

# SENATE BILL REPORT

## SB 5064

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As of January 22, 2025

**Title:** An act relating to creating an advisory council on rare diseases.

**Brief Description:** Creating an advisory council on rare diseases.

**Sponsors:** Senators Liias, Holy, Stanford, Wagoner, Lovick, Gildon, Cleveland, Cortes, Fortunato, Harris, Nobles, Riccelli and Warnick.

**Brief History:**

**Committee Activity:** Health & Long-Term Care: 1/23/25.

**Brief Summary of Bill**

- Creates an advisory council on rare diseases within the University of Washington's School of Medicine to advise the Secretary of Health on research, diagnosis, treatment, and education related to rare diseases.

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### SENATE COMMITTEE ON HEALTH & LONG-TERM CARE

**Staff:** Julie Tran (786-7283)

**Background:** The United States Congress, in the Orphan Drug Act of 1983, defines a rare disease as any disease or condition which affects less than 200,000 people in the United States. Rare diseases include genetic conditions, infections, some rare cancers, and autoimmune diseases. It is estimated that there are over 10,000 rare diseases, and rare diseases are estimated to affect more than 30 million people in the United States.

**Summary of Bill:** An advisory council on rare diseases (council) is established within the University of Washington's School of Medicine to advise the Secretary of Health on research, diagnosis, treatment, and education related to rare diseases. The council must submit annual reports on the council's work and other findings and recommendations to the Governor and Legislature beginning December 1, 2026.

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*This analysis was prepared by non-partisan legislative staff for the use of legislative members in their deliberations. This analysis is not part of the legislation nor does it constitute a statement of legislative intent.*

"Rare disease" means a disease that affects fewer than 200,000 people in the United States.

Duties of the Advisory Council on Rare Diseases. The council must advise on and coordinate efforts to study the incidence and prevalence of rare diseases in the state and the status of the rare disease community. This work includes examining issues regarding quality of care outcomes and cost effectiveness of the earlier diagnoses and treatment for rare diseases and also, access to available treatment and services to people with rare diseases in the state.

The council's duties include:

- identifying effective research-based strategies that have been developed to help diagnose, treat, and prevent rare diseases;
- making recommendations on how to better educate and inform medical providers, schools, and public health districts around the diagnosis, treatment, and access to care for people living with a rare disease; and
- developing effective strategies to raise the public awareness of rare diseases in the state.

The council must make recommendations on establishing a website for people living with a rare disease, their families, and their caregivers, or those seeking diagnosis to access, to access a centralized, public accessible repository of information and resources available to patients in the state.

The council must serve only in an advisory role and may not supersede the authority of local health jurisdictions when responding to a communicable rare disease outbreak.

Membership of the Council. The Secretary of Health must appoint 12 voting members for three-year terms to the council including:

- four clinicians and researchers specializing in rare diseases;
- four individuals representing patients;
- the Department of Health's Children and Youth with Special Health Care Needs Program Director, or their designee;
- a representative from the Health Care Authority; and
- two representatives from the life sciences industry focusing on developing therapeutic products for rare disease patients, research efforts related to those endeavors, or have a demonstrable understanding of the path to the commercialization of those products.

The council must be selected to ensure representation from both the west and east side of the state. A detailed list of requirements for specific qualifying voting members can be found in the bill.

The council must self-select a chair and the chair must convene the advisory council's first meeting within the first six months of the council's creation. After the first meeting, the

advisory council must meet at least quarterly and the council must meet upon the call of the chair or upon the request of the majority of members.

**Appropriation:** None.

**Fiscal Note:** Requested on January 19, 2025.

**Creates Committee/Commission/Task Force that includes Legislative members:** No.

**Effective Date:** Ninety days after adjournment of session in which bill is passed.