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HOUSE BILL NO. 252

Offered January 10, 2024

Prefiled January 4, 2024

A *BILL to amend the Code of Virginia by adding in Chapter 2 of Title 32.1 an article numbered 21, consisting of sections numbered 32.1-73.21 through 32.1-73.26, relating to sickle cell disease; statewide registry; collection of sickle cell disease case information; penalties; notification; annual report.*

Patrons—Cole, Helmer and Mundon King

Referred to Committee on Health and Human Services

Be it enacted by the General Assembly of Virginia:

1. That the Code of Virginia is amended by adding in Chapter 2 of Title 32.1 an article numbered 21, consisting of sections numbered 32.1-73.21 through 32.1-73.26, as follows:

*Article 21.**Statewide Sickle Cell Disease Registry.*

§ 32.1-73.21. Information from hospitals, clinics, certain laboratories, and physicians supplied to Commissioner; statewide sickle cell disease registry.

A. Each hospital, clinic, and independent pathology laboratory shall make available to the Commissioner or his agents information on patients having sickle cell disease. A physician shall report information on patients having sickle cell disease unless he has determined that a hospital, clinic, or in-state pathology laboratory has reported the information. Such information shall include the name, address, sex, race, diagnosis, trait status, newborn screening data, and any other pertinent identifying information regarding each such patient. Each hospital, clinic, independent pathology laboratory, or physician shall provide other available clinical information as defined by the Board.

B. From such information the Commissioner shall establish and maintain a statewide sickle cell disease registry. The purpose of the statewide sickle cell disease registry shall include:

1. Determining means of improving the diagnosis and treatment of sickle cell disease patients.
2. Determining the need for and means of providing better long-term, follow-up care to sickle cell disease patients.
3. Conducting epidemiological analyses of the incidence, prevalence, survival, and risk factors associated with the occurrence of sickle cell disease in Virginia.
4. Improving rehabilitative programs for sickle cell disease patients.
5. Assisting in the training of hospital personnel.
6. Determining other needs of sickle cell disease patients and health personnel.

§ 32.1-73.22. Collection of sickle cell disease case information by the Commissioner.

A. Using such funds as may be appropriated therefor, the Commissioner or his designee may perform on-site data collection of the records of patients having sickle cell disease at those consenting hospitals, clinics, independent pathology laboratories, and physician offices required to report information on such patients pursuant to the reporting requirements of § 32.1-73.21 in order to ensure the completeness and accuracy of the statewide sickle cell disease registry.

B. The selection criteria for determining which consenting hospitals, clinics, independent pathology laboratories, and physician offices may be subject to on-site data collection under the provisions of this section shall include (i) the expected annual number of sickle cell disease case reports from each such facility, (ii) the historical completeness and accuracy of reporting rates of each facility under consideration, and (iii) whether the facility maintains its own sickle cell disease registry.

C. The Board shall promulgate regulations necessary to implement the provisions of this section.

§ 32.1-73.23. Confidential nature of information supplied; publication; reciprocal data-sharing agreements.

A. The Commissioner and all persons to whom information is submitted in accordance with § 32.1-73.21 shall keep such information confidential. Except as authorized by the Commissioner in accordance with the provisions of § 32.1-41, no release of any such information shall be made except in the form of statistical or other studies that do not identify individual cases.

B. The Commissioner may enter into reciprocal data-sharing agreements with other sickle cell disease registries for the exchange of information. Upon the provision of satisfactory assurances for the preservation of the confidentiality of such information, patient-identifying information may be exchanged with other sickle cell disease registries that have entered into reciprocal data-sharing agreements with the Commissioner.

59 **§ 32.1-73.24. Penalties for unauthorized use of statewide sickle cell disease registry.**

60 *In addition to the remedies provided in § 32.1-27, any person who uses, discloses, or releases data*
61 *maintained in the statewide sickle cell disease registry in violation of § 32.1-73.23 shall be subject, in*
62 *the discretion of the court, to a civil penalty not to exceed \$25,000 for each violation, which shall be*
63 *paid to the general fund.*

64 **§ 32.1-73.25. Notification of sickle cell disease patients of statewide sickle cell disease registry**
65 **reporting.**

66 *A. Any physician diagnosing sickle cell disease shall, at such time and in such manner as considered*
67 *appropriate by such physician, notify each patient whose name and record abstract is required to be*
68 *reported to the statewide sickle cell disease registry pursuant to § 32.1-73.21 that personal identifying*
69 *information about him has been included in the registry as required by law. Any physician required to*
70 *so notify a patient that personal identifying information about him has been included in the sickle cell*
71 *disease registry may, when, in the opinion of the physician, such notice would be injurious to the*
72 *patient's health or well-being, provide the required notice to the patient's authorized representative or*
73 *next of kin in lieu of notifying the patient.*

74 *B. Upon request to the statewide sickle cell disease registry, the patient whose personal identifying*
75 *information has been submitted to such registry shall have a right to know the identity of the reporter of*
76 *his information to such registry. A patient diagnosed with sickle cell disease may self-report information*
77 *to the statewide sickle cell disease registry. A patient diagnosed with sickle cell disease shall have the*
78 *right to opt out of having his data reported to the statewide sickle cell disease registry.*

79 **§ 32.1-73.26. Annual report; sickle cell disease registry.**

80 *The Commissioner shall submit to the Governor and the General Assembly, by December 1 of each*
81 *year, a report of the information obtained under this article.*