior approval is obtained from the plan.

Coverage of Special Food Products

Coverage of special food products is limited to food products that are specially formulated to have less than one gram of protein per serving and to be used in place of normal food products. Not included are foods that are naturally low in protein or available to the general population in a grocery store. Examples are apple fiber or low protein flour used in baking, and low protein spaghetti, flour, crackers, cookies, pretzels, Jello and tomato sauce. Plan prior authorization is required. For each food item, the member must submit unit price, Nutrition Facts (including protein grams per serving), quantity requested and expected monthly consumption. Not covered is the cost of cookbooks, recipes, subscriptions, catalogues or cooking equipment (such as bread machines).

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Coverage Criteria

The following criteria are used by the plan in making coverage determinations:

**VCHCP Medical Policy 049: PKU (phenylketonuria),
Coverage Of Testing and Treatment**

Effective: 10/6/2000

Reviewed:

Reviewed/No Updates: 2/13/20, 2/11/21, 2/17/22, 2/2/22, 2/8/24,
2/20/25, 2/12/26

- a) The prescribed diet must be deemed medically necessary to avert the development of serious physical or mental disabilities or to promote normal development or function because of PKU. A blood phenylalanine of more than 6 mg/dl may signify that a special diet is needed.
- b) The prescribing provider should have expertise and experience in the treatment and care of PKU, ideally in consultation with a contracted endocrinologist.

A. Attachments: None

B. References:

SB148 (1999), Health and Safety Code §1374.56

Mead Johnson, Product Description for Health Care Professionals, Dietary management of Individuals with Metabolic Disorders

National PKU News website: www.pkunews.org

C. History:

Reviewed/No Updates: Howard Taekman, MD & Robert Sterling, MD

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Revision Date	Content Revised (Yes/No)	Contributors	Review/Revision Notes
2/13/20	No	Howard Taekman, MD; Robert Sterling, MD	Annual Review
2/11/21	No	Howard Taekman, MD; Robert Sterling, MD	Annual Review
2/17/22	No	Howard Taekman, MD; Robert Sterling, MD	Annual Review
2/2/23	No	Howard Taekman, MD; Robert Sterling, MD	Annual Review
2/8/24	No	Howard Taekman, MD; Robert Sterling, MD	Annual Review
2/20/25	Yes	Howard Taekman, MD and Robert Sterling, MD	Added ph# to Customer Service

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2/20/25, 2/12/26

			Department “(805-981-5050 option 1)” Removed “The members are also encouraged to submit comparison costs of normal foods. After coverage is authorized, the member is required to pay out of pocket and seek reimbursement from the plan (see form below).”
2/12/26	No	Robert Sterling, MD	Annual Review