

A-Engrossed
Senate Bill 460

Ordered by the Senate May 1
Including Senate Amendments dated May 1

Sponsored by Senator MONNES ANDERSON; Senators BATES, DEVLIN, HASS, JOHNSON, MONROE, MORRISETTE, ROSENBAUM, VERGER, WALKER, Representative TOMEI

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.

Directs Department of Human Services, **when department secures sufficient funding**, 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, preterm birth, fetal**
6 **growth restriction or death of the mother in childbirth.**

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 Department of Human Services.**

15 (2) **When the Department of Human Services secures sufficient funding, the department**
16 **shall:**

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

19 (b) **Adopt rules:**

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

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

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

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 cords;

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

3 (A) Investigate the incidence, trends and causes of birth anomalies and adverse preg-
4 nancy outcomes; and

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

7 (d) Appoint an advisory committee, in collaboration with the March of Dimes, to advise
8 the department in establishing and operating the registry and tracking system. The depart-
9 ment shall include health professionals and community members as members of the advisory
10 committee. Members of the advisory committee are not entitled to compensation or re-
11 imbursement for expenses and serve as volunteers on the committee.

12 (3) The department shall maintain a record of all persons who are permitted to access
13 the information in the registry. Nothing in this section prohibits the publication of statistical
14 information compiled from the registry.

15 (4) When the department collects data concerning a person diagnosed with a birth
16 anomaly or discharged with an adverse pregnancy outcome, the department shall inform the
17 person, and the parent or guardian of the person if the person is less than 18 years of age,
18 that the person may request removal of personally identifiable information from the registry
19 at any time.

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