

26:8-40

LEGISLATIVE HISTORY CHECKLIST

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LAWS OF: 2005 **CHAPTER:** 176

NJSA: 26:8-40 (Requires reporting of all cases of severe hyperbilirubinemia to DHSS)

BILL NO: A3354 (Substituted for S2046)

SPONSOR(S): Weinberg

DATE INTRODUCED: October 7, 2004

COMMITTEE: **ASSEMBLY:** Health and Human Services
SENATE: Health, Human Services and Senior Citizens

AMENDED DURING PASSAGE: No

DATE OF PASSAGE: **ASSEMBLY:** February 24, 2005

SENATE: June 30, 2005

DATE OF APPROVAL: August 5, 2005

FOLLOWING ARE ATTACHED IF AVAILABLE:

[FINAL TEXT OF BILL](#) (Assembly Committee Substitute for A3354 enacted)

A3354

[SPONSOR'S STATEMENT:](#) (Begins on page 2 of original bill) [Yes](#)

COMMITTEE STATEMENT: **ASSEMBLY:** [Yes](#)

SENATE: [Yes](#)

FLOOR AMENDMENT STATEMENT: No

LEGISLATIVE FISCAL ESTIMATE: No

S2046

[SPONSOR'S STATEMENT:](#) (Begins on page 3 of original bill) [Yes](#)

COMMITTEE STATEMENT: **ASSEMBLY:** No

SENATE: [Yes](#)

FLOOR AMENDMENT STATEMENT: No

LEGISLATIVE FISCAL ESTIMATE: No

VETO MESSAGE: No

GOVERNOR'S PRESS RELEASE ON SIGNING: No

FOLLOWING WERE PRINTED:

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REPORTS:

No

HEARINGS:

No

NEWSPAPER ARTICLES:

No

IS 9/5/07

P.L. 2005, CHAPTER 176, *approved August 5, 2005*

Assembly Committee Substitute for
Assembly, No. 3354

1 AN ACT concerning neonatal jaundice and amending P.L.1983, c.291.

2

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

5

6 1. Section 1 of P.L.1983, c.291 (C.26:8-40.20) is amended to read
7 as follows:

8 1. The Legislature finds and declares that: major birth defects
9 occur in approximately 1% of all births and are related to over 25% of
10 all infant deaths; [that] while the cause of many birth defects is
11 unknown, there is much concern that certain birth defects may be
12 related to environmental factors such as pollution and toxic chemicals;
13 about 60% of newborns develop jaundice, which is caused by a
14 buildup of bilirubin, pigment that results from the natural breakdown
15 of red blood cells, and toxic levels of bilirubin can cause severe
16 neurological damage, called kernicterus, which is associated with
17 cerebral palsy, mental retardation, hearing loss and complications with
18 vision and teeth; [that] in order to effectively address [this] these
19 public health [problem] problems, it is necessary to collect and
20 compile complete and accurate information concerning the occurrence
21 of birth defects and cases of severe hyperbilirubinemia in this State;
22 and [that] a birth defects and severe neonatal jaundice registry would
23 provide a needed base of information to analyze [this problem] these
24 problems and plan for and provide services to children with birth
25 defects and severe hyperbilirubinemia and their families.

26 (cf: P.L.1983, c.291, s.1)

27

28 2. Section 2 of P.L.1983, c.291 (C.26:8-40.21) is amended to read
29 as follows:

30 2. a. The [State] Department of Health and Senior Services shall
31 establish and maintain a birth defects and severe neonatal jaundice
32 registry, which shall contain a confidential record of all birth defects
33 and all cases of severe hyperbilirubinemia that occur in New Jersey and
34 any other information that the department deems necessary and
35 appropriate in order to conduct thorough and complete epidemiologic
36 surveys of birth defects and cases of severe hyperbilirubinemia that
37 occur in this State and plan for and provide services to children with
38 birth defects and severe hyperbilirubinemia and their families.

39 b. The department shall make available electronically on its
40 Internet website, in English and Spanish, information on 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 characteristics and effects of severe neonatal jaundice.

2 (cf: P.L.1983, c.291, s.2)

3

4 3. Section 3 of P.L.1983, c.291 (C.26:8-40.22) is amended to read
5 as follows:

6 3. a. The Commissioner of Health and Senior Services, in
7 consultation with the Public Health Council, shall require the
8 confidential reporting to the Department of Health and Senior Services
9 of all cases where an infant is diagnosed with severe
10 hyperbilirubinemia, and where a pregnancy results in a naturally
11 aborted fetus or infant affected by a birth defect, and an electively
12 aborted fetus that exhibits or is known to have a birth defect after 15
13 weeks of gestation. The reporting requirement shall apply to all
14 infants from birth through ~~one year~~ five years of age.

15 b. The Commissioner of Health and Senior Services shall
16 determine the health care providers and facilities which shall be
17 required to report all birth defects and all cases of severe
18 hyperbilirubinemia, the types of conditions or defects that shall be
19 reported, the type of information that shall be contained in the
20 confidential report and the method for making the report. In reports
21 concerning all fetuses with anomalies, the name of the mother shall not
22 be submitted.

23 (cf: P.L.1983, c.291, s.3)

24

25 4. This act shall take effect on the 180th day after enactment, but
26 the Commissioner of Health and Senior Services may take such
27 anticipatory administrative action in advance as is necessary for the
28 implementation of the act.

29

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32

33 _____
Requires reporting of all cases of severe hyperbilirubinemia to DHSS.

ASSEMBLY, No. 3354

STATE OF NEW JERSEY 211th LEGISLATURE

INTRODUCED OCTOBER 7, 2004

Sponsored by:

Assemblywoman LORETTA WEINBERG

District 37 (Bergen)

SYNOPSIS

Establishes "New Jersey Neonatal Jaundice Registry" and "New Jersey Neonatal Jaundice Program" in DHSS.

CURRENT VERSION OF TEXT

As introduced.



1 AN ACT concerning neonatal jaundice and supplementing Title 26 of
2 the Revised Statutes.

3

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

6

7 1. a. There is established in the Department of Health and Senior
8 Services a "New Jersey Neonatal Jaundice Program" to address the
9 occurrence and effects of severe neonatal jaundice. In addition to any
10 other activities that the commissioner deems appropriate, the program
11 shall serve as a central data repository, and as a resource for health
12 care providers and families.

13 b. All infants born in this State shall be tested for
14 hyperbilirubinemia.

15 c. There is established in the Department of Health and Senior
16 Services the "New Jersey Neonatal Jaundice Registry" to monitor
17 cases of severe hyperbilirubinemia in neonatals born in this State.

18 d. All cases of severe hyperbilirubinemia, as defined by the
19 Commissioner of Health and Senior Services, shall be reported to the
20 registry established pursuant to this section. Pursuant to P.L.1977,
21 c.321 (C.26:2-110 et seq.), the commissioner shall specify the
22 information that shall be reported by the health care providers to the
23 registry.

24 e. In addition to the fees collected pursuant to section 2 of
25 P.L.1977, c.321 (C.26:2-111), a surcharge of \$2 shall be imposed
26 for each infant tested. The revenues from the surcharge shall be
27 dedicated to maintaining the "New Jersey Neonatal Jaundice Program"
28 established pursuant to this act.

29 f. (1) The commissioner is authorized to contract with the
30 University of Medicine and Dentistry of New Jersey to further the
31 purposes of the program and registry.

32 (2) The commissioner may receive funds or other assistance from
33 the federal government, the State and private sources to further the
34 purposes of this act.

35

36 2. This act shall take effect on the 180th day after enactment, but
37 the commissioner may take such anticipatory administrative action in
38 advance as is necessary for the implementation of the act.

39

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STATEMENT

42

43 This bill establishes the "New Jersey Neonatal Jaundice Registry"
44 and the "New Jersey Neonatal Jaundice Program" in the Department
45 of Health and Senior Services in order to confront the critical
46 neurologic and developmental problems caused by severe jaundice.

1 About 60% of newborns develop jaundice, which is caused by a
2 buildup of bilirubin, pigment that results from the natural breakdown
3 of red blood cells. Toxic levels of bilirubin can cause severe
4 neurological damage, called kernicterus. Kernicterus is associated
5 with cerebral palsy, mental retardation, hearing loss and complications
6 with vision and teeth. Kernicterus is irreversible and once damage has
7 occurred, there is no effective treatment. However, it is preventable
8 if severe jaundice levels are reduced in a timely manner. Kernicterus
9 was thought to have been eliminated in the United States in the 1970s,
10 but national pediatric experts have documented its re-emergence and
11 estimate that 2% of infants who develop jaundice are at risk. Its
12 reemergence may be due to a combination of factors: health care
13 providers are no longer familiar with kernicterus because of successful
14 prevention efforts in the past; early discharges home following birth
15 leave infants vulnerable to late detection and intervention; and parents
16 who are unaware of the symptoms do not call their pediatrician.

17 The federal Centers for Disease Control and Prevention has urged
18 closer monitoring of jaundice and has provided funding to UMDNJ-
19 Robert Wood Johnson Medical School to research and develop
20 prevention programs that will lead to a national tracking system and
21 prevention campaign. This bill will enable New Jersey residents to
22 benefit from the work being done in New Jersey on behalf of the
23 nation's public health.

24 The bill would require that all infants born in the State be tested for
25 hyperbilirubinemia and that all cases of severe hyperbilirubinemia be
26 reported to the "New Jersey Neonatal Jaundice Registry." The
27 Commissioner of Health and Senior Services is to establish the
28 reportable data necessary for effective functioning of the registry. The
29 commissioner is currently authorized under N.J.S.A.26:2-110 et seq.
30 to require testing for preventable disorders, charge reasonable fees for
31 such tests and assist individuals who have those disorders identified
32 through testing. This bill would build on the State's newborn testing
33 program and create a special registry that focuses on severe jaundice.

34 In addition, the bill establishes the "New Jersey Neonatal Jaundice
35 Program" to address the occurrence and effects of severe neonatal
36 jaundice. The program is to serve as a central data repository, a
37 resource for health care providers and families, and any other endeavor
38 that the commissioner deems appropriate. The bill would add a
39 surcharge of \$2 to current newborn screening fees, and this additional
40 amount would be dedicated to the maintenance of the program. The
41 bill also authorizes the commissioner to contract with UMDNJ and to
42 receive funds or other assistance from, the federal government, the
43 State and private entities in furtherance of the program and registry.

ASSEMBLY HEALTH AND HUMAN SERVICES COMMITTEE

STATEMENT TO

ASSEMBLY COMMITTEE SUBSTITUTE FOR **ASSEMBLY, No. 3354**

STATE OF NEW JERSEY

DATED: JANUARY 10, 2005

The Assembly Health and Human Services Committee reports favorably an Assembly Committee Substitute for Assembly Bill No. 3354.

This committee substitute requires the confidential reporting to the Department of Health and Senior Services (DHSS) of all cases where an infant is diagnosed with severe hyperbilirubinemia.

DHSS is to include this information in the birth defects registry established pursuant to N.J.S.A.26:8-40.21, which is to be designated as the birth defects and severe neonatal jaundice registry. The registry is to contain a confidential record of all birth defects and all cases of severe hyperbilirubinemia that occur in New Jersey and any other information that DHSS deems necessary and appropriate in order to conduct thorough and complete epidemiologic surveys of birth defects and cases of severe hyperbilirubinemia that occur in New Jersey and plan for and provide services to children with birth defects and severe hyperbilirubinemia and their families.

The substitute further requires DHSS to make available electronically on its Internet website, in English and Spanish, information on the characteristics and effects of severe neonatal jaundice.

The substitute takes effect on the 180th day after enactment, but authorizes the Commissioner of Health and Senior Services to take anticipatory administrative action in advance as necessary for its implementation.

SENATE HEALTH, HUMAN SERVICES AND SENIOR
CITIZENS COMMITTEE

STATEMENT TO

ASSEMBLY COMMITTEE SUBSTITUTE FOR
ASSEMBLY, No. 3354

STATE OF NEW JERSEY

DATED: MAY 23, 2005

The Senate Health, Human Services and Senior Citizens Committee reports favorably the Assembly Committee Substitute for Assembly Bill No. 3354.

This committee substitute requires the confidential reporting to the Department of Health and Senior Services (DHSS) of all cases where an infant is diagnosed with severe hyperbilirubinemia.

DHSS is to include this information in the birth defects registry established pursuant to N.J.S.A.26:8-40.21, which is to be designated as the birth defects and severe neonatal jaundice registry. The registry is to contain a confidential record of all birth defects and all cases of severe hyperbilirubinemia that occur in New Jersey and any other information that DHSS deems necessary and appropriate in order to conduct thorough and complete epidemiologic surveys of birth defects and cases of severe hyperbilirubinemia that occur in New Jersey, and plan for and provide services to children with birth defects and severe hyperbilirubinemia and their families.

The substitute further requires DHSS to make available electronically on its Internet website, in English and Spanish, information on the characteristics and effects of severe neonatal jaundice.

The substitute takes effect on the 180th day after enactment, but authorizes the Commissioner of Health and Senior Services to take anticipatory administrative action in advance as necessary for its implementation.

As reported by the Senate Health, Human Services and Senior Citizens Committee, this Assembly Committee Substitute is identical to the Senate Committee Substitute for Senate Bill No. 2046 (Karcher/Sweeney), which the committee also reported favorably on this date.

SENATE, No. 2046

STATE OF NEW JERSEY 211th LEGISLATURE

INTRODUCED NOVEMBER 8, 2004

Sponsored by:

Senator ELLEN KARCHER

District 12 (Mercer and Monmouth)

Senator STEPHEN M. SWEENEY

District 3 (Salem, Cumberland and Gloucester)

Co-Sponsored by:

Senator Vitale

SYNOPSIS

Establishes New Jersey Neonatal Jaundice Registry and New Jersey Neonatal Jaundice Program in DHSS.

CURRENT VERSION OF TEXT

As introduced.



(Sponsorship Updated As Of: 11/9/2004)

1 AN ACT concerning neonatal jaundice and supplementing Title 26 of
2 the Revised Statutes.

3

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

6

7 1. The Legislature finds and declares that:

8 a. About 60% of newborns develop jaundice, which is caused by
9 a buildup of bilirubin, pigment that results from the natural breakdown
10 of red blood cells.

11 b. Toxic levels of bilirubin can cause severe neurological damage,
12 called kernicterus, which is associated with cerebral palsy, mental
13 retardation, hearing loss and complications with vision and teeth.

14 c. Kernicterus is irreversible and once damage has occurred, there
15 is no effective treatment, but it is preventable if severe jaundice levels
16 are reduced in a timely manner.

17 d. Kernicterus was thought to have been eliminated in the United
18 States in the 1970s, but it has re-emerged and it is estimated that 2%
19 of infants who develop jaundice are at risk. Consequently, the federal
20 Centers for Disease Control and Prevention has urged closer
21 monitoring of jaundice and has provided funding to UMDNJ-Robert
22 Wood Johnson Medical School to research and develop prevention
23 programs that will lead to a national tracking system and prevention
24 campaign.

25 e. It is fitting that New Jersey residents benefit from the work
26 being done in New Jersey on behalf of the nation's public health by
27 establishing a neonatal jaundice program and a neonatal jaundice
28 registry to assist New Jersey families and health care providers in
29 confronting this important health care problem.

30

31 2. There is established in the Department of Health and Senior
32 Services a New Jersey Neonatal Jaundice Program to address the
33 occurrence and effects of severe neonatal jaundice. In addition to any
34 other activities that the commissioner deems appropriate, the program
35 shall serve as a central data repository, and as a resource for health
36 care providers and families.

37 a. All infants born in this State shall be tested for
38 hyperbilirubinemia.

39 b. There is established in the Department of Health and Senior
40 Services the New Jersey Neonatal Jaundice Registry to monitor cases
41 of severe hyperbilirubinemia in neonatals born in this State.

42 c. All cases of severe hyperbilirubinemia, as defined by the
43 Commissioner of Health and Senior Services, shall be reported to the
44 registry established pursuant to this section. Pursuant to P.L.1977,
45 c.321 (C.26:2-110 et seq.), the commissioner shall specify the
46 information that shall be reported by health care providers to the

1 registry.

2 d. In addition to the fees collected pursuant to section 2 of
3 P.L.1977, c.321 (C.26:2-111), a surcharge of \$2 shall be imposed for
4 each infant tested. The revenues from the surcharge shall be dedicated
5 to maintaining the New Jersey Neonatal Jaundice Program.

6 e. The commissioner is authorized to contract with the University
7 of Medicine and Dentistry of New Jersey to further the purposes of the
8 program and registry.

9 f. The commissioner may receive funds or other assistance from the
10 federal government, the State and private sources to further the
11 purposes of this act.

12

13 3. This act shall take effect on the 180th day after enactment, but
14 the commissioner may take such anticipatory administrative action in
15 advance as shall be necessary for the implementation of the act.

16

17

18

STATEMENT

19

20 This bill establishes the New Jersey Neonatal Jaundice Registry and
21 the New Jersey Neonatal Jaundice Program in the Department of
22 Health and Senior Services in order to confront the serious neurologic
23 and developmental problems caused by severe jaundice.

24 About 60% of newborns develop jaundice, which is caused by a
25 buildup of pigment that results from the natural breakdown of red
26 blood cells. Toxic levels of the buildup can cause severe neurological
27 damage, called kernicterus. Kernicterus is associated with cerebral
28 palsy, mental retardation, hearing loss and complications with vision
29 and teeth. Kernicterus was thought to have been eliminated in the
30 United States in the 1970s, but national pediatric experts have
31 documented its re-emergence and estimate that 2% of infants who
32 develop jaundice are at risk.

33 The federal Centers for Disease Control and Prevention has
34 provided funding to UMDNJ-Robert Wood Johnson Medical School
35 to research and develop prevention programs that will lead to a
36 national tracking system and prevention campaign. This bill would
37 enable New Jersey residents to benefit from the work being done in
38 New Jersey on behalf of the nation's public health.

39 The bill would require that all infants born in the State be tested for
40 hyperbilirubinemia and that all cases of severe hyperbilirubinemia be
41 reported to the New Jersey Neonatal Jaundice Registry. The
42 Commissioner of Health and Senior Services is to establish the
43 reportable data necessary for effective functioning of the registry. The
44 commissioner is currently authorized under N.J.S.A.26:2-110 et seq.
45 to require testing for preventable disorders, charge reasonable fees for
46 such tests and assist individuals who have those disorders identified

S2046 KARCHER, SWEENEY

4

1 through testing. This bill would build on the State's newborn testing
2 program and create a special registry that focuses on severe jaundice.
3 In addition, the bill establishes the New Jersey Neonatal Jaundice
4 Program to address the occurrence and effects of severe neonatal
5 jaundice. The program is to serve as a central data repository, a
6 resource for health care providers and families, and any other endeavor
7 that the commissioner deems appropriate. The bill would add a
8 surcharge of \$2 to current newborn screening fees, and this additional
9 amount would be dedicated to the maintenance of the program. The
10 bill also authorizes the commissioner to contract with UMDNJ and to
11 receive funds or other assistance from the federal government, the
12 State and private entities in furtherance of the program and registry.

SENATE HEALTH, HUMAN SERVICES AND SENIOR
CITIZENS COMMITTEE

STATEMENT TO

SENATE COMMITTEE SUBSTITUTE FOR
SENATE, No. 2046

STATE OF NEW JERSEY

DATED: MAY 23, 2005

The Senate Health, Human Services and Senior Citizens Committee reports favorably a Senate Committee Substitute for Senate Bill No. 2046.

This committee substitute requires the confidential reporting to the Department of Health and Senior Services (DHSS) of all cases where an infant is diagnosed with severe hyperbilirubinemia.

DHSS is to include this information in the birth defects registry established pursuant to N.J.S.A.26:8-40.21, which is to be designated as the birth defects and severe neonatal jaundice registry. The registry is to contain a confidential record of all birth defects and all cases of severe hyperbilirubinemia that occur in New Jersey and any other information that DHSS deems necessary and appropriate in order to conduct thorough and complete epidemiologic surveys of birth defects and cases of severe hyperbilirubinemia that occur in New Jersey, and plan for and provide services to children with birth defects and severe hyperbilirubinemia and their families.

The substitute further requires DHSS to make available electronically on its Internet website, in English and Spanish, information on the characteristics and effects of severe neonatal jaundice.

The substitute takes effect on the 180th day after enactment, but authorizes the Commissioner of Health and Senior Services to take anticipatory administrative action in advance as necessary for its implementation.

This committee substitute is identical to Assembly Committee Substitute for A-3354 (Weinberg/Chivukula), which the committee also reported favorably on this date.