

House Bill 2236

Ordered printed by the Speaker pursuant to House Rule 12.00A (5). Pre-session filed (at the request of House Interim Committee on Human Services for March of Dimes, Oregon Chapter)

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 Oregon Health Authority to establish registry and advisory committee related to birth anomalies and adverse pregnancy outcomes.

A BILL FOR AN ACT

1
2 Relating to birth anomalies.

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

4 **SECTION 1. (1) As used in this section:**

5 (a) **“Adverse pregnancy outcome” means stillbirth, miscarriage, prematurity or fetal**
6 **growth restriction.**

7 (b) **“Birth anomaly” means any abnormality of structure, function or body metabolism**
8 **present at birth.**

9 (c) **“Facility” means a:**

10 (A) **Hospital;**

11 (B) **Birthing center;**

12 (C) **Clinic that regularly provides genetic counseling, prenatal diagnostic services or ser-**
13 **vices for the diagnosis or treatment of birth anomalies; or**

14 (D) **Any other facility designated by rule of the Oregon Health Authority.**

15 (2) **The Oregon Health Authority shall:**

16 (a) **Establish a uniform and statewide registry and tracking system for birth anomalies**
17 **and adverse pregnancy outcomes;**

18 (b) **Adopt rules:**

19 (A) **Requiring all facilities to identify to the authority persons who are six years of age**
20 **or younger and are newly diagnosed with a birth anomaly, and persons discharged with an**
21 **adverse pregnancy outcome;**

22 (B) **Requiring all facilities to make available to the authority certain medical information**
23 **concerning persons who have been newly diagnosed with a birth anomaly and concerning**
24 **persons discharged with an adverse pregnancy outcome; and**

25 (C) **Ensuring that personally identifiable information contained in the registry is not re-**
26 **leased to the public and that disclosure of personally identifiable information contained in the**
27 **registry is in compliance with state and federal laws regarding confidentiality of health re-**
28 **ords;**

29 (c) **Analyze the information collected under this subsection to:**

30 (A) **Investigate the incidence, trends and causes of birth anomalies and adverse preg-**
31 **nancy outcomes; and**

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 **(B) Develop, assess and evaluate measures to prevent birth anomalies and adverse preg-**
2 **nancy outcomes; and**

3 **(d) Appoint an advisory committee, in collaboration with the March of Dimes, to advise**
4 **the authority in establishing and operating the registry and tracking system. The authority**
5 **shall include health professionals and community members as members of the advisory**
6 **committee. Members of the advisory committee are not entitled to compensation or re-**
7 **imbursement for expenses and serve as volunteers.**

8 **(3) The authority shall maintain a record of all persons who are permitted to access the**
9 **information in the registry. Nothing in this section prohibits the publication of statistical**
10 **information compiled from the registry.**

11 **SECTION 2. (1) When the Oregon Health Authority determines that the authority has**
12 **received a sufficient legislative appropriation or other funding to carry out the provisions**
13 **of section 1 of this 2011 Act, the authority shall adopt a rule so indicating. The authority**
14 **shall notify Legislative Counsel upon adoption of the rule.**

15 **(2) Section 1 of this 2011 Act becomes operative on the date the rule described in sub-**
16 **section (1) of this section is adopted.**

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