
SENATE BILL 5097

State of Washington

68th Legislature

2023 Regular Session

By Senators Holy and Lias

Prefiled 12/23/22.

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.

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 The definitions in this section apply throughout this section and
2 sections 3 and 4 of this act unless the context clearly requires
3 otherwise:

4 (1) "Council" means the advisory council on rare diseases.

5 (2) "Rare disease" means a disease that affects fewer than
6 200,000 people in the United States.

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

9 (1) An advisory council on rare diseases is established within
10 the department to advise the governor, state agencies, and the
11 legislature on research, diagnosis, treatment, and education related
12 to rare diseases.

13 (2) The secretary shall appoint 12 voting members to the council
14 to include:

15 (a) Four clinicians and researchers specializing in rare
16 diseases, including:

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

19 (ii) A registered nurse, advanced practice registered nurse,
20 genetic counselor, or social worker licensed and practicing in the
21 state with experience treating rare diseases;

22 (iii) A medical researcher with experience conducting research
23 concerning rare diseases; and

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

26 (b) Four individuals representing patients, including:

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

28 (ii) A rare disease patient caregiver; and

29 (iii) A representative from a rare disease foundation or patient
30 advocacy group;

31 (c) The director, or their designee, of the children with special
32 health care needs program;

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

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

38 (3) The secretary, or their designee, shall serve an ex officio
39 nonvoting member of the council.

1 (4) Voting members shall be appointed to serve a three-year term.
2 No member may serve more than three consecutive terms. A vacancy on
3 the council must be filled in the same manner as the original
4 appointment. An individual appointed to fill a vacancy created other
5 than by expiration of a term must be appointed for the unexpired term
6 of the member whom he or she is to succeed in the same manner as the
7 original appointment.

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

10 (6) The department shall provide staff support to the council.

11 (7) The secretary shall select a chair for the council. The chair
12 shall convene the first meeting of the council no later than six
13 months after the effective date of this section. Following the first
14 meeting, the advisory council shall meet upon the call of the chair
15 or upon the request of a majority of councilmembers.

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

19 (9) The council may receive gifts, grants, or endowments from
20 public or private sources that are made from time to time, in trust
21 or otherwise, for the use and benefit of the purposes of the council
22 and spend gifts, grants, or endowments or income from the public or
23 private sources according to their terms, unless the receipt of the
24 gifts, grants, or endowments violates RCW 42.17A.560.

25 NEW SECTION. **Sec. 4.** A new section is added to chapter 43.70
26 RCW to read as follows:

27 (1) The council shall:

28 (a) Act as the advisory body on rare diseases to the legislature
29 and state departments, agencies, commission, and authorities that
30 provide services to, or are charged with the care of, persons with
31 rare diseases;

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

35 (i) Issues regarding quality of care outcomes and cost-
36 effectiveness of earlier diagnoses and treatment of rare diseases;
37 and

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

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

3 (d) Make recommendations on the implementation of a continued
4 medical education program to provide clinicians with resources to
5 support earlier diagnosis and treatment of rare diseases; and

6 (e) Develop effective strategies to raise public awareness of
7 rare diseases in the state.

8 (2) By July 1, 2026, the council shall establish a centralized,
9 publicly accessible repository of information to:

10 (a) Provide best practices to share with health care providers
11 that will ensure they are adequately informed of the most effective
12 strategies for recognizing and treating rare diseases;

13 (b) Provide informational resources for rare disease patients or
14 their families seeking access to clinical care; and

15 (c) Catalogue rare disease research ongoing in Washington state.

16 (3) Beginning December 1, 2026, and every biennium thereafter,
17 the council shall submit a report to the governor and the legislature
18 detailing the work of the council from the preceding year,
19 identifying opportunities to support programs that directly impact
20 the lives of patients with rare diseases, and providing any
21 recommendations for statutory changes to the structure and duties of
22 the council.

23 (4) The council shall serve in an advisory role only and shall
24 not supersede the authority of local health jurisdictions when
25 responding to an outbreak of a communicable rare disease.

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