

HOUSE BILL 153

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4lr0477

By: **Delegate O'Donnell**

Introduced and read first time: January 15, 2014

Assigned to: Health and Government Operations

A BILL ENTITLED

1 AN ACT concerning

2 **Health – Newborn Screening Program – Krabbe Leukodystrophy**

3 FOR the purpose of requiring that the Department of Health and Mental Hygiene's
4 Newborn Screening Program include screening for Krabbe leukodystrophy; and
5 generally relating to newborn screening.

6 BY repealing and reenacting, with amendments,
7 Article – Health – General
8 Section 13–111
9 Annotated Code of Maryland
10 (2009 Replacement Volume and 2013 Supplement)

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

13 **Article – Health – General**

14 13–111.

15 (a) The Department shall establish a coordinated statewide system for
16 screening all newborn infants in the State for certain hereditary and congenital
17 disorders associated with severe problems of health or development, except when the
18 parent or guardian of the newborn infant objects.

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

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

EXPLANATION: CAPITALS INDICATE MATTER ADDED TO EXISTING LAW.

[Brackets] indicate matter deleted from existing law.



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

2 (2) Follow-up activities to facilitate the rapid identification and
3 treatment of an affected child; AND

4 **(3) SCREENING FOR KRABBE LEUKODYSTROPHY.**

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

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

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

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

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

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

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

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

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

23 (i) Performing newborn screening tests;

24 (ii) Coordinating the reporting, follow-up, and treatment
25 activities with parents, caregivers, and health care providers; and

26 (iii) Establishing fees for newborn screening that do not exceed
27 an amount sufficient to cover the administrative, laboratory, and follow-up costs
28 associated with the performance of screening tests under this subtitle.

29 (e) Notwithstanding any other provision of law, if the Secretary of Health
30 and Human Services issues federal recommendations on critical congenital heart
31 disease screening of newborns, the Department shall adopt the federal screening
32 recommendations.

1 SECTION 2. AND BE IT FURTHER ENACTED, That this Act shall take effect
2 October 1, 2014.