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# HOUSE BILL NO. 1824

Offered January 12, 2005

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*A BILL to amend and reenact §§ 32.1-65 through 32.1-67.1 of the Code of Virginia and to repeal the second enactment of Chapter 440 of the 2002 Acts of Assembly, relating to testing of newborns for inborn errors of metabolism.*

Patrons—Frederick, Athey, Baskerville and Marshall, R.G.

Referred to Committee on Health, Welfare and Institutions

**Be it enacted by the General Assembly of Virginia:**

**1. That §§ 32.1-65 through 32.1-67.1 of the Code of Virginia are amended and reenacted as follows:**

Article 7.

~~Detection and Control of Phenylketonuria and Other Inborn Errors of Metabolism~~ *Newborn Screening*.

§ 32.1-65. Certain newborn screening required.

In order to prevent mental retardation~~,~~ *and* permanent disability or death, every infant who is born in ~~this~~ *the* Commonwealth shall be subjected to ~~a~~ screening ~~test for biotinidase deficiency, phenylketonuria, hypothyroidism, homocystinuria, galactosemia, congenital adrenal hyperplasia, medium-chain acyl-CoA dehydrogenase (MCAD or MCADH) deficiency, and Maple Syrup Urine Disease, and each infant determined at risk shall be subject to a screening test for sickle cell diseases~~ *tests for various disorders consistent with the uniform condition panel recommended by the American College of Medical Genetics in a 2004 report. Further, upon the issuance of a guideline for states' newborn screening programs by the federal Department of Health and Human Services, every infant who is born in the Commonwealth shall be screened for a panel of disorders consistent with the federal guideline*.

Any infant whose parent or guardian objects thereto on the grounds that such ~~test conflicts~~ *tests conflict* with his religious practices or tenets shall not be required to receive ~~a~~ *such* screening ~~test~~ *tests*.

The physician or certified nurse midwife in charge of the infant's care after delivery shall cause such ~~test~~ *tests* 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.

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.) of this chapter.

§ 32.1-66. Commissioner to notify physicians; reports to Commissioner.

Whenever a test result indicates suspicion of ~~biotinidase deficiency, phenylketonuria, hypothyroidism, homocystinuria, galactosemia, Maple Syrup Urine Disease or any sickle cell disease~~ *any disorder for which newborn screening is conducted pursuant to § 32.1-65*, the Commissioner shall notify forthwith the attending physician and shall perform or provide for any additional testing required to confirm or disprove the diagnosis ~~of biotinidase deficiency, phenylketonuria, hypothyroidism, homocystinuria, galactosemia, Maple Syrup Urine Disease or the sickle cell disease~~. All physicians, public health nurses and administrators of hospitals in ~~this~~ *the* Commonwealth shall report the discovery of all cases of ~~biotinidase deficiency, phenylketonuria, hypothyroidism, homocystinuria, galactosemia, Maple Syrup Urine Disease~~ *any disorder for which newborn screening is conducted pursuant to § 32.1-65* to the Commissioner~~, as well as sickle cell diseases in infants less than one year of age~~.

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

The Board shall recommend ~~procedures~~ *protocols* for ~~the treatment of biotinidase deficiency, phenylketonuria, hypothyroidism, homocystinuria, galactosemia, Maple Syrup Urine Disease and sickle cell diseases, and shall provide such treatment for infants in medically indigent families. The Board shall create procedures to provide to (i) the parents or guardian of any child or (ii) any pregnant woman, who is a legal resident of the Commonwealth and who is diagnosed as requiring treatment for phenylketonuria, the special food products required in the management of phenylketonuria out of such funds as may be appropriated for this purpose. The special food products shall include medical formulas which are designed specifically for the treatment of phenylketonuria and low protein modified foods (not foods naturally low in protein) which are designed specifically for use in the treatment for inborn errors of metabolism. The parents or guardian of any such child, or the pregnant woman, shall, in the discretion of the Department, reimburse to the local health department the cost of such special medical formulas in an amount not to exceed two percent of their gross income. The parents or guardian of any such child, or the pregnant woman, shall, with such funds as are appropriated, receive reimbursement~~

~~from the Department for the cost of such special low protein modified foods in an amount not to exceed $2,000 per diagnosed person per year. The reimbursement required by this section shall be payable quarterly by the first day of January, April, July, and October~~ *follow-up and referral of infants identified with any disorder for which newborn screening is conducted pursuant to § 32.1-65, including appropriate mechanisms and reporting for follow-up and services for infants and children of medically indigent families. Infants identified with any such disorder 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 the newborn screening program and the services available through the Children with Special Health Care Needs Program to infants and children identified as having a genetic disorder through the newborn screening program.*

§ 32.1-67.1. Confidentiality of records; prohibition of discrimination.

The results of the *newborn* screening ~~programs~~ *program* conducted pursuant to this article may be used for research and collective statistical purposes. No publication of information, biomedical research or medical data shall be made ~~which~~ *that* identifies any infant having a genetic ~~disease~~ *disorder*. All medical records maintained as part of the screening ~~programs~~ *program* shall be confidential and shall be accessible only to the Board, the Commissioner or his agents.

**2. That the second enactment of Chapter 440 of the 2002 Acts of Assembly is repealed.**

**3. That the provisions of this act shall become effective on March 1, 2006.**

**4. That, notwithstanding the provisions of the third enactment clause, the Board of Health shall promulgate regulations to implement the provisions of this act to be effective within 280 days of its enactment.**