

SENATE BILL 433

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4r1884
CF HB 111

By: ~~Senator Dyson~~ Senators Dyson, Astle, Brinkley, Feldman, Glassman, Kelley, Kittleman, Klausmeier, Mathias, Middleton, Pugh, and Ramirez

Introduced and read first time: January 24, 2014

Assigned to: Finance

Committee Report: Favorable with amendments

Senate action: Adopted

Read second time: March 28, 2014

CHAPTER _____

1 AN ACT concerning

2 ~~Public Health~~ Department of Health and Mental Hygiene – Newborn
3 Screening Program Fund – ~~Lysosomal Storage Disorders~~ Establishment

4 FOR the purpose of ~~requiring that the Department of Health and Mental Hygiene’s~~
5 ~~Newborn Screening Program include screening for certain Lysosomal Storage~~
6 ~~Disorders; and generally relating to newborn screening~~ establishing the
7 Newborn Screening Program Fund; requiring the Secretary of Health and
8 Mental Hygiene to administer the Fund; providing for the uses, purposes,
9 sources of funding, investment of money, and auditing of the Fund; providing
10 that the Fund is a continuing, nonlapsing fund not subject to certain provisions
11 of law; requiring the Secretary to pay certain fees to the Comptroller beginning
12 on a certain date; requiring the Comptroller to distribute certain fees to the
13 Fund; defining a certain term; and generally relating to the Newborn Screening
14 Program Fund in the Department of Health and Mental Hygiene.

15 BY ~~repealing and reenacting, with amendments,~~ adding to
16 Article – Health – General
17 Section ~~13–111~~ 13–111(f) and 13–113
18 Annotated Code of Maryland
19 (2009 Replacement Volume and 2013 Supplement)

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

EXPLANATION: CAPITALS INDICATE MATTER ADDED TO EXISTING LAW.

[Brackets] indicate matter deleted from existing law.

Underlining indicates amendments to bill.

~~Strike out~~ indicates matter stricken from the bill by amendment or deleted from the law by amendment.



1 Article – Health – General

2 13–111.

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

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

11 ~~(c) The system for newborn screening shall include:~~

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

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

15 ~~(3) SCREENING FOR THE FOLLOWING LYSOSOMAL STORAGE~~
16 ~~DISORDERS:~~

17 ~~(I) KRABBE LEUKODYSTROPHY;~~

18 ~~(II) POMPE DISEASE;~~

19 ~~(III) GAUCHER DISEASE;~~

20 ~~(IV) NIEMANN-PICK DISEASE;~~

21 ~~(V) FABRY DISEASE; AND~~

22 ~~(VI) HURLER SYNDROME.~~

23 ~~(d) In consultation with the State Advisory Council on Hereditary and~~
24 ~~Congenital Disorders, the Department shall:~~

25 ~~(1) Establish protocols for a health care provider to obtain and deliver~~
26 ~~test specimens to the Department’s public health laboratory;~~

27 ~~(2) Determine the screening tests that the Department’s public health~~
28 ~~laboratory is required to perform;~~

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

3 ~~(i) Communicating the results of screening tests to the health~~
4 ~~care provider of the newborn infant;~~

5 ~~(ii) Locating newborn infants with abnormal test results;~~

6 ~~(iii) Sharing newborn screening information between hospitals,~~
7 ~~health care providers, treatment centers, and laboratory personnel; and~~

8 ~~(iv) Delivering needed clinical, diagnostic, and treatment~~
9 ~~information to health care providers, parents, and caregivers; and~~

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

13 ~~(i) Performing newborn screening tests;~~

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

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

19 ~~(e) Notwithstanding any other provision of law, if the Secretary of Health~~
20 ~~and Human Services issues federal recommendations on critical congenital heart~~
21 ~~disease screening of newborns, the Department shall adopt the federal screening~~
22 ~~recommendations.~~

23 **(F) (1) BEGINNING JANUARY 1, 2015, THE SECRETARY SHALL PAY**
24 **ALL FEES COLLECTED UNDER THE PROVISIONS OF THIS SUBTITLE TO THE**
25 **COMPTROLLER.**

26 **(2) THE COMPTROLLER SHALL DISTRIBUTE THE FEES TO THE**
27 **NEWBORN SCREENING PROGRAM FUND ESTABLISHED UNDER § 13-113 OF**
28 **THIS SUBTITLE.**

29 **13-113.**

30 **(A) IN THIS SECTION, “FUND” MEANS THE NEWBORN SCREENING**
31 **PROGRAM FUND.**

32 **(B) THERE IS A NEWBORN SCREENING PROGRAM FUND.**

1 **(C) THE PURPOSE OF THE FUND IS TO PROVIDE FUNDING FOR THE**
2 **SCREENING OF NEWBORN INFANTS IN THE STATE FOR CERTAIN HEREDITARY**
3 **AND CONGENITAL DISORDERS.**

4 **(D) THE SECRETARY SHALL ADMINISTER THE FUND.**

5 **(E) (1) THE FUND IS A SPECIAL, NONLAPSING FUND THAT IS NOT**
6 **SUBJECT TO § 7-302 OF THE STATE FINANCE AND PROCUREMENT ARTICLE.**

7 **(2) THE STATE TREASURER SHALL HOLD THE FUND**
8 **SEPARATELY, AND THE COMPTROLLER SHALL ACCOUNT FOR THE FUND.**

9 **(F) THE FUND CONSISTS OF:**

10 **(1) REVENUE DISTRIBUTED TO THE FUND UNDER § 13-111(F) OF**
11 **THIS SUBTITLE;**

12 **(2) MONEY APPROPRIATED IN THE STATE BUDGET TO THE FUND;**
13 **AND**

14 **(3) ANY OTHER MONEY FROM ANY OTHER SOURCE ACCEPTED**
15 **FOR THE BENEFIT OF THE FUND.**

16 **(G) THE FUND MAY BE USED ONLY TO COVER THE ADMINISTRATIVE,**
17 **LABORATORY, AND FOLLOW-UP COSTS ASSOCIATED WITH THE PERFORMANCE**
18 **OF NEWBORN SCREENING TESTS CONDUCTED UNDER THIS SUBTITLE.**

19 **(H) THE STATE TREASURER SHALL INVEST THE MONEY OF THE FUND**
20 **IN THE SAME MANNER AS OTHER STATE MONEY MAY BE INVESTED.**

21 **(I) EXPENDITURES FROM THE FUND MAY BE MADE ONLY IN**
22 **ACCORDANCE WITH THE STATE BUDGET.**

23 **(J) THE LEGISLATIVE AUDITOR SHALL AUDIT THE ACCOUNTS AND**
24 **TRANSACTIONS OF THE FUND AS PROVIDED IN § 2-1220 OF THE STATE**
25 **GOVERNMENT ARTICLE.**

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