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HOUSE BILL NO. 1391

AMENDMENT IN THE NATURE OF A SUBSTITUTE
(Proposed by the Senate Committee on Education and Health
on March 2, 2006)

(Patron Prior to Substitute—Delegate Hogan)

A *BILL to amend and reenact §§ 32.1-69.1 and 32.1-69.2 of the Code of Virginia, relating to information sharing among users of the Virginia Congenital Anomalies Reporting and Education System.*

Be it enacted by the General Assembly of Virginia:

1. That §§ 32.1-69.1 and 32.1-69.2 of the Code of Virginia are 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 and death certificates and fetal death reports 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 that protects the confidentiality of data and information for which reporting is required, to implement the Virginia Congenital Anomalies Reporting and Education System.

At a minimum, data collected shall include, but need not be limited to, the following: (i) the infant's first and last name, date of birth, gender, state of residence, birth hospital, physician's name, date of admission, date of discharge or transfer, and diagnosis; (ii) the first and last names of the infant's mother and father; (iii) the first and last name of the primary contact person for the infant; and (iv) data pertaining to birth defects reported by hospitals and derived from birth and death certificates and fetal death reports filed with the State Registrar of Vital Records and such other sources as may be authorized by the Commissioner.

The Commissioner, as he deems necessary to facilitate the follow-up of infants whose data and health record information have been entered into the system, may authorize the integration or linking of the Virginia Congenital Anomalies Reporting and Education System with other Department of Health population-based surveillance systems.

In addition, to minimize duplication and ensure accuracy during data entry, the Commissioner may authorize hospitals required to report birth defect data to the system to view such existing data and information as may be designated by the Commissioner.

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.

§ 32.1-69.2. Confidentiality of records; publication; authority of Commissioner to contact parents and physicians.

The Commissioner and all other persons to whom data is submitted pursuant to § 32.1-69.1 shall keep such information confidential. For the purpose of only complying with the provisions of § 32.1-69.1, hospitals required to report birth defects to the Virginia Congenital Anomalies Reporting and Education System and provide patient follow-up may view personally identifiable information in the system as approved by the Commissioner and upon receipt by the Commissioner of sworn affirmation from each such person that the confidentiality of the information will be preserved. No publication of information shall be made except in the form of statistical or other studies which do not identify individuals. However, the Commissioner may contact the parents of children identified as having birth defects and their physicians to collect relevant data and to provide them with information about available

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60 public and private health care resources.