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HOUSE BILL NO. 1391

Offered January 12, 2006

A BILL to amend and reenact § 32.1-69.1 of the Code of Virginia, relating to the Virginia Congenital Anomalies Reporting and Education System.

Patron—Hogan

Referred to Committee on Health, Welfare and Institutions

Be it enacted by the General Assembly of Virginia:**1. That § 32.1-69.1 of the Code of Virginia is amended and reenacted as follows:**

§ 32.1-69.1. Virginia Congenital Anomalies Reporting and Education System.

A. In order to collect data to evaluate the possible causes of birth defects, improve the diagnosis and treatment of birth defects and establish a mechanism for informing the parents of children identified as having birth defects and their physicians about the health resources available to aid such children, the Commissioner shall establish and maintain a Virginia Congenital Anomalies Reporting and Education System using data from birth, fetal death, and death certificates filed with the State Registrar of Vital Records and data obtained from hospital medical records. The chief administrative officer of every hospital, as defined in § 32.1-123, shall make or cause to be made a report to the Commissioner of any person under two years of age diagnosed as having a congenital anomaly. This report shall include information on the parent's service in Vietnam, the duration of the service and possible exposure to Agent Orange through its development, testing or use. The Commissioner may appoint an advisory committee to assist in the design and implementation of this reporting and education system with representation from relevant groups including, but not limited to, physicians, geneticists, personnel of appropriate state agencies, persons with disabilities and the parents of children with disabilities.

B. The Commissioner shall provide for a secure system, which may include online data entry, to implement the Virginia Congenital Anomalies and Reporting System. The minimum data set collected shall include the infant's first and last name, date of birth, gender, state of residence, birth hospital, mother's first and last name, father's first and last name, primary contact's first and last name and address, physician's name, date of admission, date of discharge or transfer, and diagnosis. The secure system shall (i) contain birth defect data reported by hospitals and birth, fetal death, and death certificate data from the State Registrar of Vital Records and other sources as authorized by the Commissioner; (ii) comply with all applicable federal and state security and privacy requirements; (iii) integrate or link with other Department population-based surveillance systems as deemed necessary by the Commissioner to minimize incidence of infants lost to follow-up. Hospitals required to report birth defect data to the secure system may view existing birth data fields designated by the Commissioner to minimize duplication and ensure accuracy during data entry. All system users shall comply with applicable federal and state confidentiality and security requirements.

C. With the assistance of the advisory committee, the Board shall promulgate such regulations as may be necessary to implement this reporting and education system. These regulations may include determinations of specific genetic disorders to be monitored, the scope of the information to be collected, appropriate mechanisms for follow-up, relationships between the reporting and education system and other agencies and mechanisms for review and evaluation of the activities of the system. The reporting and education system may collect the name, address, sex, race, and any other information, determined to be pertinent by the Board, regarding persons reported to have birth defects.

INTRODUCED

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