

1 HOUSE BILL NO. 943

2 INTRODUCED BY P. TUSS

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4 A BILL FOR AN ACT ENTITLED: "AN ACT ESTABLISHING THE MONTANA RARE DISEASE ADVISORY
5 COUNCIL; PROVIDING FOR ADVISORY COUNCIL MEMBERSHIP AND DUTIES; ESTABLISHING
6 REPORTING REQUIREMENTS; PROVIDING AN APPROPRIATION; AND PROVIDING AN EFFECTIVE
7 DATE."

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9 WHEREAS, a rare disease, sometimes called an "orphan disease", is defined as a disease that affects
10 fewer than 200,000 people in the United States; and

11 WHEREAS, there are more than 10,000 known rare diseases affecting more than 30 million
12 Americans, more than half of whom are children; and

13 WHEREAS, approximately 95% of rare diseases do not have a treatment approved by the United
14 States Food and Drug Administration; and

15 WHEREAS, while the exact cause for many rare diseases remains unknown, many rare diseases are
16 genetic in origin and can be linked to mutations in a single gene or in multiple genes, which can be passed
17 down from generation to generation; and

18 WHEREAS, individuals with rare diseases face many obstacles, including delays in obtaining an
19 accurate diagnosis and finding a health care provider with expertise in treating the condition and a lack of
20 affordable access to therapies and medication used to treat rare diseases, resulting in significant physical,
21 mental, and financial challenges; and

22 WHEREAS, a state-based advisory council composed of qualified professionals and individuals living
23 with rare diseases and their caregivers would educate and advise medical professionals, government agencies,
24 legislators, and the public about rare diseases as an important public health issue and encourage research and
25 support the development of new and better policies to diagnose and treat rare diseases.

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27 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF MONTANA:
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NEW SECTION. Section 1. Rare disease advisory council -- membership. (1) There is a rare

disease advisory council within the department of public health and human services provided for in 2-15-2201 to provide guidance, education, and recommendations to the public, the legislature, and other government agencies on the needs of individuals with rare diseases living in Montana.

(2) The council consists of 17 members, who, if possible, must be full-time residents of Montana representing the geographic and population diversity of the state as follows:

(a) one representative of an academic research institution in the state that receives grant funding for rare disease research;

(b) one representative of the Montana medicaid program;

(c) one representative of the department of labor and industry;

(d) one nurse or advanced practice registered nurse licensed and practicing in Montana with experience treating rare diseases;

(e) one physician practicing in Montana with experience treating rare diseases;

(f) one geneticist or genetic counselor;

(g) one hospital administrator or the administrator's designee from a hospital in Montana that provides care to individuals diagnosed with rare diseases;

(h) two individuals with rare diseases;

(i) one caregiver of an individual with a rare disease;

(j) one representative of a rare disease patient organization that operates in Montana;

(k) one pharmacist with experience dispensing drugs used to treat rare diseases;

(l) one representative of the biopharmaceutical industry;

(m) one representative of a health plan company;

(n) one representative of the scientific community who is engaged in rare disease research, including but not limited to a medical researcher with experience conducting research on rare diseases;

(o) one mental health provider with experience treating rare disease patients in Montana; and

(p) one representative of the Montana public health laboratory.

(3) (a) (i) Within 30 days after [the effective date of this act], the governor shall appoint one member to serve as presiding officer of the advisory council for a 3-year term. The presiding officer may not

1 hold a position within state government.

2 (ii) The governor shall appoint the remaining members of the advisory council for terms of not
3 more than 4 years. The initial appointments may specify a shorter length of the initial term in order to stagger
4 terms.

5 (b) At the end of the presiding officer's 3-year term and every 2 years afterward, the members of
6 the advisory council shall elect a presiding officer by a majority vote.

7 (c) A member of the council may be reappointed.

8 (d) If a vacancy occurs, a new member must be appointed by the governor to fill the balance of the
9 unexpired term.

10 (4) Advisory council members shall serve without additional compensation but are entitled to
11 reimbursement for travel expenses as provided for in 2-18-501 through 2-18-503.

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13 **NEW SECTION. Section 2. Rare disease advisory council duties -- meetings -- reports --**

14 **funding.** (1) To benefit individuals impacted by rare diseases in the state, the advisory council shall perform the
15 following duties:

16 (a) convene public hearings, make inquiries, and solicit public comment to assist the advisory
17 council in surveying the needs of rare disease patients, caregivers, and providers in the state;

18 (b) consult with experts on rare diseases to develop policy recommendations for improving patient
19 access to and quality of rare disease specialists, affordable and comprehensive health care coverage, relevant
20 diagnostics, timely treatment, and other needed services;

21 (c) publish on the department of public health and human services' website:

22 (i) a list of existing, publicly accessible resources on research, diagnosis, treatment, and
23 education related to rare diseases in the state; and

24 (ii) meeting minutes, notice of upcoming meetings, and opportunities for the submission of public
25 comment to the advisory council;

26 (d) identify areas of unmet need for research and opportunities for collaboration with stakeholders
27 and rare disease advisory councils in other states that can inform future studies and work done by the advisory
28 council; and

(e) identify and distribute educational resources to health care providers to foster recognition and optimize treatment of rare diseases in the state.

(2) (a) The initial meeting of the advisory council must be held within 90 days after [the effective date of this act].

(b) For the first year after the advisory council is established, the advisory council shall meet no less than once a month in person or remotely for a length of time established by the presiding officer.

(c) After the first year of the advisory council's operation, the advisory council shall meet no less than once a quarter in person or remotely as determined by the presiding officer.

(3) Within 1 year after [the effective date of this act] and annually thereafter, the council shall submit a report to the governor and, in accordance with 5-11-210, to the legislature and the children, families, health, and human services interim committee describing:

(a) the activities and progress of the advisory council related to the duties described in subsection (1);

(b) the status of the funding of the advisory council, including grants that are sought, accepted, or used; and

(c) recommendations to the governor and legislature on ways to address the needs of individuals living with rare diseases in the state.

(4) The advisory council may seek gifts, donations, grants, and other sources of funding to support its activities.

NEW SECTION. Section 3. Appropriation. (1) There is appropriated \$16,000 from the general fund to the department of public health and human services for the biennium beginning July 1, 2025.

(2) The appropriation must be used to pay for costs associated with the rare disease advisory council provided for in [sections 1 and 2].

(3) The legislature intends that the appropriation in this section be considered part of the ongoing base for the next legislative session.

NEW SECTION. Section 4. Codification instruction. [Sections 1 and 2] are intended to be codified

1 as a new part in Title 50, chapter 12, and the provisions of Title 50, chapter 12, apply to [sections 1 and 2].

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3 NEW SECTION. **Section 5. Effective date.** [This act] is effective July 1, 2025.

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