

# DRAFT

## SUMMARY

Establishes Rare Disease Advisory Council to serve as forum for understanding challenges faced by patients with rare diseases and caregivers and to serve as forum for improving access to care and insurance coverage for patients and as information resource for government and public health decision makers.

Directs council to annually submit report to Governor and appropriate legislative committees summarizing activities of 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  
4 that affects fewer than 200,000 Americans to be rare; and

5 Whereas there are more than 7,000 known rare diseases in the United  
6 States, affecting between 25 and 30 million Americans across a broad spec-  
7 trum of medical conditions; and

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

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

15 Whereas this lack of awareness often contributes to obstacles faced by  
16 patients with rare diseases and their families; and

17 Whereas creating a Rare Disease Advisory Council will provide a forum

1 for patients, families and experts across Oregon to analyze the needs of the  
2 community and make recommendations on public policy to address rare dis-  
3 eases and to aid those impacted by rare diseases; now, therefore,

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

5 **SECTION 1. (1) The Rare Disease Advisory Council is established**  
6 **for the purposes of understanding challenges that patients with rare**  
7 **diseases and caregivers face, serving as a forum for improving access**  
8 **to care and insurance coverage for patients and serving as an infor-**  
9 **mation resource for government and public health decision makers.**

10 **(2) The Governor shall determine the number of members on the**  
11 **council and appoint members. The council may be composed of pa-**  
12 **tients, caregivers, health care providers, health insurance represen-**  
13 **tatives, biotechnology industry representatives, researchers,**  
14 **representatives of patient advocacy organizations, state government**  
15 **officials and public health officials.**

16 **(3) Members may not receive compensation for service on the**  
17 **council, but, subject to any applicable laws regulating travel and other**  
18 **expenses of state officers and employees, may be reimbursed for actual**  
19 **and necessary travel and other expenses incurred in the performance**  
20 **of council duties with moneys available to the council for the purpose**  
21 **of reimbursing the members.**

22 **(4) The term of service for each member is four years. Members**  
23 **are eligible for reappointment.**

24 **(5) The council shall elect a chairperson and a vice chairperson to**  
25 **serve for one-year terms.**

26 **(6) The Oregon Health Authority shall provide meeting facilities and**  
27 **administrative support to the council.**

28 **(7) The council shall meet at the call of the chair.**

29 **(8) No later than September 15 of each year, the council shall sub-**  
30 **mit a report to the Governor and to the appropriate committees of the**  
31 **Legislative Assembly that describes the work the council has under-**

1 taken over the preceding year. The report may include recommen-  
2 dations for policy changes and recommendations for proposed  
3 legislation that legislative committees or members may choose to have  
4 introduced for consideration by the Legislative Assembly.

5 **SECTION 2.** On or before March 1, 2024, members of the Rare Dis-  
6 ease Advisory Council must be appointed as described in section 1 (2)  
7 of this 2023 Act. On or before May 1, 2024, the council must begin  
8 meeting regularly.

9 **SECTION 3.** Notwithstanding section 1 (4) of this 2023 Act, one-half  
10 of the members appointed by the Governor for the initial composition  
11 of the Rare Disease Advisory Council in 2024 shall be appointed for  
12 two-year terms. The Governor shall identify which members serve  
13 two-year terms and which members serve four-year terms.

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