

# SENATE BILL REPORT

## SB 5886

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As of February 4, 2022

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

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

**Sponsors:** Senators Holy, Frockt, Keiser, Kuderer, Liias, Lovick, Muzzall, Nobles, Rivers, Rolfes, Stanford, Trudeau, Van De Wege and Warnick.

**Brief History:**

**Committee Activity:** Health & Long Term Care: 1/31/22, 2/02/22 [DPS-WM].  
Ways & Means: 2/04/22.

**Brief Summary of First Substitute Bill**

- Establishes an advisory council on rare diseases within the Department of Health to advise on research, diagnosis, treatment, and education related to rare diseases.

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### SENATE COMMITTEE ON HEALTH & LONG TERM CARE

**Majority Report:** That Substitute Senate Bill No. 5886 be substituted therefor, and the substitute bill do pass and be referred to Committee on Ways & Means.

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

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

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### SENATE COMMITTEE ON WAYS & MEANS

**Staff:** Corban Nemeth (786-7736)

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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.*

**Background:** In the Orphan Drug Act of 1983, the United States Congress defined a rare 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 that 25 to 30 million Americans may be living with a rare disease.

**Summary of Bill (First Substitute):** 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 council's work and other findings and recommendations to the Governor and Legislature beginning December 1, 2024.

"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 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. 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, 2025, 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.

**EFFECT OF CHANGES MADE BY HEALTH & LONG TERM CARE COMMITTEE (First Substitute):**

- Amends the requirement for the advisory council's chair to convene the first council meeting no later than six months after the effective date rather than three months.
- Modifies the council's reporting requirements from annual submissions beginning December 1, 2024, to a report due every biennium beginning December 1, 2025.
- Clarifies that the publicly accessible repository of information must include best practices to share with health care providers and removes the reference to standards of 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 on Original Bill (Health & Long Term Care):**

*The committee recommended a different version of the bill than what was heard.* PRO: Rare disease takes a big financial and emotional toll on patients, parents, and families. Early intervention and diagnosis saves lives. This bill would be foundational in helping this vulnerable population and well-position the advisory council to channel the needs and concerns of the rare disease patients in Washington. Rare does not generate profits. Developing new rare disease treatment and financing new disease therapies is a challenging endeavor. This is why government must help for these particular situations to find treatments and share information. Also, this bill gives voice to a broad representation of stakeholders and each representative has a valuable perspective to contribute to this process. Healthcare boards and commissions moving forward should have similar composition with those impacted directly by the illnesses and conditions to be included as members.

**Persons Testifying (Health & Long Term Care):** PRO: Senator Jeff Holy, Prime Sponsor; Carolina Sommer, Born a Hero, Research Foundation; Marc Cummings, Life Science Washington; Sarah Tompkins; Joshua Henderson, NW Rare Disease Coalition; Lindsey Topping-Schuetz, Caregiver/Parent; Tera Figueroa; Cindi Laws, Health Care for

All Washington; Michael Transue, Oregon Biosciences Association.

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

**Staff Summary of Public Testimony on First Substitute (Ways & Means):** PRO: These councils are being established all over the United States. Rare diseases affect one in ten americans. These diseases take a big financial and emotional toll on parents. Rare disease early intervention saves lives and costs. Rare diseases do not generate profit. Nobody wants to study them as they don't generate income for the medical system. This bill is a productive way to move research and treatment on these diseases forward. We are asking to have a seat at the table for the betterment of everyone who uses the healthcare system. This bill would create a vital resource for myself, family, and patient community. I am very lucky to have the coverage that I have, and others aren't so lucky. The council created in this bill would help families with rare diseases in Washington.

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

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