

# House Bill 2457

Sponsored by Representative PHAM H (Pre-session filed.)

## SUMMARY

The following summary is not prepared by the sponsors of the measure and is not a part of the body thereof subject to consideration by the Legislative Assembly. It is an editor's brief statement of the essential features of the measure **as introduced**. The statement includes a measure digest written in compliance with applicable readability standards.

Digest: The Act would create an advisory council on rare diseases. (Flesch Readability Score: 61.3).

Establishes the Rare Disease Advisory Council. Directs the council to biennially submit a report to the Governor and appropriate legislative committees summarizing the activities of the council and making policy recommendations.

## A BILL FOR AN ACT

1  
2 Relating to the Rare Disease Advisory Council.

3       Whereas the medical and health care professions consider any condition that affects fewer than  
4 200,000 Americans to be rare; and

5       Whereas there are more than 10,000 rare diseases in the United States, affecting more than 30  
6 million Americans across a broad spectrum of medical conditions; and

7       Whereas patients with rare diseases face many unique challenges every day, from obtaining an  
8 accurate diagnosis and accessing medical specialists with knowledge of their condition to obtaining  
9 fair insurance coverage for their treatment and care; and

10       Whereas due to small patient populations and the variety of rare diseases, it can be challenging  
11 for state government and public health officials to have an in-depth understanding of the rare dis-  
12 ease community's needs; and

13       Whereas this lack of awareness often contributes to obstacles faced by patients with rare dis-  
14 eases and their families; and

15       Whereas creating a Rare Disease Advisory Council will provide a forum for patients, families  
16 and experts across Oregon to analyze the needs of the community and make recommendations on  
17 public policy to address rare diseases and to aid those impacted by rare diseases; now, therefore,

18 **Be It Enacted by the People of the State of Oregon:**

19       **SECTION 1. (1) As used in this section, "rare disease" means a disease that affects fewer**  
20 **than 200,000 people in the United States.**

21       **(2) The Rare Disease Advisory Council is established in the Oregon Health Authority to:**

22       **(a) Develop policy recommendations to improve the continuum of care, services and re-**  
23 **sources for persons impacted by a rare disease.**

24       **(b) Advise the Governor, state agencies and the Legislative Assembly on research, diag-**  
25 **nos, treatment and education related to rare diseases.**

26       **(c) Provide information and support to persons with a rare disease, families of persons**  
27 **with a rare disease, health care providers serving persons with a rare disease and entities**  
28 **paying for health care services for persons with a rare disease, such as health insurance**  
29 **companies and coordinated care organizations.**

**NOTE:** Matter in **boldfaced** type in an amended section is new; matter *[italic and bracketed]* is existing law to be omitted. New sections are in **boldfaced** type.

1 (d) Make publicly available on the council's website a list of existing resources on re-  
2 search, diagnoses, treatment and education related to rare diseases.

3 (e) Develop effective strategies to raise public awareness of rare diseases in Oregon.

4 (3) The Governor, in consultation with the authority, shall appoint no fewer than 20  
5 members to the council as follows:

6 (a) One licensed physician practicing in Oregon who is not a pediatrician and who has  
7 experience diagnosing and treating rare diseases.

8 (b) One licensed pediatrician practicing in Oregon with experience diagnosing and treat-  
9 ing rare diseases.

10 (c) One geneticist or genetic counselor practicing in Oregon.

11 (d) One registered nurse, advanced practice registered nurse or licensed social worker  
12 with experience treating rare diseases in Oregon.

13 (e) One health researcher with experience researching rare diseases.

14 (f) One representative of an academic research institution in this state that receives  
15 grant funding to conduct research on rare diseases.

16 (g) One mental health care provider with experience treating persons with a rare disease.

17 (h) Two persons living with a rare disease.

18 (i) Two caregivers of persons living with a rare disease.

19 (j) One representative from a rare disease foundation or patient advocacy organization.

20 (k) One representative of the authority with expertise in public health.

21 (L) One representative of the authority with expertise in maternal and child health.

22 (m) One representative of the Department of Human Services with expertise in develop-  
23 mental disabilities.

24 (n) One representative of the authority with expertise in equity and inclusion.

25 (o) One representative from the life sciences industry who researches or develops  
26 therapeutic products for persons with a rare disease or who has expertise in the  
27 commercialization of therapeutic products for persons with a rare disease.

28 (p) One representative of the Oregon Health Plan.

29 (q) One representative from the Department of Consumer and Business Services with  
30 expertise in insurance.

31 (r) One licensed pharmacist with experience dispensing medications for the treatment  
32 of rare diseases.

33 (4) A maximum of two representatives with expertise in a specific rare disease population  
34 may serve concurrently on the council.

35 (5) Members may not receive compensation for service on the council, but, subject to any  
36 applicable laws regulating travel and other expenses of state officers and employees, may be  
37 reimbursed for actual and necessary travel and other expenses incurred in the performance  
38 of council duties with moneys available to the council for the purpose of reimbursing the  
39 members.

40 (6) The term of service for each member is four years. Members are eligible for reap-  
41 pointment up to three times.

42 (7) The Governor shall select a member to serve as the chairperson. The council shall  
43 meet at the call of the chairperson or of a majority of the members of the council.

44 (8) The authority shall provide staff support to the council.

45 (9) The council may receive financial resources from any source to support the purposes

1 of the council under this section.

2 (10) No later than December 15 of each even-numbered year, the council shall submit a  
3 report to the Governor and to the appropriate committees of the Legislative Assembly that  
4 describes the work the council has undertaken over the preceding two years and opportu-  
5 nities to support persons with rare disease in Oregon. The report may include recommen-  
6 dations for policy changes and recommendations for proposed legislation that legislative  
7 committees or members may choose to have introduced for consideration by the Legislative  
8 Assembly.

9 (11) The council may adopt rules necessary to carry out this section, including rules ad-  
10 dressing conflicts of interest for members.

11 **SECTION 2.** On or before March 1, 2026, members of the Rare Disease Advisory Council  
12 must be appointed as described in section 1 (3) of this 2025 Act. On or before June 1, 2026,  
13 the council must begin meeting regularly.

14 **SECTION 3.** Notwithstanding section 1 (6) of this 2025 Act, one-half of the members ap-  
15 pointed by the Governor for the initial composition of the Rare Disease Advisory Council in  
16 2026 shall be appointed for two-year terms. The Governor shall identify which members serve  
17 two-year terms and which members serve four-year terms.

18 **SECTION 4.** (1) The report described in section 1 of this 2025 Act is first due on Decem-  
19 ber 15, 2028.

20 (2)(a) The Rare Disease Advisory Council shall prepare a report on the number and needs  
21 of persons with a rare disease in Oregon, caregivers for persons with a rare disease in  
22 Oregon and health care providers for persons with a rare disease in Oregon.

23 (b) The report described in paragraph (a) of this subsection is due by July 1, 2027.  
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