

SENATE BILL 160

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CF 9lr1611

By: **Senators Kelley, Currie, Forehand, and Lenett**
Introduced and read first time: January 20, 2009
Assigned to: Finance

A BILL ENTITLED

1 AN ACT concerning

2 **Hereditary and Congenital Disorders – Newborn Screening**

3 FOR the purpose of authorizing a parent or guardian of a newborn to object to a
4 certain newborn screening only under certain circumstances; prohibiting the
5 statewide system for newborn screening to provide an exemption for certain
6 hereditary and congenital disorders; requiring the Department of Health and
7 Mental Hygiene to adopt certain regulations; and generally relating to
8 screening of newborns for hereditary and congenital disorders.

9 BY repealing and reenacting, with amendments,
10 Article – Health – General
11 Section 13–111
12 Annotated Code of Maryland
13 (2005 Replacement Volume and 2008 Supplement)

14 Preamble

15 WHEREAS, Metabolic screenings of newborns, followed by appropriate medical
16 treatment, would prevent many serious life–long disabilities and deaths; and

17 WHEREAS, Newborn screening policy should be based upon the best interest of
18 affected newborns; and

19 WHEREAS, The State does not have a parental waiver for newborn hearing
20 screening or administration of prophylactic eye drops to newborns; and

21 WHEREAS, The General Assembly and the Maryland Judiciary have rejected
22 several attempts to add religious exemptions to civil and criminal child–neglect laws;
23 and

EXPLANATION: CAPITALS INDICATE MATTER ADDED TO EXISTING LAW.

[Brackets] indicate matter deleted from existing law.



1 WHEREAS, In 2008, the enactment of legislation establishing a coordinated
2 system of newborn screening allows a parent or guardian to object to the screening for
3 any reason; and

4 WHEREAS, There are effective treatments for many, but not all, hereditary and
5 congenital disorders associated with severe problems of health or development; now,
6 therefore,

7 SECTION 1. BE IT ENACTED BY THE GENERAL ASSEMBLY OF
8 MARYLAND, That the Laws of Maryland read as follows:

9 **Article - Health - General**

10 13-111.

11 (a) (1) The Department shall establish a coordinated statewide system for
12 screening all newborn infants in the State for certain hereditary and congenital
13 disorders associated with severe problems of health or development[, except when the
14 parent or guardian of the newborn infant objects].

15 (2) (I) **THE SYSTEM FOR NEWBORN SCREENING MAY NOT**
16 **PROVIDE AN EXEMPTION FROM SCREENING FOR HEREDITARY AND CONGENITAL**
17 **DISORDERS ASSOCIATED WITH SEVERE PROBLEMS OF HEALTH OR**
18 **DEVELOPMENT FOR WHICH THERE ARE EFFECTIVE TREATMENTS.**

19 (II) **A PARENT OR GUARDIAN OF A NEWBORN INFANT MAY**
20 **OBJECT TO SCREENING FOR HEREDITARY AND CONGENITAL DISORDERS FOR**
21 **WHICH THERE IS NO TREATMENT THAT HAS PROVEN EFFECTIVE.**

22 (b) Except as provided in § 13-112 of this subtitle, the Department's public
23 health laboratory is the sole laboratory authorized to perform tests on specimens from
24 newborn infants collected to screen for hereditary and congenital disorders as
25 determined under subsection (d)(2) of this section.

26 (c) The system for newborn screening shall include:

27 (1) Laboratory testing and the reporting of test results; and

28 (2) Follow-up activities to facilitate the rapid identification and
29 treatment of an affected child.

30 (d) In consultation with the State Advisory Council on Hereditary and
31 Congenital Disorders, the Department shall:

32 (1) Establish protocols for a health care provider to obtain and deliver
33 test specimens to the Department's public health laboratory;

1 (2) Determine the screening tests that the Department's public health
2 laboratory is required to perform;

3 (3) Maintain a coordinated statewide system for newborn screening
4 that carries out the purpose described in subsection (c) of this section that includes:

5 (i) Communicating the results of screening tests to the health
6 care provider of the newborn infant;

7 (ii) Locating newborn infants with abnormal test results;

8 (iii) Sharing newborn screening information between hospitals,
9 health care providers, treatment centers, and laboratory personnel; and

10 (iv) Delivering needed clinical, diagnostic, and treatment
11 information to health care providers, parents, and caregivers; and

12 (4) Adopt regulations that set forth the standards and requirements
13 for newborn screening for hereditary and congenital disorders that are required under
14 this subtitle, including:

15 (i) Performing newborn screening tests;

16 (ii) Coordinating the reporting, follow-up, and treatment
17 activities with parents, caregivers, and health care providers; [and]

18 (iii) Establishing fees for newborn screening that do not exceed
19 an amount sufficient to cover the administrative, laboratory, and follow-up costs
20 associated with the performance of screening tests under this subtitle; **AND**

21 **(IV) ESTABLISHING A LIST OF HEREDITARY AND**
22 **CONGENITAL DISORDERS COVERED UNDER THE SYSTEM FOR NEWBORN**
23 **SCREENING FOR WHICH THERE ARE EFFECTIVE TREATMENTS.**

24 SECTION 2. AND BE IT FURTHER ENACTED, That this Act shall take effect
25 October 1, 2009.