

# House Bill 2047

Introduced and printed pursuant to House Rule 12.00. Pre-session filed (at the request of House Interim Committee on Health Care for Representative Rob Nosse)

## 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**.

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 that affects fewer than  
4 200,000 Americans to be rare; and

5       Whereas there are more than 7,000 known rare diseases in the United States, affecting between  
6 25 and 30 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) The Rare Disease Advisory Council is established for the purposes of**  
20 **understanding challenges that patients with rare diseases and caregivers face, serving as a**  
21 **forum for improving access to care and insurance coverage for patients and serving as an**  
22 **information resource for government and public health decision makers.**

23       **(2) The Governor shall determine the number of members on the council and appoint**  
24 **members. The council may be composed of patients, caregivers, health care providers, health**  
25 **insurance representatives, biotechnology industry representatives, researchers, represen-**  
26 **tatives of patient advocacy organizations, state government officials and public health offi-**  
27 **cial.**

28       **(3) Members may not receive compensation for service on the council, but, subject to any**

**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 applicable laws regulating travel and other expenses of state officers and employees, may be  
2 reimbursed for actual and necessary travel and other expenses incurred in the performance  
3 of council duties with moneys available to the council for the purpose of reimbursing the  
4 members.

5 (4) The term of service for each member is four years. Members are eligible for reap-  
6 pointment.

7 (5) The council shall elect a chairperson and a vice chairperson to serve for one-year  
8 terms.

9 (6) The Oregon Health Authority shall provide meeting facilities and administrative sup-  
10 port to the council.

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

12 (8) No later than September 15 of each year, the council shall submit a report to the  
13 Governor and to the appropriate committees of the Legislative Assembly that describes the  
14 work the council has undertaken over the preceding year. The report may include recom-  
15 mendations for policy changes and recommendations for proposed legislation that legislative  
16 committees or members may choose to have introduced for consideration by the Legislative  
17 Assembly.

18 SECTION 2. On or before March 1, 2024, members of the Rare Disease Advisory Council  
19 must be appointed as described in section 1 (2) of this 2023 Act. On or before May 1, 2024,  
20 the council must begin meeting regularly.

21 SECTION 3. Notwithstanding section 1 (4) of this 2023 Act, one-half of the members ap-  
22 pointed by the Governor for the initial composition of the Rare Disease Advisory Council in  
23 2024 shall be appointed for two-year terms. The Governor shall identify which members serve  
24 two-year terms and which members serve four-year terms.