

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

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

1. The Legislature finds and declares that:

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

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

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

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

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

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

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

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

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.

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

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

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

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

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

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

(6) best practices to provide psychological and emotional support to the mother and family following a stillbirth, including referring to the fetus by name, and offering the family the opportunity to cut the umbilical cord, hold the baby with privacy and without time restrictions, and prepare a memory box with keepsakes, such as a handprint, footprint, blanket, bracelet, lock of hair, and photographs;

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

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

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

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

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

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

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

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

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

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

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

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

6. The Commissioner of Health, pursuant to the “Administrative Procedure Act,” P.L.1968, c.410 (C.52:14B-1 et seq.), shall adopt

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such rules and regulations as the commissioner determines necessary to effectuate the purposes of this act.

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

STATEMENT

This bill, which is designated the “Autumn Joy Stillbirth Research and Dignity Act” in honor of a baby who was stillborn in this State, 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 the establishment of a database 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 still birth 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 fetal death evaluation protocol to incorporate best practices for a thorough evaluation of a stillborn fetus. The bill requires that DOH establish the fetal death evaluation protocol to ensure that comprehensive data are collected in a consistent manner and reported to DOH. This requirement 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. The data are to be made available generally for research, and 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 may include any recommendations for legislative action that the commissioner deems appropriate.

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

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

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