

Senate Bill 460

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 **as introduced**.

Directs Department of Human Services 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) **The Department of Human Services shall establish a uniform and statewide registry**
16 **and tracking system for birth anomalies and adverse pregnancy outcomes.**

17 (3) **The department shall adopt rules requiring all facilities to:**

18 (a) **Identify to the department persons who are six years of age or younger and are newly**
19 **diagnosed with a birth anomaly, and persons discharged with an adverse pregnancy outcome.**

20 (b) **Make available to the department certain medical information concerning persons**
21 **who have been newly diagnosed with a birth anomaly and concerning persons discharged with**
22 **an adverse pregnancy outcome.**

23 (4) **The department shall analyze the information collected under this section to:**

24 (a) **Investigate the incidence, trends and causes of birth anomalies and adverse preg-**
25 **nancy outcomes;**

26 (b) **Develop, assess and evaluate measures to prevent birth anomalies and adverse preg-**
27 **nancy outcomes; and**

28 (c) **Ensure efficient referral to and delivery of services for persons diagnosed with birth**
29 **anomalies or discharged with adverse pregnancy outcomes.**

30 (5) **The department shall adopt rules ensuring that personally identifiable information**
31 **contained in the registry is not released to the public and that disclosure of personally**

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 identifiable information contained in the registry is in compliance with state and federal laws
2 regarding confidentiality of health records. The department shall maintain a record of all
3 persons who are permitted to access the information in the registry. Nothing in this section
4 prohibits the publication of statistical information compiled from the registry.

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

9 (7) The department shall appoint an advisory committee to advise the department in es-
10 tablishing and operating the registry and tracking system. The department shall include
11 health professionals and community members as members of the advisory committee.
12 Members of the advisory committee are not entitled to compensation or reimbursement for
13 expenses and serve as volunteers on the committee.

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