

REVENUE: No revenue impact

FISCAL: Minimal fiscal impact, no statement issued

Action: Do Pass

Vote: 10 - 0 - 0

Yeas: Bruun, Cannon, Dembrow, Garrett, Harker, Kennemer, Kotek, Maurer, Thompson, Greenlick

Nays: 0

Exc.: 0

Prepared By: Roxie Cuellar, Administrator

Meeting Dates: 5/6, 5/18, 5/20

WHAT THE MEASURE DOES: Removes sunset on requirement that health insurers, health care service contractors, and multiple employer welfare arrangements provide coverage for treatment of inborn errors of metabolism under specified conditions. Declares an emergency; effective July 1, 2009.

ISSUES DISCUSSED:

- Legislative history and evolution of Oregon's phenylketonuria (PKU) legislation
- Oregon Medical Foods law
- Importance of early and immediate detection
- Impact of a mandate
- Health insurers' support
- Medical food treatment as a lifetime therapy
- Proposed amendment
- Relating to clause

EFFECT OF COMMITTEE AMENDMENT: No amendment.

BACKGROUND: The Oregon Medical Foods law was first passed in 1997 (and again in 2003) because parents of children diagnosed with Inborn Errors of Metabolism were being denied reimbursement for the medical foods needed to treat these conditions. The United States Food and Drug Administration (FDA) definition of medical food is "a food which is formulated to be consumed or administered entirely under the supervision of a physician, and intended for the specific dietary management of a disease." Dietary therapy must be continued throughout life.

PKU is an inherited disease, which prevents an individual's body from processing phenylalanine, and the excess accumulates in the blood and begins to damage the brain. Without treatment or prevention the brain damage is severe and irreversible. The use of medical foods can prevent mental retardation, gross motor dysfunction, strokes, tremors, seizures, coma and death.

Treatment for PKU is so successful that all newborns are, by law, screened for it. Oregon was the first state to require screening for this disorder. Expansion of newborn screening in Oregon now allows the pre-symptomatic detection and treatment of over 30 inborn errors of metabolism. Ten infants with this disease are born each year in Oregon. For the past 46 years, the Public Health Division, in partnership with Oregon Health & Sciences University, has provided early detection, medical consultation, follow-up, and clinical intervention for metabolic disorders to prevent early mortality or lifelong disability. They have screened 1.7 million Oregon infants and identified over 650 with metabolic disorders in need of treatment.

5/21/2009 4:12:00 PM

This summary has not been adopted or officially endorsed by action of the committee.