



Legislative Fiscal Office  
 83<sup>rd</sup> Oregon Legislative Assembly  
 2025 Regular Session

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**Bill Title:** Relating to the Rare Disease Advisory Council.

**Government Unit(s) Affected:** Oregon Health Authority

**Summary of Fiscal Impact**

2025-27 Biennium	General Fund	Lottery Funds	Other Funds	Federal Funds	Total Funds	Positions	FTE
Oregon Health Authority	\$ 760,986	\$ -	\$ -	\$ 134,295	\$ 895,281	4	3.00
<b>Total Fiscal Impact</b>	<b>\$ 760,986</b>	<b>\$ -</b>	<b>\$ -</b>	<b>\$ 134,295</b>	<b>\$ 895,281</b>	<b>4</b>	<b>3.00</b>

2027-29 Biennium	General Fund	Lottery Funds	Other Funds	Federal Funds	Total Funds	Positions	FTE
Oregon Health Authority	\$ 1,028,465	\$ -	\$ -	\$ 181,493	\$ 1,209,958	4	4.00
<b>Total Fiscal Impact</b>	<b>\$ 1,028,465</b>	<b>\$ -</b>	<b>\$ -</b>	<b>\$ 181,493</b>	<b>\$ 1,209,958</b>	<b>4</b>	<b>4.00</b>

**Measure Description**

The measure establishes the Rare Disease Advisory Council within the Oregon Health Authority (OHA). The Council is directed to inform, educate, and support stakeholders through policy recommendations, online resources and education while promoting awareness in Oregon of rare diseases. The council is directed to create two reports, one due by July 1, 2027, and the other due by December 15, 2028, and every even-numbered year thereafter. The Governor is directed to appoint a minimum of 20 members to the council and designate a Chairperson by March 1, 2026. The measure requires the council to meet regularly by June 1, 2026, and requires OHA to provide support staff. The measure prohibits members from receiving compensation for their services but permits public officials and employees to be compensated for travel and other expenses.

**Fiscal Analysis**

The Rare Disease Advisory Council creates a new body of work for OHA. Based on the staffing and support requirements for similar groups budgeted with OHA, the fiscal impact of the measure for 2025-27 includes \$730,506 General Fund, \$128,916 Federal Funds for four permanent full-time positions (3.00 FTE) which includes personal services and standard position-related services and supplies cost. An additional, \$30,480 General Fund and \$5,379 Federal Funds is needed to host accessible council meetings and provide travel reimbursement for council members. New positions include one manager to oversee staff and advise and consult with the Governor and council leadership, two analysts to create and analyze data and produce the two reports required by the measure, and one position to provide administrative support for the council.

The fiscal impact for the 2027-29 biennium is \$1.2 million total funds and four positions (4.00 FTE), the increase reflects a full 24 months of position costs and council meeting costs.

**Relevant Dates**

Beginning December 15, 2028, and by December 15 of each even-numbered year thereafter, the council will submit a report on its activities over the previous two years and identify opportunities to support individuals with rare disease in Oregon.

By March 1, 2026, the Rare Disease Advisory Council members must be appointed.

By June 1, 2026, the council must meet regularly.

By July 1, 2027, the council must report on the number of individuals with a rare disease in Oregon and their needs, as well as the number of caregivers and health care providers for individuals with a rare disease in Oregon.