

House Bill 2529

Sponsored by Representatives SMITH WARNER, MCLANE; Representative NOSSE, Senator BENTZ (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**.

Directs Governor, with recommendations from Oregon Health and Science University Board of Directors, to appoint Rare Disease Ombudsman. Allows Rare Disease Ombudsman to solicit and accept gifts, grants and donations.

Establishes Rare Disease Ombudsman Fund. Continuously appropriates moneys in fund to office of Rare Disease Ombudsman for certain purposes.

Declares emergency, effective on passage.

A BILL FOR AN ACT

1
2 Relating to rare diseases; and declaring an emergency.

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

4 **SECTION 1. (1) The office of the Rare Disease Ombudsman is established within the**
5 **Oregon Health and Science University.**

6 **(2)(a) The Governor, with recommendations by the Oregon Health and Science University**
7 **Board of Directors, shall appoint the Rare Disease Ombudsman for a term of four years. The**
8 **appointment of the Rare Disease Ombudsman is subject to Senate confirmation under ORS**
9 **171.562 and 171.565.**

10 **(b) A vacancy shall be filled within 60 days in the same manner as an appointment is**
11 **made.**

12 **(c) The Rare Disease Ombudsman shall serve at the pleasure of the Governor and may**
13 **be removed for just cause upon recommendation to the Governor by the Oregon Health and**
14 **Science University Board of Directors.**

15 **(3) The Rare Disease Ombudsman shall:**

16 **(a) Advocate for persons diagnosed with rare diseases, including persons eligible for en-**
17 **rollment in a medical assistance program.**

18 **(b) Ensure that necessary medical services are provided to persons diagnosed with rare**
19 **diseases, either by a licensed health care provider or by referral to an appropriate social**
20 **services provider.**

21 **(c) Perform other duties related to rare diseases as determined necessary by the Rare**
22 **Disease Ombudsman and the Oregon Health and Science University Board of Directors.**

23 **(4) The Rare Disease Ombudsman may adopt rules to carry out this section, including**
24 **rules to define "rare disease."**

25 **(5) The Rare Disease Ombudsman may solicit and accept gifts, grants and donations from**
26 **public and private sources for the purpose of carrying out the duties described in subsection**
27 **(3) of this section, and the moneys shall be deposited in the Rare Disease Ombudsman Fund**
28 **established under section 2 of this 2019 Act.**

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.

