

SENATE BILL REPORT

SB 5097

As of February 21, 2023

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

Brief Description: Creating an advisory council on rare diseases.

Sponsors: Senators Holy, Lias, Braun, Kuderer, Lovick, Muzzall, Pedersen, Rolfes, Stanford and Wilson, L..

Brief History:

Committee Activity: Health & Long Term Care: 1/19/23, 2/09/23 [DP-WM].
Ways & Means: 2/21/23.

Brief Summary of Bill

- Creates an advisory council on rare diseases to provide information and recommendations to the Governor, state agencies, and Legislature.

SENATE COMMITTEE ON HEALTH & LONG TERM CARE

Majority Report: Do pass and be referred to Committee on Ways & Means.

Signed by Senators Cleveland, Chair; Robinson, Vice Chair; Rivers, Ranking Member; Muzzall, Assistant Ranking Member; Conway, Dhingra, Holy, Padden, Randall and Van De Wege.

Staff: Andie Parnell (786-7439)

SENATE COMMITTEE ON WAYS & MEANS

Staff: Monica Fontaine (786-7341)

Background: In the Orphan Drug Act of 1983, the United States Congress defined a rare

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disease as any condition that affects fewer than 200,000 people in the nation. Rare diseases include genetic conditions, infections, some rare cancers, and autoimmune diseases. The National Institutes of Health estimates there may be as many as 7000 rare diseases, and collectively, about 30 million people in the United States have a rare disease.

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

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

Members of the Advisory Council on Rare Diseases. The council acting as the advisory body on rare diseases consists of 12 voting members serving three year-terms including four clinicians and researchers specializing in rare diseases; four individuals representing patients; the Children and Youth with Special Health Care Needs program director; 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 commercialization of such products. A vacancy on the council must be filled in the same manner as the original appointment. The Secretary of Health must serve as an ex-officio nonvoting member and select the council's chair, who must convene the first council's meeting no later than three months after the bill's effective date.

The four clinicians and researchers specializing in rare diseases must include a Washington State licensed physician with experience researching, diagnosing, or treating rare diseases; a registered nurse, advanced practice registered nurse, genetic counselor, or social worker licensed and practicing in Washington with experience treating rare diseases; a medical researcher with experience conducting research concerning rare diseases; and a representative from an academic research institution in Washington that receives any grant funding for rare disease research. The four council members representing patients must include two patients living with a rare disease; a rare disease patient caregiver; and a representative from a rare disease foundation or patient advocacy group.

Duties of the Council. The council's duties include identifying effective research-based strategies to help diagnose, treat, and prevent rare diseases; making recommendations on the implementation of a continued medical education program to provide clinicians with resources to support earlier diagnosis and treatment of rare diseases; and developing effective strategies to raise public awareness of rare diseases in the state. The council must also coordinate efforts for the study of incidence prevalence of rare diseases in the state and the status of the rare disease community, including examination of issues regarding quality of care outcomes and cost effectiveness of earlier diagnoses and treatment of rare diseases and access to treatment and services available to persons with rare diseases in the state.

Public Repository of Information. By July 1, 2026, the council must establish a centralized, publicly accessible repository of information that catalogs ongoing rare research in the state and provides best practice standards of care for health care providers containing the most effective strategies for recognizing and treating rare diseases and informational resources for rare disease patients seeking access to clinical care.

Appropriation: None.

Fiscal Note: Available.

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

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

Staff Summary of Public Testimony (Health & Long Term Care): PRO: An advisory council on rare diseases would give the rare disease community a stronger voice in state government. There is no insurance code for rare diseases as a whole because rare disease prevalence is unknown in Washington, which is necessary for Medicaid coverage. Rare disease diagnosis is also limited to certain providers with specialized knowledge. This council would give a platform to the rare disease community through continuing medical education programs, and a central database to track rare disease prevalence in the state. A central database could connect rare disease patients with one another, and with specialized providers across the state. The database could also help families find caregivers and other adequate services.

Persons Testifying (Health & Long Term Care): PRO: Senator Jeff Holy, Prime Sponsor; Carolina Sommer, NW Rare Disease Coalition; Lindsey Topping-Scheutz, NW Rare Disease Coalition; Mary McDirmid, NW Rare Disease Coalition.

Persons Signed In To Testify But Not Testifying (Health & Long Term Care): No one.

Staff Summary of Public Testimony (Ways & Means): PRO: This is a foundational piece of legislation for Washington. This advisory council will improve advocacy, outreach, education, and leadership, and will give people with rare diseases a voice in state government. The fiscal note does not seem accurate, and more work may need to be done to adjust it.

Persons Testifying (Ways & Means): PRO: Carolina Sommer, Born a Hero, Research Foundation; Rose Feliciano, NW Rare Disease Coalition; Sarah Tompkins, NW Rare Disease Coalition; Lindsey Topping-Schuetz, NW Rare Disease Coalition & Parent Advocate.

Persons Signed In To Testify But Not Testifying (Ways & Means): No one.