
SUBSTITUTE SENATE BILL 5064

State of Washington

69th Legislature

2025 Regular Session

By Senate Health & Long-Term Care (originally sponsored by Senators Liiias, Holy, Stanford, Wagoner, Lovick, Gildon, Cleveland, Cortes, Fortunato, Harris, Nobles, Riccelli, and Warnick)

READ FIRST TIME 01/31/25.

1 AN ACT Relating to creating an advisory council on rare diseases;
2 adding new sections to chapter 43.70 RCW; and creating a new section.

3 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF WASHINGTON:

4 NEW SECTION. **Sec. 1.** The legislature finds that:

5 (1) Rare diseases are those that affect fewer than 200,000 people
6 in the United States. There are over 7,000 rare diseases affecting
7 approximately 30,000,000 Americans and 50 percent of those are
8 children;

9 (2) The exact cause for many rare diseases remains unknown.
10 However, 80 percent of rare diseases are genetic in origin and can be
11 linked to mutations in a single gene or in multiple genes which can
12 be passed down from generation to generation; and

13 (3) A person suffering with a rare disease faces a wide range of
14 challenges, including delays in obtaining a diagnosis, being
15 misdiagnosed, shortages of medical specialists who can provide
16 treatment for rare diseases, and a lack of therapies and medications
17 that are used by doctors to treat rare diseases.

18 NEW SECTION. **Sec. 2.** A new section is added to chapter 43.70
19 RCW to read as follows:

1 (1) An advisory council on rare diseases is established within
2 the University of Washington school of medicine to advise the
3 secretary of health on research, diagnosis, treatment, and education
4 related to rare diseases.

5 (2) The secretary of health shall appoint 12 voting members to
6 the council to include:

7 (a) Four clinicians and researchers specializing in rare
8 diseases, including at least one representative from a pediatric
9 hospital, at least one representative from a hospital or academic
10 research institution east of the crest of the Cascade mountains, and
11 at least one representative from a hospital or academic research
12 institution west of the crest of the Cascade mountains, from the
13 following professions:

14 (i) A physician licensed and practicing in the state with
15 experience researching, diagnosing, or treating rare diseases;

16 (ii) A registered nurse, advanced practice registered nurse,
17 genetic counselor, or social worker licensed and practicing in the
18 state with experience with patients with rare diseases;

19 (iii) A medical researcher with experience conducting research
20 concerning rare diseases; and

21 (iv) A representative from an academic research institution in
22 this state that receives any grant funding for rare disease research;

23 (b) Four individuals, who are Washington residents, representing
24 patients, including:

25 (i) Two patients living with a rare disease;

26 (ii) A rare disease patient caregiver; and

27 (iii) A representative from a rare disease foundation or patient
28 advocacy group;

29 (c) The director of the department of health of the children and
30 youth with special health care needs program, or their designee;

31 (d) A representative from the health care authority; and

32 (e) Two representatives from the life sciences industry that
33 focus on developing therapeutic products for rare disease patients,
34 research efforts related to those endeavors, or have a demonstrable
35 understanding of the path to commercialization of such products.

36 (3) Members must be selected to ensure representation from both
37 east and west of the crest of the Cascade mountains.

38 (4) Voting members shall be appointed to serve a three-year term.
39 No member may serve more than three consecutive terms. A vacancy on
40 the council must be filled in the same manner as the original

1 appointment. An individual appointed to fill a vacancy created other
2 than by expiration of a term must be appointed for the unexpired term
3 of the member whom the individual is to succeed in the same manner as
4 the original appointment.

5 (5) Members of the council may be reimbursed for travel expenses
6 as provided in RCW 43.03.050 and 43.03.060.

7 (6) Subject to amounts appropriated for this specific purpose,
8 the University of Washington shall provide staff support to the
9 council including physician leadership.

10 (7) The council shall self-select a chair. The chair shall
11 convene the first meeting of the council no later than six months
12 after the effective date of this section. Following the first
13 meeting, the council shall meet upon the call of the chair or upon
14 the request of a majority of the members, but no less than once per
15 quarter after the first meeting.

16 (8) A majority of the members shall constitute a quorum. A
17 majority vote of a quorum shall be required for any official action
18 of the council.

19 (9) For purposes of this section, "rare disease" means a disease
20 that affects fewer than 200,000 people in the United States.

21 NEW SECTION. **Sec. 3.** A new section is added to chapter 43.70
22 RCW to read as follows:

23 (1) The advisory council on rare diseases established in section
24 2 of this act shall:

25 (a) Act as the advisory body on rare diseases to the secretary of
26 health on research, diagnosis, treatment, and education related to
27 rare diseases;

28 (b) Advise on and coordinate efforts for the study of incidence
29 and prevalence of rare diseases in the state and the status of the
30 rare disease community, including examination of:

31 (i) Issues regarding quality of care outcomes and cost
32 effectiveness of earlier diagnoses and treatment of rare diseases;
33 and

34 (ii) Access to treatment and services available to persons with
35 rare diseases in the state;

36 (c) Identify effective research-based strategies that have been
37 developed to help diagnose, treat, and prevent rare diseases;

38 (d) Make recommendations on how to better educate and inform
39 medical providers, schools, and public health districts around the

1 diagnosis, treatment, and access to care for persons living with a
2 rare disease, including support for their families and caregivers;

3 (e) Develop effective strategies to raise public awareness of
4 rare diseases in the state; and

5 (f) Make recommendations on establishing a website for persons
6 living with a rare disease, their families, and their caregivers, or
7 those seeking diagnosis, to access a centralized, publicly accessible
8 repository of information and resources available to patients in
9 Washington state.

10 (2) Beginning December 1, 2026, and every biennium thereafter,
11 and in accordance with RCW 43.01.036, the council shall submit a
12 report to the governor and the legislature detailing the work of the
13 council from the preceding biennium, identifying opportunities to
14 support programs that directly impact the lives of patients with rare
15 diseases, and providing any recommendations for statutory changes to
16 the structure and duties of the council.

17 (3) The council shall serve in an advisory role only and may not
18 supersede the authority of local health jurisdictions when responding
19 to an outbreak of a communicable rare disease.

20 (4) For purposes of this section, "rare disease" means a disease
21 that affects fewer than 200,000 people in the United States.

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