ASSEMBLY, No. 5705

STATE OF NEW JERSEY

222nd LEGISLATURE

INTRODUCED OCTOBER 22, 2026

Sponsored by:
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SYNOPSIS

Expands responsibilities of Newborn Screening Advisory Review Committee.

CURRENT VERSION OF TEXT

As introduced.

AN ACT concerning the Newborn Screening Advisory Review Committee and amending and supplementing P.L.2019, c.296.

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

1. Section 1 of P.L.2019, c.296 (C.26:2-110a) is amended to read as follows:

2. The Commissioner of Health shall establish a Newborn Screening Advisory Review Committee to annually review <u>and advise the commissioner on</u> the disorders included in the Newborn Screening Program, screening technologies, treatment options, **[**and**]** educational programs and follow-up procedures<u>, and new developments and areas of interest relating to newborn screening, genetics, and early identification of heritable disorders</u>. The committee shall include, but need not be limited to, medical, hospital, and public health professionals, scientific experts, <u>consultants with expertise in the diagnosis and treatment of the disorders included in the Newborn Screening Program and in the provision of genetic counseling,</u> and consumer representatives and advocates. The committee shall meet annually to review and revise the list of disorders recommended for inclusion in the Newborn Screening Program. The committee shall allow for public input in the course of conducting its review and issue recommendations to the commissioner on the improvement of the Newborn Screening Program.

(cf:P.L.2019, c.296, s.1)

2. (New section) a. Beginning on January 1, 2027, the Newborn Screening Advisory Review Committee shall review all disorders added to the Recommended Uniform Screening Panel of the United States Secretary of Health and Human Services' Advisory Committee on Heritable Disorders in Newborns and Children within one year after the condition is added to the Screening Panel.

b. (1) The review conducted by the committee pursuant to subsection a. of this section shall commence if both of the following criteria are met:

(a) a newborn screening assay is available for the disorder; and

(b) there is a therapeutic intervention or a treatment for the disorder approved by the United States Food and Drug Administration.

(2) If the Recommended Uniform Screening Panel includes disorders not screened by the State pursuant to P.L.2019, c.296 (C.26:2-110a et seq.) and the criteria listed in paragraph (1) of

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 <u>thus</u> is new matter.

subsection b. of this section are met, the committee shall begin a review of such disorders no later than one year after the effective date of this act.

(3) If a disorder is not included in the Recommended Uniform Screening Panel and the criteria listed in paragraph (1) of subsection b. of this section are met, the committee shall begin a review of such disorders no later than two years after the effective date of this act.

(4) Upon completion of the reviews conducted pursuant to paragraphs (2) and (3) of this subsection, the committee shall make a formal recommendation to the Commissioner of Health on whether the disorder should be added in the State's Newborn Screening Program.

c. (1) Beginning on October 1, 2027, the committee shall conduct a review to be completed by October 1, 2028 of the following conditions to determine if they meet the criteria in paragraph (1) of subsection b. of this section for inclusion in the Newborn Screening Program:

(a) Sanfilippo syndrome type A or mucopolysaccharidosis type IIIA;

(b) Morquio syndrome type A or mucopolysaccharidosis type IVA;

(c) Maroteaux Lamy syndrome or mucopolysaccharidosis type VI;

(d) Sly syndrome or mucopolysaccharidosis type MPS VII;

(e) Batten disease type 2, CLN2;

(f) Fabry disease;

(g) Gaucher disease; and

(h) Acid sphingomyelinase deficiency.

(2) If, based on a determination that any of the disorders reviewed in paragraph (1) of this subsection meet the criteria listed in paragraph (1) of subsection b. of this section, the committee recommends the inclusion of such disorders in the Newborn Screening Program, and the recommendation is approved by the commissioner, the department shall implement policies and procedures to assure that newborns are screened in a manner approved by the commissioner, at least 60 days prior to requiring the screening.

(3) If the commissioner does not approve the inclusion of any of the disorders reviewed in paragraph (1) of this subsection in the Newborn Screening Program, the commissioner shall provide information to the Newborn Screening Advisory Review Committee regarding the reasons why the commissioner did not approve the recommendation and make the reasons why available to the public, and any information the commissioner deems necessary for reconsideration of approval.

d. Nothing in this section shall be construed to prevent the review and recommendation of additional disorders not currently included on the Recommended Uniform Screening Panel.

3. The committee shall submit a report by January 1, 2028 to the Governor, and to the Legislature pursuant to section 2 of P.L.1991, c.164 (C.52:14-19.1) on:

a. the disorders reviewed by the committee pursuant to section 1 of this act;

b. the recommendations made to, and approved by, the commissioner relating to the inclusion of any of the disorders reviewed by the committee in the Newborn Screening Program pursuant to section 2 of this act;

c. the recommendations relating to the inclusion of any of the disorders reviewed by the committee in the Newborn Screening Program pursuant to section 2 of this act not approved by the commissioner, the reason why the recommendations were not approved, and information deemed necessary for reconsideration of approval; and

d. the status of the implementation of policies and procedures to assure that newborns are screened in a manner approved by the commissioner pursuant to paragraph (2) of subsection c. of section 2 of this act.

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

5. This act shall take effect immediately.

STATEMENT

This bill amends section 1 of P.L.2019, c.296 (C.26:2-110a) to expand the Newborn Screening Advisory Review Committee's (the committee) responsibilities to include advising the Commissioner of Health (the commissioner) on, and reviewing, new developments and areas of interest relating to newborn screening, genetics, and early identification of heritable disorders.

Current law requires the committee to review aspects of the Newborn Screening Program (screening program) but does not require the committee to review such aspects, and advise the commissioner on new developments and areas of interest relating to newborn screening, genetics, and early identification of heritable disorders.

The bill also amends the law to expand the committee's membership to include consultants with expertise in the diagnosis

and treatment of the disorders included in the screening program and the provision of genetic counseling.

The bill stipulates that if certain criteria listed in the bill are met, the committee, beginning on January 1, 2027, is to review all disorders added to the Recommended Uniform Screening Panel (RUSP) within one year after their addition.

If the RUSP includes disorders not screened by the State and the criteria are met, the committee is to review such disorders no later than one year after the bill's effective date. If a disorder is not included in the RUSP and the criteria are met, the committee is to review such disorder no later than two years after the bill's effective date.

At the end of the reviews, the committee is to make a formal recommendation to the commissioner on whether the disorders should be included in the screening program.

The bill enumerates disorders that are to be reviewed by October 1, 2028 if they meet the criteria for inclusion in the Newborn Screening Program, outlines the procedures to be followed when the commissioner approves recommendations to include the disorders in the screening program, and delineates the commissioner's responsibilities if the recommendations are not approved.

The bill also requires the committee to submit a report to the Governor and the Legislature by January 1, 2028 on various aspects of the bill's provisions.