

REVENUE: No revenue impact

FISCAL: Minimal fiscal impact, no statement issued

Action: Do Pass
Vote: 5 - 0 - 0
Yeas: Bates, Kruse, Morrisette, Morse, Monnes Anderson
Nays: 0
Exc.: 0
Prepared By: Robert Shook, Administrator
Meeting Dates: 2/12, 2/19

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. Becomes effective July 1, 2009.

ISSUES DISCUSSED:

- Sunset provisions and history of Oregon Medical Foods law
- Inherited metabolic diseases, causes and treatment
- Insurance coverage for medical foods prescribed

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 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.

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. 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. Prior to universal PKU screening, one percent of all admissions to Oregon’s Fairview Training Center were for untreated PKU. After PKU screening began, there was never another such admission.

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.