

## SENATE AMENDMENTS TO SENATE BILL 460

By COMMITTEE ON HEALTH CARE AND VETERANS' AFFAIRS

May 1

- 1       On page 1 of the printed bill, delete lines 15 through 31 and delete page 2 and insert:
- 2       “(2) When the Department of Human Services secures sufficient funding, the department shall:
- 3       “(a) Establish a uniform and statewide registry and tracking system for birth anomalies and
- 4       adverse pregnancy outcomes;
- 5       “(b) Adopt rules:
- 6       “(A) Requiring all facilities to identify to the department persons who are six years of age or
- 7       younger and are newly diagnosed with a birth anomaly, and persons discharged with an adverse
- 8       pregnancy outcome;
- 9       “(B) Requiring all facilities to make available to the department certain medical information
- 10       concerning persons who have been newly diagnosed with a birth anomaly and concerning persons
- 11       discharged with an adverse pregnancy outcome; and
- 12       “(C) Ensuring that personally identifiable information contained in the registry is not released
- 13       to the public and that disclosure of personally identifiable information contained in the registry is
- 14       in compliance with state and federal laws regarding confidentiality of health records;
- 15       “(c) Analyze the information collected under this subsection to:
- 16       “(A) Investigate the incidence, trends and causes of birth anomalies and adverse pregnancy
- 17       outcomes; and
- 18       “(B) Develop, assess and evaluate measures to prevent birth anomalies and adverse pregnancy
- 19       outcomes; and
- 20       “(d) Appoint an advisory committee, in collaboration with the March of Dimes, to advise the
- 21       department in establishing and operating the registry and tracking system. The department shall
- 22       include health professionals and community members as members of the advisory committee. Mem-
- 23       bers of the advisory committee are not entitled to compensation or reimbursement for expenses and
- 24       serve as volunteers on the committee.
- 25       “(3) The department shall maintain a record of all persons who are permitted to access the in-
- 26       formation in the registry. Nothing in this section prohibits the publication of statistical information
- 27       compiled from the registry.
- 28       “(4) When the department collects data concerning a person diagnosed with a birth anomaly or
- 29       discharged with an adverse pregnancy outcome, the department shall inform the person, and the
- 30       parent or guardian of the person if the person is less than 18 years of age, that the person may re-
- 31       quest removal of personally identifiable information from the registry at any time.”.
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