

## HB 2457 STAFF MEASURE SUMMARY

### House Committee On Behavioral Health and Health Care

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**Prepared By:** Brian Nieubuurt, LPRO Analyst

**Sub-Referral To:** Joint Committee On Ways and Means

**Meeting Dates:** 1/30

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#### **WHAT THE MEASURE DOES:**

The measure establishes the Rare Disease Advisory Council in the Oregon Health Authority.

#### Detailed Summary

- Defines "rare disease" as disease affecting fewer than 200,000 people in the United States
- Establishes the Rare Disease Advisory Council in the Oregon Health Authority and specifies responsibilities and membership
- Beginning in 2028, requires Advisory Council to submit a report in each even-numbered year to the Governor and Legislative Assembly

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

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

#### **ISSUES DISCUSSED:**

#### **EFFECT OF AMENDMENT:**

No amendment.

#### **BACKGROUND:**

According to the National Organization for Rare Diseases (NORD), there are over 10,000 rare diseases that together affect more than 30 million Americans. There are currently 28 states with rare disease advisory councils (RDACs). RDACs serve as an advising body and liaison between the rare disease community and state government, helping to inform, evaluate, and offer recommendations on policies and issues relevant to the rare disease community.

House Bill establishes the Rares Disease Advisory Council in the Oregon Health Authority.