

SB 215 STAFF MEASURE SUMMARY

Senate Committee On Health Care

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Sub-Referral To: Joint Committee On Ways and Means

Meeting Dates: 2/16, 3/23

WHAT THE MEASURE DOES:

Requires the Oregon Health Authority (OHA) to establish, operate and evaluate a database to collect information on the treatment of rare diseases. Defines the term “rare disease.” Specifies an initial set of rules to govern access to and use of the database including data confidentiality and authorized users. Requires OHA to establish an advisory committee to oversee the database.

REVENUE: May have revenue impact, but no statement yet issued.

FISCAL: May have fiscal impact, but no statement yet issued.

ISSUES DISCUSSED:

- Federal Office of Rare Diseases, which maintains a centralized database on rare disease clinical research supported by the National Institute of Health (NIH)
- Challenge among providers to know the existence and use of medical treatment protocols for rare diseases
- Potential data breaches, liability clause, and immunity for health care professionals who would use the rare disease database
- Allow individuals to opt-in and share their information vs. opting out.
- Use of Oregon’s Physician Orders for Life-Sustaining Treatment (POLST) to potentially build the rare disease database.

EFFECT OF AMENDMENT:

No amendment.

BACKGROUND:

Approximately 7,000 rare diseases are listed in the Global Rare Diseases Registry with an estimated 25 million people in the United States living with a rare disease. According to the National Institutes of Health, a rare disease is a disease or condition affecting fewer than 200,000 persons in the United States. Reliable information about rare diseases from research studies and clinical studies is difficult to find for health care providers to help diagnoses and treat such diseases. Individuals and families are often unable to locate information, resources or services for people living with a rare disease, once diagnosed.

Senate Bill 215 establishes a statewide database for health care providers, hospitals, urgent care centers and State police to access information to treat rare diseases.