S-0252.1

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**SENATE BILL 5097**

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**State of Washington 68th Legislature 2023 Regular Session**

**By** Senators Holy, Liias, Braun, Kuderer, Lovick, Muzzall, Pedersen, Rolfes, Stanford, and L. Wilson

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

(b) Four individuals representing patients, including:

(i) Two patients living with a rare disease;

(ii) A rare disease patient caregiver; and

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

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

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

(e) Two representatives from the life sciences industry that focus 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.

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

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

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

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

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

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

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

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

(1) The council shall:

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

(b) Advise on and 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:

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

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

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

(d) Make 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

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

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

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

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

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

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

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

**--- END ---**