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SENATE BILL NO. 449

Offered January 10, 2018

Prefiled January 9, 2018

A *BILL to amend and reenact §§ 32.1-65 and 32.1-67 of the Code of Virginia and to repeal § 32.1-65.1 of the Code of Virginia, relating to newborn screening; lysosomal storage disorders.*

Patron—Chafin

Referred to Committee on Education and Health

Be it enacted by the General Assembly of Virginia:**1. That §§ 32.1-65 and 32.1-67 of the Code of Virginia are amended and reenacted as follows:****§ 32.1-65. Certain newborn screening required; exemption.**

A. In order to prevent intellectual disability and permanent disability or death, every infant who is born in the Commonwealth shall be subjected to screening tests for various disorders consistent with, but not necessarily identical to, the uniform condition panel recommended by the U.S. Secretary of Health and Human Services and the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children; *however, such screening shall include screening for Pompe disease, mucopolysaccharidosis type 1 (MPS-1), and other lysosomal storage disorders for which a screening test approved by the U.S. Food and Drug Administration exists. Screening tests required pursuant to this subsection shall be performed by the Division of Consolidated Laboratory Services or any other laboratory the Department of Health has contracted with to provide this service.*

B. *In addition to the screening tests required pursuant to subsection A, every infant born in a hospital in the Commonwealth that has a newborn nursery shall be screened for critical congenital heart defect, using pulse oximetry or other Board-approved screening test that is based on standards set forth by the American Academy of Pediatrics. Such screening shall be performed when the infant is at least 24 hours old but no more than 48 hours old or, in cases in which the infant is discharged from the hospital prior to reaching 24 hours of age, prior to discharging the infant.*

C. Any infant whose parent or guardian objects ~~thereto~~ to the performance of testing required pursuant to this section on the grounds that such tests conflict with his religious practices or tenets shall not be required to receive such screening tests.

D. The physician ~~or~~, certified nurse midwife, or other health care provider in charge of the infant's care after delivery shall cause ~~such~~ the tests required pursuant to this section to be performed. ~~The screening tests shall be performed by the Division of Consolidated Laboratory Services or any other laboratory the Department of Health has contracted with to provide this service.~~

E. The program for screening infants for sickle cell diseases shall be conducted in addition to the programs provided for in Article 8 (§ 32.1-68 et seq.).

§ 32.1-67. Duty of Board for follow-up and referral protocols; regulations.

Infants identified with any condition for which newborn screening is conducted pursuant to § 32.1-65 ~~or 32.1-65.1~~ shall be eligible for the services of the Children with Special Health Care Needs Program administered by the Department of Health. The Board of Health shall promulgate such regulations as may be necessary to implement Newborn Screening Services and the Children with Special Health Care Needs Program. The Board's regulations shall include, but not be limited to, a list of newborn screening tests conducted pursuant to §§ 32.1-65 and ~~32.1-65.1~~, notification processes conducted pursuant to § 32.1-66, follow-up procedures, appropriate referral processes, and services available for infants and children who have a heritable disorder or genetic disease identified through Newborn Screening Services.

2. That § 32.1-65.1 of the Code of Virginia is repealed.

INTRODUCED

SB449