

# Senate Bill 873

Sponsored by Senator MONNES ANDERSON, Representative TOMEI; Senators ATKINSON, AVAKIAN, BROWN, BURDICK, CARTER, DECKERT, DEVLIN, L GEORGE, GORDLY, KRUSE, METSGER, MONROE, MORRISETTE, MORSE, NELSON, PROZANSKI, STARR, VERGER, WALKER, WESTLUND, Representatives BARKER, BARNHART, BEYER, BONAMICI, BOONE, BUCKLEY, BUTLER, CANNON, CLEM, COWAN, DINGFELDER, C EDWARDS, ESQUIVEL, GARRARD, GELSER, GILMAN, GIROD, GREENLICK, HOLVEY, HUNT, KOTEK, KRIEGER, MACPHERSON, MERKLEY, OLSON, READ, RILEY, ROBLAN, ROSENBAUM, G SMITH, WITT (at the request of Oregon March of Dimes)

## 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 congenital defect and birth abnormality registry system. Allows Department of Human Services to collect and share information obtained through registry system for certain purposes.

## A BILL FOR AN ACT

1  
2 Relating to birth abnormality registry system.

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

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

5 (a) **"Birth abnormality" means any abnormality that occurs in the development of the**  
6 **body, its function or its chemical or metabolic composition.**

7 (b) **"Congenital defect" means a physical or mental impairment that limits a person's**  
8 **functional capabilities.**

9 (c) **"Poor pregnancy outcomes" means pregnancy outcomes including, but not limited to,**  
10 **fetal wasting, preterm birth and fetal growth restriction.**

11 (2) **The Department of Human Services shall establish a uniform and statewide registry**  
12 **and tracking system. The purpose of the registry system shall be to:**

13 (a) **Obtain information on the incidence, trends and possible causes of congenital defects,**  
14 **birth abnormalities and poor pregnancy outcomes from Oregon hospitals, birthing centers**  
15 **and diagnostic facilities;**

16 (b) **Develop strategies for reducing the incidence of congenital defects, birth abnor-**  
17 **malities and poor pregnancy outcomes;**

18 (c) **Provide the parent or guardian and the health care provider of a newborn child with**  
19 **information regarding congenital defects, birth abnormalities and poor pregnancy outcomes;**  
20 **and**

21 (d) **Refer the parent or guardian of a newborn child who was born with a congenital de-**  
22 **fect or birth abnormality, or a patient who has been discharged with a poor pregnancy out-**  
23 **come diagnosis, to relevant public services and private support organizations.**

24 (3) **The department shall adopt rules:**

25 (a) **Implementing this section;**

26 (b) **Ensuring the privacy of individuals about whom information is collected pursuant to**  
27 **this section; and**

28 (c) **Specifying the forms to be used by hospitals, birthing centers and diagnostic facilities**

**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 to provide the information required under this section.

2 (4) The department may adopt rules requiring all Oregon hospitals to:

3 (a) Maintain a record of patients up to six years of age who were born with a congenital  
4 defect or birth abnormality and of patients discharged with a poor pregnancy outcome diag-  
5 nosis, and make this record available to the department; and

6 (b) Make available certain medical information concerning patients who have been diag-  
7 nosed with a congenital defect or birth abnormality and concerning patients who have been  
8 discharged with a poor pregnancy outcome diagnosis.

9 (5) The department shall analyze the information collected under this section to:

10 (a) Investigate the causes of congenital defects, birth abnormalities and poor pregnancy  
11 outcomes;

12 (b) Develop, assess and evaluate measures to reduce and prevent the occurrence of con-  
13 genital defects, birth abnormalities and poor pregnancy outcomes; and

14 (c) Ensure efficient delivery of services for patients diagnosed with congenital defects,  
15 birth abnormalities or poor pregnancy outcomes and their families.

16 (6) The department may establish an advisory committee, if deemed necessary, to advise  
17 the department in establishing and operating the registry system. Members of the advisory  
18 committee are not entitled to compensation, but may be reimbursed for actual and necessary  
19 travel expenses incurred by them in the performance of their official duties from funds  
20 available to the department.

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