

REVENUE: No revenue impact

FISCAL: Fiscal statement issued

Action:	Do Pass as Amended, Be Printed Engrossed, and Be Referred to the Committee on Ways and Means
Vote:	5 - 0 - 0
Yeas:	Bates, Kruse, Morrisette, Morse, Monnes Anderson
Nays:	0
Exc.:	0
Prepared By:	Robert Shook, Administrator
Meeting Dates:	3/17, 3/31, 4/23

WHAT THE MEASURE DOES: Directs Department of Human Services to establish, once sufficient funding is secured, a registry and advisory committee related to birth anomalies and adverse pregnancy outcomes. Develops collaborative partnership with March of Dimes to operate and maintain the registry and tracking system.

ISSUES DISCUSSED:

- Advantages of a birth anomalies registry
- Prevention strategies and high risk populations
- Potential funding from Centers for Disease Control and Prevention
- Oregon is one of only four states that without a birth anomalies registry

EFFECT OF COMMITTEE AMENDMENT: Clarifies that the registry will be established when the Department secures sufficient funding, and that the March of Dimes will collaborate with the Department in establishing, operating, and maintaining the registry and tracking system.

BACKGROUND: A birth anomaly or birth defect means any abnormality of structure, function or body metabolism, present at birth. An adverse pregnancy outcome means stillbirth, miscarriage, preterm birth, fetal growth restriction, or death of the mother in childbirth. Birth defects are found in two to three percent of all newborn infants, and almost 20 percent of deaths in newborns are caused by birth defects.

Currently, there is no state-wide registry to collect and analysis medical information regarding persons who have been newly diagnosed with a birth anomaly or persons discharged with an adverse pregnancy outcome. With the presence of a statewide registry and tracking system, the state is in a position to better investigate the incidence, trends and causes of birth defects and adverse pregnancy outcomes, better able to develop, assess and evaluate measures to prevent birth defects, and better able to help in the development of strategies to improve the access of children with birth anomalies to health and early intervention services. Oregon is one of only four states without a birth anomalies registry.

Senate Bill 460-A establishes a birth anomalies registry that includes provisions for confidentiality of information, the creation of an advisory committee of health professionals and community members serving as volunteers to advise the Department of Human Services in the operational aspects of registry and tracking system, and strengthen Oregon's ability to understand and respond to birth anomalies among children through prevention and early intervention.