

AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: Late 1003
(A-16)

Introduced by: American College of Medical Genetics and Genomics

Subject: Health Coverage for Nutritional Products for Inborn Errors of Metabolism

Referred to: Reference Committee A
(A. Patrice Burgess, MD, Chair)

- 1 Whereas, Individuals with inborn errors of metabolism (e.g., ornithine transcarbamylase [OTC]
2 deficiency) require specialized nutrition for health and survival; and
3
4 Whereas, Nineteen of the core newborn screening conditions (e.g., phenylketonuria [PKU]) on
5 the Recommended Uniform Screening Panel (RUSP) utilize medical foods and would not be on
6 the RUSP if it weren't for these treatments; and
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8 Whereas, Failure to treat can result in intellectual disability, stroke, or death, depending on the
9 condition; and
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11 Whereas, This medical food is of necessity manufactured and is not a natural food; and
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13 Whereas, These products are expensive to produce for a small population, and are therefore
14 costly; and
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16 Whereas, These products are not considered medication nor considered an essential health
17 benefit under the Affordable Care Act despite the inclusion of screening for conditions that are
18 treated with medical foods; and
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20 Whereas, Only some Medicaid Departments provide coverage for these products, many don't
21 and many private insurer and self-funded insurance plans do not; and
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23 Whereas, Existing AMA Policy H-185.945 supports efforts to establish a uniform requirement
24 that health plans offer coverage of medical foods and foods modified to be low in protein for
25 conditions identified through newborn screening; therefore be it
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27 RESOLVED, That our American Medical Association support legislation mandating insurance
28 coverage with minimal deductible or copays for specialized medical food products used to treat
29 inborn errors of metabolism(New HOD Policy); and be it further
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31 RESOLVED, That our AMA advocate with the Department of HHS and members of Congress
32 for the regulation of specialized nutritional products for the medical treatment of inborn errors of
33 metabolism as drugs. (New HOD Policy)

Fiscal Note: Not yet determined

Received: 05/20/16

RELEVANT AMA POLICY

Medical Foods H-185.945

Our American Medical Association:

- (1) supports legislation to establish a uniform requirement that health plans offer coverage of medical foods and foods modified to be low protein for those conditions recommended by the US Department of Health and Human Services Advisory Committee on Heritable Disorders in Newborns and Children. Health plans would include federal insurance programs' (Children's Health Insurance Program, Tricare, and Medicaid) and those plans governed by the Employment Retirement Income Security Act (ERISA) and would not be subject to state exclusions;
- (2) supports amending Medicaid's enabling legislation (Title XIX of the Social Security Act) to ensure more uniform coverage by state Medicaid programs of medical foods and foods modified to be low protein for those conditions recommended by the US Department of Health and Human Services Advisory Committee on Heritable Disorders in Newborns and Children. (Medical foods are not mentioned in the federal Medicaid statute allowing significant variation across states with respect to the coverage of medical foods. Amending ?1905(a) of the federal statute would encourage best practices and ensure greater uniformity.);
- (3) supports that medical foods (as defined by the FDA and for those conditions tested for in newborn screening programs) delivered either orally or by tube (both are enteral) and foods modified to be low protein used under the direction of a physician for the treatment of an inborn error of metabolism should be included as medical benefits and not restricted to pharmacy benefits;
- (4) supports that pharmacological doses of vitamins and amino acids used specifically for the treatment of inborn errors of metabolism for those conditions tested for in newborn screening programs under the direction of a physician will be covered; and
- (5) supports that a minimum yearly coverage should be set for all health insurance plans, including those covered by the Children's Health Insurance Program, Tricare, and Medicaid and those governed under the ERISA. The Secretary of Health and Human Services will have authority to set age-specific minimum levels of coverage and periodically update these levels based on a standard cost of living index.

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