

ASSEMBLY, No. 2705

STATE OF NEW JERSEY 218th LEGISLATURE

INTRODUCED FEBRUARY 1, 2018

Sponsored by:

Assemblyman JOHN F. MCKEON

District 27 (Essex and Morris)

Co-Sponsored by:

Assemblywoman McKnight

SYNOPSIS

Revises Newborn Screening program in DHSS.

CURRENT VERSION OF TEXT

As introduced.



(Sponsorship Updated As Of: 3/8/2019)

1 AN ACT concerning screening for disorders in newborn infants,
2 amending P.L.1977, c.321, and supplementing Title 26 of the
3 Revised Statutes.

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

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

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

16 The Legislature finds and declares that:

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

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

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

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

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

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 limited to, medical, hospital, and public health professionals,
2 scientific experts, and consumer representatives and advocates. The
3 committee shall meet annually to review and revise the list of
4 disorders recommended for inclusion in the Newborn Screening
5 program. The committee shall allow for public input in the course
6 of conducting its review and issue recommendations to the
7 commissioner on the improvement of the Newborn Screening
8 program.

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

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

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

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

1 Speaker of the General Assembly [and chairmen of the standing
2 reference committees on Revenue, Finance and Appropriations and
3 Institutions, Health and Welfare of his determination].

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

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

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

33 The provisions of this section shall not apply if the parents of a
34 newborn infant object in writing to the [testing] screening on the
35 grounds that it would conflict with their religious tenets or
36 practices.

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

38

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

43

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

STATEMENT

This bill revises the State's newborn screening program for congenital disorders by requiring the Commissioner of Health and Senior Services to annually review a list of disorders recommended by an advisory committee (established in the bill) to determine the disorders for which newborn infants will be screened by the department. The bill also makes several other changes to the program, including formally designating it as the "Newborn Screening" program.

According to information from the March of Dimes and the CARES Foundation, Inc., the State is currently screening newborns for 50 disorders. This legislation ensures that the disorders included in the Newborn Screening program will be evaluated on a yearly basis and that the program will expand to include more disorders as technology and State resources allow.

Specifically, the bill makes the following changes to the screening, follow-up, treatment, and education components of the Newborn Screening program: the commissioner is directed to establish a Newborn Screening Advisory Committee consisting of medical, hospital, and public health professionals, as well as scientific experts and consumer representatives, and convene a meeting of the committee at least once a year to make recommendations on the disorders screened for, screening technologies, treatment options, and educational and follow-up procedures; the commissioner is required to annually review a list of disorders promulgated by the advisory committee and to determine, based on the list, the disorders for which newborn infants will be screened; 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 referral to specialists and treatment centers for newborn infants with confirmed positive diagnoses of the disorders screened for pursuant to the bill; the commissioner is required to adopt regulations establishing qualifications for centers that receive grants to provide treatment for newborns that are diagnosed with certain disorders through the program, and to establish qualifications for medical personnel working at the centers; the commissioner is required to systematically collect data to track and monitor newborns and children with confirmed positive diagnoses of disorders screened for through the program until they reach 21 years of age, and evaluate the long-term outcomes of treatment; the educational program on newborn screening shall provide materials and information on follow-up, rehabilitative, medical, and early intervention services for newborn infants with confirmed positive diagnoses of disorders; the fee charged to hospitals by the department is increased from \$71 to a minimum of \$100, to support the screening, follow-up, and treatment of newborns, and the education of physicians, nurses, and the public; a portion of the fee charged to hospitals by the department is to be used for infrastructure upgrades, including providing electronic access to physicians to obtain

1 screening results, follow-up recommendations, and information on the
2 treatment provided by the Newborn Screening program; and parents of
3 newborn infants are required to provide notice in writing if they object
4 to screening on the grounds that it would conflict with their religious
5 tenets or practices.