

HB 2457 STAFF MEASURE SUMMARY

House Committee On Behavioral Health and Health Care

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Sub-Referral To: Joint Committee On Ways and Means

Meeting Dates: 1/30, 2/20

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: Fiscal impact issued

REVENUE: No revenue impact

ISSUES DISCUSSED:

- RDACs impacts in other states
- Access and quality of care challenges for people with rare diseases
- Prevalence of rare disease in Oregon
- Potential interaction with Health Evidence Review Commission (HERC)

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 2457 establishes the Rares Disease Advisory Council in the Oregon Health Authority.