

[First Reprint]

SENATE, No. 484

STATE OF NEW JERSEY
218th LEGISLATURE

PRE-FILED FOR INTRODUCTION IN THE 2018 SESSION

Sponsored by:

Senator JOSEPH F. VITALE

District 19 (Middlesex)

Senator NIA H. GILL

District 34 (Essex and Passaic)

Assemblyman JOHN F. MCKEON

District 27 (Essex and Morris)

Assemblywoman SHANIQUE SPEIGHT

District 29 (Essex)

Assemblywoman VALERIE VAINIERI HUTTLE

District 37 (Bergen)

Co-Sponsored by:

Senators Greenstein, Ruiz, Pou, Assemblywomen McKnight, Reynolds-Jackson, Pintor Marin, Assemblyman Conaway and Assemblywoman Murphy

SYNOPSIS

Revises Newborn Screening program in DOH.

CURRENT VERSION OF TEXT

As amended by the Senate on December 17, 2018.



(Sponsorship Updated As Of: 12/17/2019)

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

3
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 ¹【must provide the infrastructure for universal
21 access and rapid and effective follow-up】 shall be a coordinated and
22 comprehensive effort to provide education, screening, follow-up,
23 diagnosis, treatment and management, and program evaluation
24 activities¹ ;

25 b. Ongoing advances in technologies and treatment modalities
26 make it possible to screen newborn infants for a wide array of
27 ¹biochemical¹ disorders. It is imperative that the State adjust its
28 ¹【newborn screening program】 Newborn Screening Program¹ to
29 incorporate these ¹biochemical¹ disorders to ensure that the
30 program remains at the forefront of these advances; and

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

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

42
43 2. (New section) The Commissioner of Health shall establish
44 a Newborn Screening Advisory Review Committee to annually
45 review the disorders included in the Newborn Screening

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.

Matter enclosed in superscript numerals has been adopted as follows:

¹Senate floor amendments adopted December 17, 2018.

1 ~~'[program] Program'~~¹, screening technologies, treatment options,
2 and educational and follow-up procedures. The committee shall
3 include, but need not be limited to, medical, hospital, and public
4 health professionals, scientific experts, and consumer
5 representatives and advocates. The committee shall meet annually
6 to review and revise the list of disorders recommended for inclusion
7 in the Newborn Screening ~~'[program] Program'~~¹. The committee
8 shall allow for public input in the course of conducting its review
9 and issue recommendations to the commissioner on the
10 improvement of the Newborn Screening ~~'[program] Program'~~¹.

11

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

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

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

40 ~~【The】~~ Based on the recommendations of the Newborn Screening
41 Advisory Review Committee established pursuant to section 2 of
42 P.L. , c. (C.) (pending before the Legislature as this bill),
43 the commissioner may also require 【testing】 the screening of
44 newborn infants for other 【preventable biochemical】 disorders if
45 reliable and efficient 【testing】 screening techniques are available.
46 If the commissioner determines that an additional test shall be
47 required, 【90】 the commissioner, at least 60 days prior to requiring

1 the test **【he】**, shall so advise the President of the Senate **【,】** and the
2 Speaker of the General Assembly **【and chairmen of the standing**
3 reference committees on Revenue, Finance and Appropriations and
4 Institutions, Health and Welfare of his determination**】**.

5 The commissioner shall provide 'laboratory services and' a
6 follow-up program **【of reviewing and following up】** on positive
7 screen cases in order that measures may be taken to prevent **【mental**
8 retardation】 death or intellectual or other permanent disabilities.
9 The program shall provide timely '【intervention and, as
10 appropriate, referrals】 information and recommendations for
11 referral' to specialist treatment centers for newborn infants who
12 screen positive for disorders pursuant to this section.

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

28 The department shall **【conduct an intensive educational and】**
29 provide education or training on the Newborn Screening
30 '【program】 Program' **【among】** to physicians, 【hospitals】 hospital
31 staffs, 【public health】 nurses, and the public concerning 【those
32 biochemical disorders】 newborn screening. 【This program shall
33 include information concerning the nature of the disorders, testing
34 for the detection of these disorders and treatment modalities for
35 these disorders.】

36 The provisions of this section shall not apply if the parents of a
37 newborn infant 'provide written notice to the hospital or birthing
38 facility where the newborn infant was delivered, in a manner
39 designated by the commissioner, that they' object '【in writing】' to
40 the **【testing】** screening on the grounds that it would conflict with
41 their religious tenets or practices.

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

43
44 4. The Department of Health may adopt, pursuant to the
45 "Administrative Procedure Act," P.L.1968 c.410 (C.52:14B-
46 1 et seq.), rules and regulations necessary to implement the
47 provisions of this act.

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