

26:8-40.27 to 26:8-40.32
LEGISLATIVE HISTORY CHECKLIST
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LAWS OF: 2013 **CHAPTER:** 217

NJSA: 26:8-40.27 to 26:8-40.32 ("Autumn Joy Stillbirth Research and Dignity Act"; requires DOH to establish protocols for stillbirths, establishes stillbirth research data base)

BILL NO: S2843 (Substituted for A4280)

SPONSOR(S) Weinberg and others

DATE INTRODUCED: June 3, 2013

COMMITTEE: **ASSEMBLY:** Women and Children

SENATE: Health, Human Services and Senior Citizens

AMENDED DURING PASSAGE: Yes

DATE OF PASSAGE: **ASSEMBLY:** January 6, 2014

SENATE: January 13, 2014

DATE OF APPROVAL: January 17, 2014

FOLLOWING ARE ATTACHED IF AVAILABLE:

FINAL TEXT OF BILL (Second reprint enacted)

S2843

SPONSOR'S STATEMENT:	(Begins on page 5 of introduced bill)	Yes
COMMITTEE STATEMENT:	ASSEMBLY:	Yes
	SENATE:	Yes

(Audio archived recordings of the committee meetings, corresponding to the date of the committee statement, **may possibly** be found at www.njleg.state.nj.us)

FLOOR AMENDMENT STATEMENT:	No
LEGISLATIVE FISCAL ESTIMATE:	Yes 7-5-13 1-7-14

A4280

SPONSOR'S STATEMENT:	(Begins on page 5 of introduced bill)	Yes
COMMITTEE STATEMENT:	ASSEMBLY:	Yes
	SENATE:	No

FLOOR AMENDMENT STATEMENT:	No
LEGISLATIVE FISCAL ESTIMATE:	Yes

(continued)

VETO MESSAGE: No

GOVERNOR'S PRESS RELEASE ON SIGNING: No

FOLLOWING WERE PRINTED:

To check for circulating copies, contact New Jersey State Government Publications at the State Library (609) 278-2640 ext.103 or <mailto:refdesk@njstatelib.org>

REPORTS: No

HEARINGS: No

NEWSPAPER ARTICLES: Yes

"Christie's 'pocket veto' kills bill requiring health workers to get flu shots," NJSpotlight, January 22, 2014

"Christie quietly vetoes 44 bills and signs 100," The Star-Ledger, January 22, 2014

"New law to help reduce stillbirths," CourierPostOnline.com, January 22, 2014

LAW/KR

(CORRECTED COPY)

P.L.2013, CHAPTER 217, *approved January 17, 2014*
Senate, No. 2843 (*Second Reprint*)

1 AN ACT concerning stillbirths and supplementing Title 26 of the
2 Revised Statutes, and designated the “Autumn Joy Stillbirth
3 Research and Dignity Act.”
4

5 **BE IT ENACTED** by the Senate and General Assembly of the State
6 of New Jersey:
7

8 1. The Legislature finds and declares that:

9 a. Stillbirths are unintended fetal deaths and are traditionally
10 identified as those which occur after 20 weeks of pregnancy or
11 involve the unintended death of fetuses weighing 350 or more
12 grams;

13 b. Approximately one in every 160 pregnancies in the United
14 States ends in stillbirth each year, a rate which is high compared
15 with other developed countries;

16 c. Families experiencing a stillbirth suffer severe anguish, and
17 many health care facilities in the State do not adequately ensure that
18 grieving families are treated with sensitivity and informed about
19 what to expect when a stillbirth occurs, nor are families who have
20 experienced a stillbirth always advised of the importance of an
21 autopsy and thorough evaluation of the ¹**【fetus】** stillborn child¹;

22 d. While studies have identified many factors that may cause
23 stillbirths, researchers still do not know the causes of a majority of
24 stillbirths, in part due to a lack of uniform protocols for evaluating
25 and classifying stillbirths, and to decreasing autopsy rates;

26 e. The State currently collects some data related to fetal deaths,
27 but full autopsy and laboratory data related to stillbirths could be
28 more consistently collected and more effectively used to better
29 understand risk factors and causes of stillbirths, and thus more
30 effectively inform strategies for their prevention; and

31 f. It is in the public interest to establish mandatory protocols
32 for health care facilities in the State, so that each child who is
33 stillborn and each family experiencing a stillbirth in the State is
34 treated with dignity, each family experiencing a stillbirth receives
35 appropriate follow-up care provided in a sensitive manner, and
36 comprehensive data related to stillbirths are consistently collected

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 SHH committee amendments adopted June 13, 2013.

²Assembly AWC committee amendments adopted December 16, 2013.

1 by the State and made available to researchers seeking to prevent
2 and reduce the incidence of stillbirths.

3
4 2. a. The Commissioner of Health, in consultation with the
5 State Board of Medical Examiners, the New Jersey Board of
6 Nursing, the State Board of Psychological Examiners, and the State
7 Board of Social Work Examiners, shall develop and prescribe by
8 regulation comprehensive policies and procedures to be followed by
9 health care facilities that provide birthing and newborn care
10 services in the State when a stillbirth occurs.

11 b. The Commissioner of Health shall require as a condition of
12 licensure that each health care facility in the State that provides
13 birthing and newborn care services adhere to the policies and
14 procedures prescribed in this section. The policies and procedures
15 shall include, at a minimum:

16 (1) protocols for assigning primary responsibility to one
17 physician, who shall communicate the condition of the fetus to the
18 mother and family, and inform and coordinate staff to assist with
19 labor, delivery, and postmortem procedures;

20 (2) guidelines to assess a family's level of awareness and
21 knowledge regarding the stillbirth;

22 (3) the establishment of a bereavement checklist, and an
23 informational pamphlet to be given to a family experiencing a
24 stillbirth that includes information about funeral and cremation
25 options;

26 (4) provision of one-on-one nursing care for the duration of the
27 mother's stay at the facility;

28 (5) training of physicians, nurses, psychologists, and social
29 workers to ensure that information is provided to the mother and
30 family experiencing a stillbirth in a sensitive manner, including
31 information about what to expect, the availability of grief
32 counseling, the opportunity to develop a plan of care that meets the
33 family's social, religious, and cultural needs, and the importance of
34 an autopsy and thorough evaluation of the ¹**[fetus]** stillborn child¹;

35 (6) best practices to provide psychological and emotional support
36 to the mother and family following a stillbirth, including referring
37 to the ¹**[fetus]** stillborn child¹ by name, and offering the family the
38 opportunity to cut the umbilical cord, hold the ¹**[baby]** stillborn
39 child¹ with privacy and without time restrictions, and prepare a
40 memory box with keepsakes, such as a handprint, footprint, blanket,
41 bracelet, lock of hair, and photographs, and provisions for retaining
42 the keepsakes for one year if the family chooses not to take them at
43 discharge;

44 (7) protocols to ensure that the physician assigned primary
45 responsibility for communicating with the family discusses the
46 importance of an autopsy for the family, including the significance
47 of autopsy findings on future pregnancies and the significance that
48 data from the autopsy may have for other families;

1 (8) protocols to ensure coordinated visits to the family by a
2 hospital staff trained to address the psychosocial needs of a family
3 experiencing a stillbirth, provide guidance in the bereavement
4 process, assist with completing any forms required in connection
5 with the stillbirth and autopsy, and offer the family the opportunity
6 to meet with the hospital chaplain or other individual from the
7 family's religious community; and

8 (9) guidelines for educating health care professionals and
9 hospital staff on caring for families after stillbirth.

10 ²c. The State Board of Medical Examiners and the New Jersey
11 Board of Nursing shall require physicians and nurses, respectively,
12 to adhere to the policies and procedures prescribed in subsection a.
13 of this section.²

14
15 3. The Department of Health shall establish a fetal death
16 evaluation protocol, which a hospital licensed pursuant to P.L.1971,
17 c.136 (C.26:2H-1 et seq.) shall follow in collecting data relevant to
18 each stillbirth. The information required to be collected shall
19 include, but not be limited to:

20 a. the race, age of the mother, maternal and paternal family
21 history, comorbidities, prenatal care history, antepartum findings,
22 history of past obstetric complications, exposure to viral infections,
23 smoking, drug and alcohol use, fetal growth restriction, placental
24 abruption, chromosomal and genetic abnormalities obtained pre-
25 delivery, infection in premature fetus, cord accident, including
26 evidence of obstruction or circulatory compromise, history of
27 thromboembolism, and whether the mother gave birth before; and

28 b. documentation of the evaluation of a stillborn ¹**['fetus]**
29 **child¹**, placenta, and cytologic specimen that conform to the
30 standards established by the American College of Obstetricians and
31 Gynecologists and meet any other requirements deemed by the
32 Commissioner of Health as necessary, including, but not limited to,
33 the following components:

34 (1) if the parents consent to a complete autopsy: the weight of
35 the ¹**['fetus] stillborn child¹** and placenta, head circumference,
36 length of ¹**['fetus] stillborn child¹**, foot length if stillbirth occurred
37 before 23 weeks of gestation, and notation of any dysmorphic
38 feature; photograph of the whole body, frontal and profile of face,
39 extremities and palms, close-up of any specific abnormalities;
40 examination of the placenta and umbilical cord; and gross and
41 microscopic examination of membranes and umbilical cord; or

42 (2) if the parents do not consent to a complete autopsy, an
43 evaluation of a ¹**['fetus] stillborn child¹** as set forth in paragraph (1)
44 of this subsection, and appropriate alternatives to a complete
45 autopsy, including a placental examination, external
46 examination¹**[',']**¹, selected biopsies, X-rays, MRI, and ultrasound.

1 4. a. ²**[The]** Within two years after the effective date of this
2 act, the² Department of Health shall establish and maintain a ²new²
3 database², or update an existing database.² that contains a
4 confidential record of all data obtained pursuant to section 3 of this
5 act ², except that if the department develops the technical
6 capability, the department shall establish and maintain the new, or
7 update the existing, database prior to the two years after the
8 effective date of this act².

9 b. The data shall be made available to the public through the
10 department website, except that no data shall identify any person to
11 whom the data relate.

12
13 5 a. The Department of Health shall evaluate the data
14 obtained pursuant to section 3 of this act for purposes of identifying
15 the causes of, and ways to prevent, stillbirths, and may contract
16 with a third party, including, but not limited to, a public institution
17 of higher education in the State or a foundation, to undertake the
18 evaluation.

19 b. No later than five years after the effective date of this ²**[act]**
20 section², the Commissioner of Health shall report to the Governor,
21 and to the Legislature pursuant to section 2 of P.L.1991, c.164
22 (C.52:14-19.1), on the findings of the evaluation required pursuant
23 to this section, and shall include in the report any recommendations
24 for legislative action that the commissioner deems appropriate.

25
26 6. The Commissioner of Health, pursuant to the
27 “Administrative Procedure Act,” P.L.1968, c.410 (C.52:14B-1 et
28 seq.), shall adopt such rules and regulations as the commissioner
29 determines necessary to effectuate the purposes of this act.

30
31 7. This act shall take effect one year after the date of
32 enactment, but the Commissioner of Health may take such
33 anticipatory administrative action in advance thereof as shall be
34 necessary for the implementation of this act.

35
36
37
38
39 “Autumn Joy Stillbirth Research and Dignity Act”; requires
40 DOH to establish protocols for stillbirths, establishes stillbirth
41 research database.

SENATE, No. 2843

STATE OF NEW JERSEY
215th LEGISLATURE

INTRODUCED JUNE 3, 2013

Sponsored by:

Senator LORETTA WEINBERG

District 37 (Bergen)

Senator DAWN MARIE ADDIEGO

District 8 (Atlantic, Burlington and Camden)

SYNOPSIS

“Autumn Joy Stillbirth Research and Dignity Act”; requires DOH to establish protocols for stillbirths, establishes stillbirth research database.

CURRENT VERSION OF TEXT

As introduced.



1 AN ACT concerning stillbirths and supplementing Title 26 of the
2 Revised Statutes, and designated the “Autumn Joy Stillbirth
3 Research and Dignity Act.”

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

7
8 1. The Legislature finds and declares that:

9 a. Stillbirths are unintended fetal deaths and are traditionally
10 identified as those which occur after 20 weeks of pregnancy or
11 involve the unintended death of fetuses weighing 350 or more
12 grams;

13 b. Approximately one in every 160 pregnancies in the United
14 States ends in stillbirth each year, a rate which is high compared
15 with other developed countries;

16 c. Families experiencing a stillbirth suffer severe anguish, and
17 many health care facilities in the State do not adequately ensure that
18 grieving families are treated with sensitivity and informed about
19 what to expect when a stillbirth occurs, nor are families who have
20 experienced a stillbirth always advised of the importance of an
21 autopsy and thorough evaluation of the fetus;

22 d. While studies have identified many factors that may cause
23 stillbirths, researchers still do not know the causes of a majority of
24 stillbirths, in part due to a lack of uniform protocols for evaluating
25 and classifying stillbirths, and to decreasing autopsy rates;

26 e. The State currently collects some data related to fetal deaths,
27 but full autopsy and laboratory data related to stillbirths could be
28 more consistently collected and more effectively used to better
29 understand risk factors and causes of stillbirths, and thus more
30 effectively inform strategies for their prevention; and

31 f. It is in the public interest to establish mandatory protocols for
32 health care facilities in the State, so that each child who is stillborn
33 and each family experiencing a stillbirth in the State is treated with
34 dignity, each family experiencing a stillbirth receives appropriate
35 follow-up care provided in a sensitive manner, and comprehensive
36 data related to stillbirths are consistently collected by the State and
37 made available to researchers seeking to prevent and reduce the
38 incidence of stillbirths.

39

40 2. a. The Commissioner of Health, in consultation with the
41 State Board of Medical Examiners, the New Jersey Board of
42 Nursing, the State Board of Psychological Examiners, and the State
43 Board of Social Work Examiners, shall develop and prescribe by
44 regulation comprehensive policies and procedures to be followed by
45 health care facilities that provide birthing and newborn care
46 services in the State when a stillbirth occurs.

47 b. The Commissioner of Health shall require as a condition of
48 licensure that each health care facility in the State that provides

1 birthing and newborn care services adhere to the policies and
2 procedures prescribed in this section. The policies and procedures
3 shall include, at a minimum:

4 (1) protocols for assigning primary responsibility to one
5 physician, who shall communicate the condition of the fetus to the
6 mother and family, and inform and coordinate staff to assist with
7 labor, delivery, and postmortem procedures;

8 (2) guidelines to assess a family's level of awareness and
9 knowledge regarding the stillbirth;

10 (3) the establishment of a bereavement checklist, and an
11 informational pamphlet to be given to a family experiencing a
12 stillbirth that includes information about funeral and cremation
13 options;

14 (4) provision of one-on-one nursing care for the duration of the
15 mother's stay at the facility;

16 (5) training of physicians, nurses, psychologists, and social
17 workers to ensure that information is provided to the mother and
18 family experiencing a stillbirth in a sensitive manner, including
19 information about what to expect, the availability of grief
20 counseling, the opportunity to develop a plan of care that meets the
21 family's social, religious, and cultural needs, and the importance of
22 an autopsy and thorough evaluation of the fetus;

23 (6) best practices to provide psychological and emotional
24 support to the mother and family following a stillbirth, including
25 referring to the fetus by name, and offering the family the
26 opportunity to cut the umbilical cord, hold the baby with privacy
27 and without time restrictions, and prepare a memory box with
28 keepsakes, such as a handprint, footprint, blanket, bracelet, lock of
29 hair, and photographs, and provisions for retaining the keepsakes
30 for one year if the family chooses not to take them at discharge;

31 (7) protocols to ensure that the physician assigned primary
32 responsibility for communicating with the family discusses the
33 importance of an autopsy for the family, including the significance
34 of autopsy findings on future pregnancies and the significance that
35 data from the autopsy may have for other families;

36 (8) protocols to ensure coordinated visits to the family by a
37 hospital staff trained to address the psychosocial needs of a family
38 experiencing a stillbirth, provide guidance in the bereavement
39 process, assist with completing any forms required in connection
40 with the stillbirth and autopsy, and offer the family the opportunity
41 to meet with the hospital chaplain or other individual from the
42 family's religious community; and

43 (9) guidelines for educating health care professionals and
44 hospital staff on caring for families after stillbirth.

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46 3. The Department of Health shall establish a fetal death
47 evaluation protocol, which a hospital licensed pursuant to P.L.1971,
48 c.136 (C.26:2H-1 et seq.) shall follow in collecting data relevant to

1 each stillbirth. The information required to be collected shall
2 include, but not be limited to:

3 a. the race, age of the mother, maternal and paternal family
4 history, comorbidities, prenatal care history, antepartum findings,
5 history of past obstetric complications, exposure to viral infections,
6 smoking, drug and alcohol use, fetal growth restriction, placental
7 abruption, chromosomal and genetic abnormalities obtained pre-
8 delivery, infection in premature fetus, cord accident, including
9 evidence of obstruction or circulatory compromise, history of
10 thromboembolism, and whether the mother gave birth before; and

11 b. documentation of the evaluation of a stillborn fetus, placenta,
12 and cytologic specimen that conform to the standards established by
13 the American College of Obstetricians and Gynecologists and meet
14 any other requirements deemed by the Commissioner of Health as
15 necessary, including, but not limited to, the following components:

16 (1) if the parents consent to a complete autopsy: the weight of
17 the fetus and placenta, head circumference, length of fetus, foot
18 length if stillbirth occurred before 23 weeks of gestation, and
19 notation of any dysmorphic feature; photograph of the whole body,
20 frontal and profile of face, extremities and palms, close-up of any
21 specific abnormalities; examination of the placenta and umbilical
22 cord; and gross and microscopic examination of membranes and
23 umbilical cord; or

24 (2) if the parents do not consent to a complete autopsy, an
25 evaluation of a fetus as set forth in paragraph (1) of this subsection,
26 and appropriate alternatives to a complete autopsy, including a
27 placental examination, external examination, selected biopsies, X-
28 rays, MRI, and ultrasound.

29
30 4. a. The Department of Health shall establish and maintain a
31 database that contains a confidential record of all data obtained
32 pursuant to section 3 of this act.

33 b. The data shall be made available to the public through the
34 department website, except that no data shall identify any person to
35 whom the data relate.

36
37 5 a. The Department of Health shall evaluate the data obtained
38 pursuant to section 3 of this act for purposes of identifying the
39 causes of, and ways to prevent, stillbirths, and may contract with a
40 third party, including, but not limited to, a public institution of
41 higher education in the State or a foundation, to undertake the
42 evaluation.

43 b. No later than five years after the effective date of this act, the
44 Commissioner of Health shall report to the Governor, and to the
45 Legislature pursuant to section 2 of P.L.1991, c.164 (C.52:14-19.1),
46 on the findings of the evaluation required pursuant to this section,
47 and shall include in the report any recommendations for legislative
48 action that the commissioner deems appropriate.

1 6. The Commissioner of Health, pursuant to the “Administrative
2 Procedure Act,” P.L.1968, c.410 (C.52:14B-1 et seq.), shall adopt
3 such rules and regulations as the commissioner determines
4 necessary to effectuate the purposes of this act.

5

6 7. This act shall take effect one year after the date of enactment,
7 but the Commissioner of Health may take such anticipatory
8 administrative action in advance thereof as shall be necessary for
9 the implementation of this act.

10

11

12

STATEMENT

13

14 This bill, which is designated the “Autumn Joy Stillbirth
15 Research and Dignity Act” in honor of a baby who was stillborn in
16 this State, requires the establishment of policies and procedures that
17 will ensure the dignified and sensitive management of each
18 stillbirth and of a family’s grieving process following a stillbirth.
19 The bill further requires that complete autopsy information related
20 to stillbirths that occur in the State be collected and reported to the
21 Department of Health (DOH), and requires the establishment of a
22 database for research purposes in order to advance the goal of
23 preventing and reducing the incidence of stillbirths.

24

25 Specifically, the bill directs the Commissioner of Health, in
26 consultation with the State Board of Medical Examiners, State
27 Board of Nursing, State Board of Psychological Examiners, and
28 State Board of Social Work Examiners, to develop policies to
29 ensure that families experiencing a stillbirth receive psychological
30 and emotional support. In addition, the bill requires that the
31 significance of autopsies be discussed with the family and requires
32 the establishment of fetal death evaluation protocol to incorporate
33 best practices for a thorough evaluation of a stillborn fetus. The bill
34 requires that DOH establish the fetal death evaluation protocol to
35 ensure that comprehensive data are collected in a consistent manner
36 and reported to DOH. This requirement is informed by practices
37 required by the Iowa Department Public Health in its Fetal Death
38 Evaluation Protocol.

38

39 DOH is further required to establish a database to serve as a
40 research resource. The data are to be made available generally for
41 research, and without disclosing the personal identities of any
42 individual to which the data relate. In addition, DOH is directed to
43 evaluate the data, which it may do by contracting with a public
44 institution of higher education in the State, a foundation, or other
45 third party. The bill directs the Commissioner of DOH to report to
46 the Governor and the Legislature within five years after the
47 effective date of the bill on the findings of the evaluation and to
include any recommendations for legislative action that the

S2843 WEINBERG, ADDIEGO

6

- 1 commissioner deems appropriate.
- 2 The bill would take effect one year after the date of enactment.

SENATE HEALTH, HUMAN SERVICES AND SENIOR
CITIZENS COMMITTEE

STATEMENT TO

SENATE, No. 2843

with committee amendments

STATE OF NEW JERSEY

DATED: JUNE 13, 2013

The Senate Health, Human Services and Senior Citizens Committee reports favorably and with amendments Senate Bill No. 2843.

As amended, this bill, designated the “Autumn Joy Stillbirth Research and Dignity Act,” requires the establishment of policies and procedures that will ensure the dignified and sensitive management of each stillbirth and of a family’s grieving process following a stillbirth. The bill further requires that complete autopsy information related to stillbirths that occur in the State be collected and reported to the Department of Health (DOH), and requires that a database be established for research purposes in order to advance the goal of preventing and reducing the incidence of stillbirths.

Specifically, the bill directs the Commissioner of Health, in consultation with the State Board of Medical Examiners, State Board of Nursing, State Board of Psychological Examiners, and State Board of Social Work Examiners, to develop policies to ensure that families experiencing a stillbirth receive psychological and emotional support. In addition, the bill requires that the significance of autopsies be discussed with the family and requires the establishment of evaluation protocol to incorporate best practices for a thorough evaluation of a stillborn child. The bill requires that DOH establish evaluation protocol to ensure that comprehensive data are collected in a consistent manner and reported to DOH. This aspect of the bill is informed by practices required by the Iowa Department Public Health in its Fetal Death Evaluation Protocol.

DOH is further required to establish a database to serve as a research resource. Data are to be made available generally for research, without disclosing the personal identities of any individual to which the data relate. In addition, DOH is directed to evaluate the data, which it may do by contracting with a public institution of higher education in the State, a foundation, or other third party. The bill directs the Commissioner of DOH to report to the Governor and the Legislature within five years after the effective date of the bill on the

findings of the evaluation and to include any recommendations for legislative action that the commissioner deems appropriate.

The bill would take effect one year after the date of enactment.

The committee amended the bill to correct references related to the term “stillborn child.”

LEGISLATIVE FISCAL ESTIMATE

[First Reprint]

SENATE, No. 2843

STATE OF NEW JERSEY 215th LEGISLATURE

DATED: JULY 5, 2013

SUMMARY

- Synopsis:** “Autumn Joy Stillbirth Research and Dignity Act”; requires DOH to establish protocols for stillbirths, establishes stillbirth research database.
- Type of Impact:** A State expenditure increase, which may be offset by increased revenue from increased licensure and inspection fees.
- Agencies Affected:** Department of Health (DOH).

Office of Legislative Services Estimate

Fiscal Impact	<u>Years 1-3</u>
State Cost	Indeterminate – See comments below

- The Office of Legislative Services (OLS) finds that the bill would lead to an indeterminate increase in costs at the Department of Health (DOH) related to oversight and inspection of certain health care facilities, and related to collecting, storing, and evaluating data pertaining to stillborn children.
- The DOH may increase license and inspection fees to offset additional costs it incurs.

BILL DESCRIPTION

Senate Bill No. 2843 (1R) of 2013, designated the “Autumn Joy Stillbirth Research and Dignity Act,” requires the establishment of policies and procedures at birthing and newborn care facilities to ensure that families experiencing a stillbirth receive psychological and emotional support. The bill further requires that, when available, complete autopsy information related to stillbirths that occur in the State be collected and reported to the DOH, and requires that a database be established to store this information for research purposes in order to advance the goal of preventing and reducing the incidence of stillbirths.

Specifically, the bill directs the Commissioner of Health, in consultation with the State Board of Medical Examiners, State Board of Nursing, State Board of Psychological Examiners, and State Board of Social Work Examiners, to develop policies to ensure that families experiencing a stillbirth receive psychological and emotional support, to which birthing and newborn care facilities would be required to adhere, as a condition of licensure. In addition, the bill requires that the significance of autopsies be discussed with the family, and requires the establishment of protocols to incorporate best practices for a thorough evaluation of a stillborn child.

The bill further requires that the DOH establish a fetal death evaluation protocol, to which hospitals would be required to adhere, to ensure that comprehensive data are collected in a consistent manner and reported to the DOH. The DOH is further required to establish a database to store information gathered pursuant to the fetal death evaluation protocol, which is to serve as a research resource. Data are to be made available generally for research, without disclosing the personal identities of any individual to which the data relate. In addition, the DOH is directed to evaluate the data, which it may do by contracting with a public institution of higher education in the State, a foundation, or other third party. The bill directs the Commissioner of Health to report to the Governor and the Legislature within five years after the effective date of the bill on the findings of the evaluation and to include any recommendations for legislative action that the commissioner deems appropriate.

FISCAL ANALYSIS

EXECUTIVE BRANCH

None received.

OFFICE OF LEGISLATIVE SERVICES

The OLS finds that the bill would lead to an indeterminate increase in costs at the DOH related to the enforcement of the required policies and procedures for facilities that provide birthing and newborn care services. Specifically, the DOH may determine that it must inspect birthing and newborn care facilities, and audit their records, more often or more closely to ensure that the facilities are in compliance with the policies and procedures specified by the bill. If costs to oversee these facilities increase, the DOH may increase the various regulatory fees it charges to these facilities. Most of the facilities that would be affected by the bill are currently licensed as birth centers, and are subject to the following fees (in addition to fees for other services on each facility's license): \$1,750 for a license application; \$750 annually for a license renewal; \$200 for a required biennial inspection; and other fees for administrative changes, such as a change in ownership.

The OLS also finds that the DOH would incur costs to collect, store, and evaluate data relevant to stillbirth, which would lead to an indeterminate increase in costs. In order to collect data, the DOH must develop a fetal death evaluation protocol and ensure that hospitals adhere to the protocol and report data to the department. Any significant State costs related to data collection would likely be offset by regulatory fees charged to hospitals. Costs related to data storage are expected to be modest, as the quantity of data that the bill would require is not large. (It is estimated that approximately 700 stillbirths occur in New Jersey each year, based on a national prevalence rate of 1 in 160 births, and an estimated 110,000 births per year. For each stillborn child, the bill requires that the database store several pieces of numerical and textual information and, if the parents consent to a complete autopsy, several photographs of the

stillborn child. The DOH may require additional data, as well, which may require a larger database.) Finally, it is expected that the DOH would contract with a third party to conduct the evaluation of the stillbirth data, the cost of which would depend upon the scope of the analysis and the availability of federal or private resources to support the research. This evaluation, and its cost, would likely be delayed until several years' worth of data could be assembled, permitting a more robust analysis than would be possible with a smaller set of data.

Section: Human Services

*Analyst: David Drescher
Associate Fiscal Analyst*

*Approved: David J. Rosen
Legislative Budget and Finance Officer*

This fiscal estimate has been prepared pursuant to P.L.1980, c.67 (C.52:13B-6 et seq.).

ASSEMBLY WOMEN AND CHILDREN COMMITTEE

STATEMENT TO

[First Reprint]

SENATE, No. 2843

with committee amendments

STATE OF NEW JERSEY

DATED: DECEMBER 16, 2013

The Assembly Women and Children Committee reports favorably and with committee amendments, Senate Bill No. 2843(1R).

As amended by the committee, this bill, designated the “Autumn Joy Stillbirth Research and Dignity Act,” requires the establishment of policies and procedures that will ensure the dignified and sensitive management of each stillbirth and of a family’s grieving process following a stillbirth. The bill further requires that complete autopsy information related to stillbirths that occur in the State be collected and reported to the Department of Health (DOH), and requires that a database be established for research purposes in order to advance the goal of preventing and reducing the incidence of stillbirths.

Specifically, the bill directs the Commissioner of Health, in consultation with the State Board of Medical Examiners, State Board of Nursing, State Board of Psychological Examiners, and State Board of Social Work Examiners, to develop policies to ensure that families experiencing a stillbirth receive psychological and emotional support. In addition, the bill requires that the significance of autopsies be discussed with the family and requires the establishment of evaluation protocols to incorporate best practices for a thorough evaluation of a stillborn child. The bill requires that DOH establish evaluation protocols to ensure that comprehensive data are collected in a consistent manner and reported to DOH. This aspect of the bill is informed by practices required by the Iowa Department Public Health in its Fetal Death Evaluation Protocol. The bill also directs the State Board of Medical Examiners and the State Board of Nursing to require physicians and nurses, respectively, to adhere to the polices developed by the commissioner pursuant to the bill.

DOH is further required to establish a new database or update an existing database to serve as a research resource. Data are to be made available generally for research, without disclosing the personal identities of any individual to which the data relate. In addition, DOH is directed to evaluate the data, which it may do by contracting with a public institution of higher education in the State, a foundation, or

other third party. The bill directs the Commissioner of DOH to report to the Governor and the Legislature within eight years after the effective date of the bill on the findings of the evaluation and to include any recommendations for legislative action that the commissioner deems appropriate. The bill would take effect one year after the date of enactment. The requirements to establish and maintain the new database or update an existing database and the stipulation that DOH evaluate the data obtained pursuant to the bill would take effect two years after the date of the bill's enactment, except that if the department develops the technical capability, the department would establish and maintain the new, or update the existing, database prior to that time.

This bill is identical to Assembly Bill No. 4280 (Lampitt/Decroce/Mosquera/Casagrande), which the committee also reported on this date.

COMMITTEE AMENDMENTS

The committee amended the bill to direct the State Board of Medical Examiners and the State Board of Nursing to require physicians and nurses, respectively, to adhere to the policies developed by the commissioner pursuant to the bill. The committee also amended the bill to clarify that DOH is required to establish a new database or update an existing database to serve as a research resource. The amendments also clarify that the provisions concerning the requirements to establish and maintain the new, and update the existing, database and the stipulation that DOH evaluate the data obtained pursuant to the bill would take effect two years after the date of the bill's enactment, except that if the department develops the technical capability, the department would establish and maintain the new, or update the existing, database prior to that time. The amendments also stipulate that the Commissioner of DOH report to the Governor and the Legislature within eight years after the effective date of the bill on the findings of the evaluation.

LEGISLATIVE FISCAL ESTIMATE

[Second Reprint]

SENATE, No. 2843

STATE OF NEW JERSEY 215th LEGISLATURE

DATED: JANUARY 7, 2014

SUMMARY

- Synopsis:** “Autumn Joy Stillbirth Research and Dignity Act”; requires DOH to establish protocols for stillbirths, establishes stillbirth research database.
- Type of Impact:** A State expenditure increase, which may be offset by increased revenue from increased licensure and inspection fees.
- Agencies Affected:** Department of Health (DOH); State Board of Medical Examiners; New Jersey Board of Nursing.

Office of Legislative Services Estimate

Fiscal Impact	<u>Years 1-3</u>
State Cost	Indeterminate – See comments below

- The Office of Legislative Services (OLS) finds that the bill would lead to an indeterminate increase in costs at the Department of Health (DOH) related to oversight and inspection of certain health care facilities, and related to collecting, storing, and evaluating data pertaining to stillborn children. The DOH may increase license and inspection fees to offset additional costs it incurs.
- The State Board of Medical Examiners and the New Jersey Board of Nursing may increase licensure actions and penalties against licensees, but this increased enforcement activity is expected to be minimal, and have no significant net effect on State costs and revenues.

BILL DESCRIPTION

Senate Bill No. 2843 (2R) of 2013, designated the “Autumn Joy Stillbirth Research and Dignity Act,” requires the establishment of policies and procedures for use by birthing and newborn care facilities, and physicians and nurses providing care therein, to ensure that families experiencing a stillbirth receive psychological and emotional support. The bill further requires that, when available, complete autopsy information related to stillbirths that occur in the State be

collected and reported to the DOH, and requires that a database be established to store this information for research purposes in order to advance the goal of preventing and reducing the incidence of stillbirths.

Specifically, the bill directs the Commissioner of Health, in consultation with the State Board of Medical Examiners, New Jersey Board of Nursing, State Board of Psychological Examiners, and State Board of Social Work Examiners, to develop policies to ensure that families experiencing a stillbirth receive psychological and emotional support, to which birthing and newborn care facilities, and the physicians and nurses providing care therein, would be required to adhere. In addition, the bill requires that the significance of autopsies be discussed with the family, and requires the establishment of protocols to incorporate best practices for a thorough evaluation of a stillborn child.

The bill further requires that the DOH establish a fetal death evaluation protocol, to which hospitals would be required to adhere, to ensure that comprehensive data are collected in a consistent manner and reported to the DOH. Within two years of the bill's effective date, the DOH is further required to establish a database to store information gathered pursuant to the fetal death evaluation protocol, which is to serve as a research resource. Data are to be made available generally for research, without disclosing the personal identities of any individual to which the data relate. In addition, the DOH is directed to evaluate the data, which it may do by contracting with a public institution of higher education in the State, a foundation, or other third party. The bill directs the Commissioner of Health to report to the Governor and the Legislature within five years of the effective date on the findings of the evaluation and to include any recommendations for legislative action that the commissioner deems appropriate.

FISCAL ANALYSIS

EXECUTIVE BRANCH

None received.

OFFICE OF LEGISLATIVE SERVICES

The OLS finds that the bill would lead to an indeterminate increase in costs at the DOH related to the enforcement of the required policies and procedures for facilities that provide birthing and newborn care services. Specifically, the DOH may determine that it must inspect birthing and newborn care facilities, and audit their records, more often or more closely to ensure that the facilities are in compliance with the policies and procedures specified by the bill. If costs to oversee these facilities increase, the DOH may increase the various regulatory fees it charges to these facilities. Most of the facilities that would be affected by the bill are currently licensed as birth centers, and are subject to the following fees (in addition to fees for other services on each facility's license): \$1,750 for a license application; \$750 annually for a license renewal; \$200 for a required biennial inspection; and other fees for administrative changes, such as a change in ownership.

The State Board of Medical Examiners and the New Jersey Board of Nursing would not be specifically required to inspect or audit records, but may increase licensure actions and penalties against licensees who fail to follow the policies and procedures required by the bill when providing care at health care facilities that provide birthing and newborn care services. This increased enforcement activity is expected to be minimal, and have no significant net effect on State costs and revenues.

The OLS also finds that the DOH would incur costs to collect, store, and evaluate data relevant to stillbirth, which would lead to an indeterminate increase in costs. In order to collect data, the DOH must develop a fetal death evaluation protocol and ensure that hospitals adhere to the protocol and report data to the department. Any significant State costs related to data collection would likely be offset by regulatory fees charged to hospitals. Costs related to data storage are expected to be modest, as the quantity of data that the bill would require is not large. (It is estimated that approximately 700 stillbirths occur in New Jersey each year, based on a national prevalence rate of 1 in 160 births, and an estimated 110,000 births per year. For each stillborn child, the bill requires that the database store several pieces of numerical and textual information and, if the parents consent to a complete autopsy, several photographs of the stillborn child. The DOH may require additional data, as well, which may require a larger database.) If the DOH is able to update an existing database, costs may be less than if it must establish a new one. Finally, it is expected that the DOH would contract with a third party to conduct the evaluation of the stillbirth data, the cost of which would depend upon the scope of the analysis and the availability of federal or private resources to support the research. This evaluation, and its cost, would likely be delayed until several years' worth of data could be assembled, permitting a more robust analysis than would be possible with a smaller set of data.

Section: Human Services

*Analyst: David Drescher
Associate Fiscal Analyst*

*Approved: David J. Rosen
Legislative Budget and Finance Officer*

This legislative fiscal estimate has been produced by the Office of Legislative Services due to the failure of the Executive Branch to respond to our request for a fiscal note.

This fiscal estimate has been prepared pursuant to P.L.1980, c.67 (C.52:13B-6 et seq.).

ASSEMBLY, No. 4280

STATE OF NEW JERSEY 215th LEGISLATURE

INTRODUCED JUNE 24, 2013

Sponsored by:

Assemblywoman PAMELA R. LAMPITT

District 6 (Burlington and Camden)

Assemblywoman BETTYLOU DECROCE

District 26 (Essex, Morris and Passaic)

Assemblywoman GABRIELA M. MOSQUERA

District 4 (Camden and Gloucester)

Assemblywoman CAROLINE CASAGRANDE

District 11 (Monmouth)

Co-Sponsored by:

Assemblywomen McHose and Vainieri Huttle

SYNOPSIS

“Autumn Joy Stillbirth Research and Dignity Act”; requires DOH to establish protocols for stillbirths, establishes stillbirth research database.

CURRENT VERSION OF TEXT

As introduced.



(Sponsorship Updated As Of: 12/17/2013)

1 AN ACT concerning stillbirths and supplementing Title 26 of the
2 Revised Statutes, and designated the “Autumn Joy Stillbirth
3 Research and Dignity Act.”

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

7
8 1. The Legislature finds and declares that:

9 a. Stillbirths are unintended fetal deaths and are traditionally
10 identified as those which occur after 20 weeks of pregnancy or
11 involve the unintended death of fetuses weighing 350 or more
12 grams;

13 b. Approximately one in every 160 pregnancies in the United
14 States ends in stillbirth each year, a rate which is high compared
15 with other developed countries;

16 c. Families experiencing a stillbirth suffer severe anguish, and
17 many health care facilities in the State do not adequately ensure that
18 grieving families are treated with sensitivity and informed about
19 what to expect when a stillbirth occurs, nor are families who have
20 experienced a stillbirth always advised of the importance of an
21 autopsy and thorough evaluation of the stillborn child;

22 d. While studies have identified many factors that may cause
23 stillbirths, researchers still do not know the causes of a majority of
24 stillbirths, in part due to a lack of uniform protocols for evaluating
25 and classifying stillbirths, and to decreasing autopsy rates;

26 e. The State currently collects some data related to fetal deaths,
27 but full autopsy and laboratory data related to stillbirths could be
28 more consistently collected and more effectively used to better
29 understand risk factors and causes of stillbirths, and thus more
30 effectively inform strategies for their prevention; and

31 f. It is in the public interest to establish mandatory protocols
32 for health care facilities in the State, so that each child who is
33 stillborn and each family experiencing a stillbirth in the State is
34 treated with dignity, each family experiencing a stillbirth receives
35 appropriate follow-up care provided in a sensitive manner, and
36 comprehensive data related to stillbirths are consistently collected
37 by the State and made available to researchers seeking to prevent
38 and reduce the incidence of stillbirths.

39
40 2. a. The Commissioner of Health, in consultation with the
41 State Board of Medical Examiners, the New Jersey Board of
42 Nursing, the State Board of Psychological Examiners, and the State
43 Board of Social Work Examiners, shall develop and prescribe by
44 regulation comprehensive policies and procedures to be followed by
45 health care facilities that provide birthing and newborn care
46 services in the State when a stillbirth occurs.

47 b. The Commissioner of Health shall require as a condition of
48 licensure that each health care facility in the State that provides

- 1 birthing and newborn care services adhere to the policies and
2 procedures prescribed in this section. The policies and procedures
3 shall include, at a minimum:
- 4 (1) protocols for assigning primary responsibility to one
5 physician, who shall communicate the condition of the fetus to the
6 mother and family, and inform and coordinate staff to assist with
7 labor, delivery, and postmortem procedures;
 - 8 (2) guidelines to assess a family's level of awareness and
9 knowledge regarding the stillbirth;
 - 10 (3) the establishment of a bereavement checklist, and an
11 informational pamphlet to be given to a family experiencing a
12 stillbirth that includes information about funeral and cremation
13 options;
 - 14 (4) provision of one-on-one nursing care for the duration of the
15 mother's stay at the facility;
 - 16 (5) training of physicians, nurses, psychologists, and social
17 workers to ensure that information is provided to the mother and
18 family experiencing a stillbirth in a sensitive manner, including
19 information about what to expect, the availability of grief
20 counseling, the opportunity to develop a plan of care that meets the
21 family's social, religious, and cultural needs, and the importance of
22 an autopsy and thorough evaluation of the stillborn child;
 - 23 (6) best practices to provide psychological and emotional
24 support to the mother and family following a stillbirth, including
25 referring to the stillborn child by name, and offering the family the
26 opportunity to cut the umbilical cord, hold the stillborn child with
27 privacy and without time restrictions, and prepare a memory box
28 with keepsakes, such as a handprint, footprint, blanket, bracelet,
29 lock of hair, and photographs, and provisions for retaining the
30 keepsakes for one year if the family chooses not to take them at
31 discharge;
 - 32 (7) protocols to ensure that the physician assigned primary
33 responsibility for communicating with the family discusses the
34 importance of an autopsy for the family, including the significance
35 of autopsy findings on future pregnancies and the significance that
36 data from the autopsy may have for other families;
 - 37 (8) protocols to ensure coordinated visits to the family by a
38 hospital staff trained to address the psychosocial needs of a family
39 experiencing a stillbirth, provide guidance in the bereavement
40 process, assist with completing any forms required in connection
41 with the stillbirth and autopsy, and offer the family the opportunity
42 to meet with the hospital chaplain or other individual from the
43 family's religious community; and
 - 44 (9) guidelines for educating health care professionals and
45 hospital staff on caring for families after stillbirth.
- 46
- 47 3. The Department of Health shall establish a fetal death
48 evaluation protocol, which a hospital licensed pursuant to P.L.1971,

1 c.136 (C.26:2H-1 et seq.) shall follow in collecting data relevant to
2 each stillbirth. The information required to be collected shall
3 include, but not be limited to:

4 a. the race, age of the mother, maternal and paternal family
5 history, comorbidities, prenatal care history, antepartum findings,
6 history of past obstetric complications, exposure to viral infections,
7 smoking, drug and alcohol use, fetal growth restriction, placental
8 abruption, chromosomal and genetic abnormalities obtained pre-
9 delivery, infection in premature fetus, cord accident, including
10 evidence of obstruction or circulatory compromise, history of
11 thromboembolism, and whether the mother gave birth before; and

12 b. documentation of the evaluation of a stillborn child,
13 placenta, and cytologic specimen that conform to the standards
14 established by the American College of Obstetricians and
15 Gynecologists and meet any other requirements deemed by the
16 Commissioner of Health as necessary, including, but not limited to,
17 the following components:

18 (1) if the parents consent to a complete autopsy: the weight of
19 the stillborn child and placenta, head circumference, length of
20 stillborn child, foot length if stillbirth occurred before 23 weeks of
21 gestation, and notation of any dysmorphic feature; photograph of
22 the whole body, frontal and profile of face, extremities and palms,
23 close-up of any specific abnormalities; examination of the placenta
24 and umbilical cord; and gross and microscopic examination of
25 membranes and umbilical cord; or

26 (2) if the parents do not consent to a complete autopsy, an
27 evaluation of a stillborn child as set forth in paragraph (1) of this
28 subsection, and appropriate alternatives to a complete autopsy,
29 including a placental examination, external examination, selected
30 biopsies, X-rays, MRI, and ultrasound.

31

32 4. a. The Department of Health shall establish and maintain a
33 database that contains a confidential record of all data obtained
34 pursuant to section 3 of this act.

35 b. The data shall be made available to the public through the
36 department website, except that no data shall identify any person to
37 whom the data relate.

38

39 5. a. The Department of Health shall evaluate the data
40 obtained pursuant to section 3 of this act for purposes of identifying
41 the causes of, and ways to prevent, stillbirths, and may contract
42 with a third party, including, but not limited to, a public institution
43 of higher education in the State or a foundation, to undertake the
44 evaluation.

45 b. No later than five years after the effective date of this act,
46 the Commissioner of Health shall report to the Governor, and to the
47 Legislature pursuant to section 2 of P.L.1991, c.164 (C.52:14-19.1),
48 on the findings of the evaluation required pursuant to this section,

1 and shall include in the report any recommendations for legislative
2 action that the commissioner deems appropriate.

3

4 6. The Commissioner of Health, pursuant to the
5 “Administrative Procedure Act,” P.L.1968, c.410 (C.52:14B-1 et
6 seq.), shall adopt such rules and regulations as the commissioner
7 determines necessary to effectuate the purposes of this act.

8

9 7. This act shall take effect one year after the date of
10 enactment, but the Commissioner of Health may take such
11 anticipatory administrative action in advance thereof as shall be
12 necessary for the implementation of this act.

13

14

15

STATEMENT

16

17 This bill, designated the “Autumn Joy Stillbirth Research and
18 Dignity Act,” requires the establishment of policies and procedures
19 that will ensure the dignified and sensitive management of each
20 stillbirth and of a family’s grieving process following a stillbirth.
21 The bill further requires that complete autopsy information related
22 to stillbirths that occur in the State be collected and reported to the
23 Department of Health (DOH), and requires that a database be
24 established for research purposes in order to advance the goal of
25 preventing and reducing the incidence of stillbirths.

26

27 Specifically, the bill directs the Commissioner of Health, in
28 consultation with the State Board of Medical Examiners, State
29 Board of Nursing, State Board of Psychological Examiners, and
30 State Board of Social Work Examiners, to develop policies to
31 ensure that families experiencing a stillbirth receive psychological
32 and emotional support. In addition, the bill requires that the
33 significance of autopsies be discussed with the family and requires
34 the establishment of evaluation protocol to incorporate best
35 practices for a thorough evaluation of a stillborn child. The bill
36 requires that DOH establish evaluation protocol to ensure that
37 comprehensive data are collected in a consistent manner and
38 reported to DOH. This aspect of the bill is informed by practices
39 required by the Iowa Department Public Health in its Fetal Death
40 Evaluation Protocol.

41

42 DOH is further required to establish a database to serve as a
43 research resource. Data are to be made available generally for
44 research, without disclosing the personal identities of any individual
45 to which the data relate. In addition, DOH is directed to evaluate
46 the data, which it may do by contracting with a public institution of
47 higher education in the State, a foundation, or other third party.
48 The bill directs the Commissioner of DOH to report to the Governor
and the Legislature within five years after the effective date of the
bill on the findings of the evaluation and to include any

A4280 LAMPITT, B.DECROCE

6

- 1 recommendations for legislative action that the commissioner
- 2 deems appropriate.
- 3 The bill would take effect one year after the date of enactment.

ASSEMBLY WOMEN AND CHILDREN COMMITTEE

STATEMENT TO

ASSEMBLY, No. 4280

with committee amendments

STATE OF NEW JERSEY

DATED: DECEMBER 16, 2013

The Assembly Women and Children Committee reports favorably and with committee amendments, Assembly Bill No. 4280

This bill, designated the “Autumn Joy Stillbirth Research and Dignity Act,” requires the establishment of policies and procedures that will ensure the dignified and sensitive management of each stillbirth and of a family’s grieving process following a stillbirth. The bill further requires that complete autopsy information related to stillbirths that occur in the State be collected and reported to the Department of Health (DOH), and requires that a database be established for research purposes in order to advance the goal of preventing and reducing the incidence of stillbirths.

Specifically, the bill directs the Commissioner of Health, in consultation with the State Board of Medical Examiners, State Board of Nursing, State Board of Psychological Examiners, and State Board of Social Work Examiners, to develop policies to ensure that families experiencing a stillbirth receive psychological and emotional support. In addition, the bill requires that the significance of autopsies be discussed with the family and requires the establishment of evaluation protocols to incorporate best practices for a thorough evaluation of a stillborn child. The bill requires that DOH establish evaluation protocols to ensure that comprehensive data are collected in a consistent manner and reported to DOH. This aspect of the bill is informed by practices required by the Iowa Department Public Health in its Fetal Death Evaluation Protocol. The bill also directs the State Board of Medical Examiners and the State Board of Nursing to require physicians and nurses, respectively, to adhere to the polices developed by the commissioner pursuant to the bill.

DOH is further required to establish a new database or update an existing database to serve as a research resource. Data are to be made available generally for research, without disclosing the personal identities of any individual to which the data relate. In addition, DOH is directed to evaluate the data, which it may do by contracting with a public institution of higher education in the State, a foundation, or other third party. The bill directs the Commissioner of DOH to report

to the Governor and the Legislature within eight years after the effective date of the bill on the findings of the evaluation and to include any recommendations for legislative action that the commissioner deems appropriate. The bill would take effect one year after the date of enactment. The requirements to establish and maintain the new database or update an existing database and the stipulation that DOH evaluate the data obtained pursuant to the bill would take effect two years after the date of the bill's enactment, except that if the department develops the technical capability, the department would establish and maintain the new, or update the existing, database prior to that time.

This bill is identical to Senate Bill No. 2843 (1R) (Weinberg/Addiego), which the committee also reported on this date.

COMMITTEE AMENDMENTS

The committee amended the bill to direct the State Board of Medical Examiners and the State Board of Nursing to require physicians and nurses, respectively, to adhere to the policies developed by the commissioner pursuant to the bill. The committee also amended the bill to clarify that DOH is required to establish a new database or update an existing database to serve as a research resource. The amendments also clarify that the provisions concerning the requirements to establish and maintain the new, and update the existing, database and the stipulation that DOH evaluate the data obtained pursuant to the bill would take effect two years after the date of the bill's enactment, except that if the department develops the technical capability, the department would establish and maintain the new, or update the existing, database prior to that time. The amendments also stipulate that the Commissioner of DOH report to the Governor and the Legislature within eight years after the effective date of the bill on the findings of the evaluation.

LEGISLATIVE FISCAL ESTIMATE

[First Reprint]

ASSEMBLY, No. 4280

STATE OF NEW JERSEY 215th LEGISLATURE

DATED: JANUARY 7, 2014

SUMMARY

- Synopsis:** “Autumn Joy Stillbirth Research and Dignity Act”; requires DOH to establish protocols for stillbirths, establishes stillbirth research database.
- Type of Impact:** A State expenditure increase, which may be offset by increased revenue from increased licensure and inspection fees.
- Agencies Affected:** Department of Health (DOH); State Board of Medical Examiners; New Jersey Board of Nursing.

Office of Legislative Services Estimate

Fiscal Impact	<u>Years 1-3</u>
State Cost	Indeterminate – See comments below

- The Office of Legislative Services (OLS) finds that the bill would lead to an indeterminate increase in costs at the Department of Health (DOH) related to oversight and inspection of certain health care facilities, and related to collecting, storing, and evaluating data pertaining to stillborn children. The DOH may increase license and inspection fees to offset additional costs it incurs.
- The State Board of Medical Examiners and the New Jersey Board of Nursing may increase licensure actions and penalties against licensees, but this increased enforcement activity is expected to be minimal, and have no significant net effect on State costs and revenues.

BILL DESCRIPTION

Assembly Bill No. 4280 (1R) of 2013, designated the “Autumn Joy Stillbirth Research and Dignity Act,” requires the establishment of policies and procedures for use by birthing and newborn care facilities, and physicians and nurses providing care therein, to ensure that families experiencing a stillbirth receive psychological and emotional support. The bill further requires that, when available, complete autopsy information related to stillbirths that occur in the State be

collected and reported to the DOH, and requires that a database be established to store this information for research purposes in order to advance the goal of preventing and reducing the incidence of stillbirths.

Specifically, the bill directs the Commissioner of Health, in consultation with the State Board of Medical Examiners, New Jersey Board of Nursing, State Board of Psychological Examiners, and State Board of Social Work Examiners, to develop policies to ensure that families experiencing a stillbirth receive psychological and emotional support, to which birthing and newborn care facilities, and the physicians and nurses providing care therein, would be required to adhere. In addition, the bill requires that the significance of autopsies be discussed with the family, and requires the establishment of protocols to incorporate best practices for a thorough evaluation of a stillborn child.

The bill further requires that the DOH establish a fetal death evaluation protocol, to which hospitals would be required to adhere, to ensure that comprehensive data are collected in a consistent manner and reported to the DOH. Within two years of the bill's effective date, the DOH is further required to establish a database to store information gathered pursuant to the fetal death evaluation protocol, which is to serve as a research resource. Data are to be made available generally for research, without disclosing the personal identities of any individual to which the data relate. In addition, the DOH is directed to evaluate the data, which it may do by contracting with a public institution of higher education in the State, a foundation, or other third party. The bill directs the Commissioner of Health to report to the Governor and the Legislature within five years of the effective date on the findings of the evaluation and to include any recommendations for legislative action that the commissioner deems appropriate.

FISCAL ANALYSIS

EXECUTIVE BRANCH

None received.

OFFICE OF LEGISLATIVE SERVICES

The OLS finds that the bill would lead to an indeterminate increase in costs at the DOH related to the enforcement of the required policies and procedures for facilities that provide birthing and newborn care services. Specifically, the DOH may determine that it must inspect birthing and newborn care facilities, and audit their records, more often or more closely to ensure that the facilities are in compliance with the policies and procedures specified by the bill. If costs to oversee these facilities increase, the DOH may increase the various regulatory fees it charges to these facilities. Most of the facilities that would be affected by the bill are currently licensed as birth centers, and are subject to the following fees (in addition to fees for other services on each facility's license): \$1,750 for a license application; \$750 annually for a license renewal; \$200 for a required biennial inspection; and other fees for administrative changes, such as a change in ownership.

The State Board of Medical Examiners and the New Jersey Board of Nursing would not be specifically required to inspect or audit records, but may increase licensure actions and penalties against licensees who fail to follow the policies and procedures required by the bill when providing care at health care facilities that provide birthing and newborn care services. This

increased enforcement activity is expected to be minimal, and have no significant net effect on State costs and revenues.

The OLS also finds that the DOH would incur costs to collect, store, and evaluate data relevant to stillbirth, which would lead to an indeterminate increase in costs. In order to collect data, the DOH must develop a fetal death evaluation protocol and ensure that hospitals adhere to the protocol and report data to the department. Any significant State costs related to data collection would likely be offset by regulatory fees charged to hospitals. Costs related to data storage are expected to be modest, as the quantity of data that the bill would require is not large. (It is estimated that approximately 700 stillbirths occur in New Jersey each year, based on a national prevalence rate of 1 in 160 births, and an estimated 110,000 births per year. For each stillborn child, the bill requires that the database store several pieces of numerical and textual information and, if the parents consent to a complete autopsy, several photographs of the stillborn child. The DOH may require additional data, as well, which may require a larger database.) If the DOH is able to update an existing database, costs may be less than if it must establish a new one. Finally, it is expected that the DOH would contract with a third party to conduct the evaluation of the stillbirth data, the cost of which would depend upon the scope of the analysis and the availability of federal or private resources to support the research. This evaluation, and its cost, would likely be delayed until several years' worth of data could be assembled, permitting a more robust analysis than would be possible with a smaller set of data.

Section: Human Services

*Analyst: David Drescher
Associate Fiscal Analyst*

*Approved: David J. Rosen
Legislative Budget and Finance Officer*

This legislative fiscal estimate has been produced by the Office of Legislative Services due to the failure of the Executive Branch to respond to our request for a fiscal note.

This fiscal estimate has been prepared pursuant to P.L.1980, c.67 (C.52:13B-6 et seq.).