

**SENATE, No. 1283**

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**STATE OF NEW JERSEY**  
**217th LEGISLATURE**

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INTRODUCED FEBRUARY 8, 2016

**Sponsored by:**

**Senator JOSEPH F. VITALE**

**District 19 (Middlesex)**

**SYNOPSIS**

Revises Newborn Screening program in DOH.

**CURRENT VERSION OF TEXT**

As introduced.



1 AN ACT concerning screening for disorders in newborn infants and  
2 amending and supplementing P.L.1977, c.321.

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4 **BE IT ENACTED** by the Senate and General Assembly of the State  
5 of New Jersey:

6

7 1. Section 1 of P.L.1977, c.321 (C.26:2-110) is amended to  
8 read as follows:

9 1. **【It is hereby declared to be the public policy of this State**  
10 **that in the interests of public health every effort should be made to**  
11 **detect in newborn infants, hypothyroidism, galactosemia,**  
12 **phenylketonuria, and other preventable biochemical disorders**  
13 **which may cause mental retardation or other permanent disabilities**  
14 **and to treat affected individuals.】**

15 The Legislature finds and declares that:

16 a. Newborn screening is an essential public health activity that  
17 strives to screen every newborn infant for a variety of congenital  
18 disorders, which, if not detected and managed early, can result in  
19 significant morbidity, mortality, and disability. The State's newborn  
20 screening system must provide the infrastructure for universal  
21 access and rapid and effective follow-up;

22 b. Ongoing advances in technologies and treatment modalities  
23 make it possible to screen newborn infants for a wide array of  
24 disorders. It is imperative that the State adjust its newborn  
25 screening program to incorporate these disorders to ensure that the  
26 program remains at the forefront of these advances; and

27 c. It is the intent of this act to protect the health and quality of  
28 life of newborn infants born in this State by enhancing the capacity  
29 to screen for congenital disorders and by providing: all newborn  
30 infants with screens for certain conditions and with appropriate  
31 referrals and early medical intervention when warranted; and  
32 newborn data collection is standardized, and conditions detected by  
33 newborn screening are tracked and monitored. Further, information  
34 on newborn screening and conditions for which a newborn can be  
35 screened should be readily accessible, current, and understandable  
36 to both health care providers and parents or guardians.

37 (cf: P.L.1988, c.24, s.2)

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39 2. (New section) The Commissioner of Health shall establish a  
40 Newborn Screening Advisory Review Committee to annually  
41 review the disorders included in the Newborn Screening program,  
42 screening technologies, treatment options, and educational and  
43 follow-up procedures. The committee shall include, but need not be  
44 limited to, medical, hospital, and public health professionals,  
45 scientific experts, and consumer representatives and advocates. The

**EXPLANATION – Matter enclosed in bold-faced brackets **【thus】** in the above bill is not enacted and is intended to be omitted in the law.**

**Matter underlined thus is new matter.**

1 committee shall meet annually to review and revise the list of  
2 disorders recommended for inclusion in the Newborn Screening  
3 program. The committee shall allow for public input in the course  
4 of conducting its review and issue recommendations to the  
5 commissioner on the improvement of the Newborn Screening  
6 program.

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8 3. Section 2 of P.L.1977, c.321 (C.26:2-111) is amended to  
9 read as follows:

10 2. **【All】** The Newborn Screening Program in the Department of  
11 Health shall screen all infants born in this State **【shall be tested for**  
12 **hypothyroidism, galactosemia and phenylketonuria】** based on the  
13 list of disorders that is recommended by the Newborn Screening  
14 Advisory Review Committee and approved by the Commissioner of  
15 Health, consistent with the Recommended Uniform Screening Panel  
16 of the United States Secretary of Health and Human Services. The  
17 Commissioner of Health **【shall】** may issue regulations to assure  
18 that newborns are **【so tested】** screened in a manner approved by the  
19 commissioner. **【The commissioner shall ensure that treatment**  
20 **services are available to all identified individuals.】**

21 The **【State】** Department of Health **【may】** shall charge a  
22 reasonable fee for the **【tests】** screening, follow-up, treatment, and  
23 education performed pursuant to this act. The amount of the fee  
24 **【and the】** shall be adjusted by the commissioner as necessary to  
25 support the screening, follow-up, and treatment of newborn infants,  
26 and the education of physicians, hospital staffs, nurses, and the  
27 public as required by this act. The procedures for collecting the fee  
28 shall be determined by the commissioner. The commissioner shall  
29 apply all revenues collected from the fees to the 【testing】  
30 screening, follow-up, education, and treatment procedures  
31 performed pursuant to this act. The fee shall be used to support the  
32 program, including, but not limited to, ongoing infrastructure  
33 upgrades, including provides electronic access to physicians to  
34 obtain screening results, and follow-up recommendations.

35 **【The】** Based on the recommendations of the Newborn Screening  
36 Advisory Review Committee established pursuant to section 2 of  
37 P.L. , c. (C. ) (pending before the Legislature as this bill),  
38 the commissioner may also require 【testing】 the screening of  
39 newborn infants for other **【preventable biochemical】** disorders if  
40 reliable and efficient **【testing】** screening techniques are available.  
41 If the commissioner determines that an additional test shall be  
42 required, **【90】** the commissioner, at least 60 days prior to requiring  
43 the test 【he】<sub>1</sub> shall so advise the President of the Senate 【,】 and the  
44 Speaker of the General Assembly 【and chairmen of the standing  
45 reference committees on Revenue, Finance and Appropriations and  
46 Institutions, Health and Welfare of his determination】.

1 The commissioner shall provide a follow-up program **【of**  
2 **reviewing and following up】** on positive screen cases in order that  
3 measures may be taken to prevent **【mental retardation】** death or  
4 intellectual or other permanent disabilities. The program shall  
5 provide timely intervention and, as appropriate, referrals to  
6 specialist treatment centers for newborn infants who screen positive  
7 for disorders pursuant to this section.

8 The commissioner shall collect screening information on  
9 newborn infants in a standardized manner and develop a system for  
10 quality assurance which includes the periodic assessment of  
11 indicators that are measurable, functional, and appropriate to the  
12 conditions for which newborn infants are screened pursuant to this  
13 section. The commissioner shall have the authority to use the  
14 information collected to provide follow-up to newborn infants and  
15 children with screened positive diagnoses to provide appropriate  
16 referral. Information on newborn infants **【and their families】**  
17 compiled pursuant to this section **【may】** shall be used by the  
18 department and agencies designated by the commissioner for the  
19 purposes of carrying out this act, but otherwise the information  
20 shall be confidential and not divulged or made public so as to  
21 disclose the identity of any person to which it relates, except as  
22 provided by law.

23 The department shall **【conduct an intensive educational and】**  
24 provide education or training on the Newborn Screening program  
25 **【among】** to physicians, 【hospitals】 hospital staffs, 【public health】  
26 nurses, and the public concerning 【those biochemical disorders】  
27 newborn screening. 【This program shall include information  
28 concerning the nature of the disorders, testing for the detection of  
29 these disorders and treatment modalities for these disorders.】

30 The provisions of this section shall not apply if the parents of a  
31 newborn infant object in writing to the **【testing】** screening on the  
32 grounds that it would conflict with their religious tenets or  
33 practices.

34 (cf: P.L.1988, c.24, s.3)

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36 4. The Department of Health may adopt, pursuant to the  
37 "Administrative Procedure Act," P.L.1968 c.410 (C.52:14B-1 et  
38 seq.), rules and regulations necessary to implement the provisions  
39 of this act.

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41 5. This act shall take effect on the 180th day following  
42 enactment, except that the Commissioner of Health may take such  
43 anticipatory action in advance as shall be necessary for its  
44 implementation.

STATEMENT

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This bill revises the State’s newborn screening program for congenital disorders by requiring the Commissioner of Health to establish a Newborn Screening Advisory Review Committee consisting of medical, hospital, and public health professionals, as well as scientific experts and consumer representatives, which would be authorized to make recommendations on the disorders to be screened for by the department, as well as on screening technologies, treatment options, and educational and follow-up procedures, to be used in the State’s newborn screening program. The committee would be required to meet annually to review and revise the list of disorders that are recommended for inclusion in the program. The bill also makes several other changes to the program, including formally designating it as the “Newborn Screening” program.

Specifically, the bill makes the following changes to the screening, follow-up, treatment, and education components of the Newborn Screening program:

- the commissioner is required to annually review a list of disorders recommended by the advisory committee and approved by the Commissioner, consistent with the Recommended Uniform Screening Panel of the United States Secretary of Health and Human Services, to determine the disorders for which newborn infants will be screened by the department;
- the commissioner, within 60 days of adding a new disorder to the program, must advise the President of the Senate and the Speaker of the General Assembly;
- the commissioner is required to provide timely intervention and appropriate referral to specialist treatment centers for newborn infants who screen positive for disorders pursuant to the bill;
- the commissioner is required to collect screening information on newborn infants in a standardized manner and develop a system for quality assurance with includes the periodic assessment of measurable indicators, and is further authorized to use the collected information to provide follow-up and appropriate referral to newborns and children with screened positive diagnoses, without regard to the age of the infant or child;
- the commissioner is required to provide education or training on the Newborn Screening program to physicians, hospital staffs, nurses, and the public;
- the reasonable fee charged by the department shall be for the screening, follow-up, and treatment of newborns, and the education of physicians, nurses, and the public, as required by the bill, with a portion of the fee to be used for ongoing infrastructure upgrades, including providing electronic access to physicians to obtain screening results and follow-up recommendations; and

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1 • parents of newborn infants are required to provide notice in  
2 writing if they object to screening on the grounds that it would  
3 conflict with their religious tenets or practices.

4 The Department of Health currently requires that, within 48  
5 hours after birth, all newborns shall be screened for 54 disorders.  
6 One heel prick of the newborn provides enough blood to test for all  
7 54 disorders.