

HOUSE BILL 111

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By: **Delegate Hubbard**

Introduced and read first time: January 9, 2014

Assigned to: Health and Government Operations

A BILL ENTITLED

1 AN ACT concerning

2 **Public Health – Newborn Screening Program – Lysosomal Storage Disorders**

3 FOR the purpose of requiring that the Department of Health and Mental Hygiene’s
4 Newborn Screening Program include screening for certain Lysosomal Storage
5 Disorders; and 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 THE FOLLOWING LYSOSOMAL STORAGE**
5 **DISORDERS:**

6 **(I) KRABBE LEUKODYSTROPHY;**

7 **(II) POMPE DISEASE;**

8 **(III) GAUCHER DISEASE;**

9 **(IV) NIEMANN-PICK DISEASE;**

10 **(V) FABRY DISEASE; AND**

11 **(VI) HURLER SYNDROME.**

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

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

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

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

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

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

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

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

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

- 1 (i) Performing newborn screening tests;
- 2 (ii) Coordinating the reporting, follow-up, and treatment
3 activities with parents, caregivers, and health care providers; and
- 4 (iii) Establishing fees for newborn screening that do not exceed
5 an amount sufficient to cover the administrative, laboratory, and follow-up costs
6 associated with the performance of screening tests under this subtitle.
- 7 (e) Notwithstanding any other provision of law, if the Secretary of Health
8 and Human Services issues federal recommendations on critical congenital heart
9 disease screening of newborns, the Department shall adopt the federal screening
10 recommendations.

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