

SB 215 STAFF MEASURE SUMMARY

Senate Committee On Health Care

Action Date: 03/23/17

Action: Without recommendation as to passage and be returned to President's desk for referral to another committee.

Vote: 5-0-0-0

Yeas: 5 - Beyer, Knopp, Kruse, Monnes Anderson, Steiner Hayward

Fiscal: Fiscal impact issued

Revenue: No revenue impact

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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.

ISSUES DISCUSSED:

- Federal Office of Rare Diseases maintains a centralized database on rare disease clinical research supported by the National Institutes 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 that use the database
- Allow individuals to opt-in and share their information versus opting out
- Use of Oregon's Physician Orders for Life-Sustaining Treatment (POLST) to build the database

EFFECT OF AMENDMENT:

No amendment.

BACKGROUND:

Approximately 7,000 rare diseases are currently 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 diagnose and treat such diseases. Additionally, it is often difficult for individuals and families to locate information, resources or services for people diagnosed and living with a rare disease.

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