

SENATE, No. 4857

STATE OF NEW JERSEY
222nd LEGISLATURE

INTRODUCED OCTOBER 19, 2026

Sponsored by:
Senator JOSEPH F. VITALE
District 19 (Middlesex)

SYNOPSIS

Expands responsibilities of Newborn Screening Advisory Review Committee.

CURRENT VERSION OF TEXT

As introduced.



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

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.2019, c.296 (C.26:2-110a) is amended to
8 read as follows:

9 2. The Commissioner of Health shall establish a Newborn
10 Screening Advisory Review Committee to annually review and
11 advise the commissioner on the disorders included in the Newborn
12 Screening Program, screening technologies, treatment options,
13 **[and]** educational programs and follow-up procedures, and new
14 developments and areas of interest relating to newborn screening,
15 genetics, and early identification of heritable disorders. The
16 committee shall include, but need not be limited to, medical,
17 hospital, and public health professionals, scientific experts,
18 consultants with expertise in the diagnosis and treatment of the
19 disorders included in the Newborn Screening Program and in the
20 provision of genetic counseling, and consumer representatives and
21 advocates. The committee shall meet annually to review and revise
22 the list of disorders recommended for inclusion in the Newborn
23 Screening Program. The committee shall allow for public input in
24 the course of conducting its review and issue recommendations to
25 the commissioner on the improvement of the Newborn Screening
26 Program.
27 (cf:P.L.2019, c.296, s.1)

28
29 2. (New section) a. Beginning on January 1, 2027, the
30 Newborn Screening Advisory Review Committee shall review all
31 disorders added to the Recommended Uniform Screening Panel of
32 the United States Secretary of Health and Human Services'
33 Advisory Committee on Heritable Disorders in Newborns and
34 Children within one year after the condition is added to the
35 Screening Panel.

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

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

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

43 (2) If the Recommended Uniform Screening Panel includes
44 disorders not screened by the State pursuant to P.L.2019, c.296
45 (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 thus is new matter.

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

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

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

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

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

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

23 (c) Maroteaux Lamy syndrome or mucopolysaccharidosis type
24 VI;

25 (d) Sly syndrome or mucopolysaccharidosis type MPS VII;

26 (e) Batten disease type 2, CLN2;

27 (f) Fabry disease;

28 (g) Gaucher disease; and

29 (h) Acid sphingomyelinase deficiency.

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

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

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

4
5 3. The committee shall submit a report by January 1, 2028 to the
6 Governor, and to the Legislature pursuant to section 2 of P.L.1991,
7 c.164 (C.52:14-19.1) on:

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

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

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

20 d. the status of the implementation of policies and procedures to
21 assure that newborns are screened in a manner approved by the
22 commissioner pursuant to paragraph (2) of subsection c. of section
23 2 of this act.

24
25 4. The Commissioner of Health shall adopt rules and
26 regulations, pursuant to the "Administrative Procedure Act,"
27 P.L.1968, c.410 (C.52:14B-1 et seq.), to implement the provisions
28 of this act.

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30 5. This act shall take effect immediately.

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33 STATEMENT

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

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

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

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

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

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

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

16 The bill enumerates disorders that are to be reviewed by October
17 1, 2028 if they meet the criteria for inclusion in the Newborn
18 Screening Program, outlines the procedures to be followed when the
19 commissioner approves recommendations to include the disorders
20 in the screening program, and delineates the commissioner's
21 responsibilities if the recommendations are not approved.

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