
Health Care & Wellness Committee

SSB 5886

Brief Description: Creating an advisory council on rare diseases.

Sponsors: Senate Committee on Health & Long Term Care (originally sponsored by Senators Holy, Frockt, Keiser, Kuderer, Lias, Lovick, Muzzall, Nobles, Rivers, Rolfes, Stanford, Trudeau, Van De Wege and Warnick).

Brief Summary of 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.

Hearing Date: 2/17/22

Staff: Phillip Craig (786-7291) and Christopher Blake (786-7392).

Background:

In the Rare Diseases Act of 2002, 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 (NIH) estimates there may be as many as 7,000 rare diseases, and that 25 to 30 million Americans may be living with a rare disease.

Federally, the NIH supports the National Center for Advancing Translational Sciences (NCATS), which focuses on providing new cures and treatments to patients suffering from rare diseases. The NCATS coordinates a number of research programs for rare diseases, as well as the Genetic and Rare Disease Information Center, which provides information about rare and genetic diseases to patients, health care providers, researchers, and the public.

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.

Summary of Bill:

An advisory council on rare diseases (Council) is established within the Department of Health to advise the Governor, state agencies, and the Legislature on research, diagnosis, treatment, and education related to rare diseases. A rare disease is defined as any disease that affects fewer than 200,000 people in the United States.

Members of the Advisory Council on Rare Diseases.

The Council consists of 12 voting members appointed to three-year terms by the Secretary of Health (Secretary), including:

- four clinicians and researchers specializing in rare diseases;
- four individuals representing patients;
- the Director of the Children with Special Health Care Needs program;
- a representative from the Health Care Authority; and
- two representatives from the life sciences industry that focus on developing or researching therapeutic products for rare disease patients.

The Secretary serves as an ex-officio nonvoting member of the Council and must select a chair for the Council. The chair must convene the first meeting of the Council no later than six months after the effective date of the bill. The Department of Health must provide staff support for the Council.

Duties of the Council.

The Council acts as the advisory body on rare diseases to the Legislature, the state departments, agencies, commission, and authorities serving persons with rare diseases. The Council advises on treatment and care outcomes for rare diseases, access to treatment and services in the state, and research-based strategies that have been developed to diagnose, treat, and prevent rare diseases. The Council makes recommendations on implementing educational programs and strategies to support earlier diagnosis of rare diseases and raise public awareness in the state.

Beginning December 1, 2025, the Council must submit a report to the Governor and the Legislature every biennium detailing the work of the Council from the preceding year. The report must identify opportunities to support programs that directly impact the lives of patients with rare diseases and identify any recommended changes to the Council.

Public Repository of Information.

By July 1, 2025, the Council must establish a centralized, publicly accessible repository of information that catalogs ongoing rare disease research in the state and provides best practice standards of care for health care providers treating rare diseases. The public repository must also provide informational resources to rare disease patients and their families seeking access to clinical care.

Appropriation: None.

Fiscal Note: Preliminary fiscal note available.

Effective Date: The bill takes effect 90 days after adjournment of the session in which the bill is passed.