# ASSEMBLY, No. 5008

# STATE OF NEW JERSEY

## 219th LEGISLATURE

INTRODUCED NOVEMBER 19, 2020

**Sponsored by:** 

Assemblywoman PAMELA R. LAMPITT
District 6 (Burlington and Camden)
Assemblyman DANIEL R. BENSON
District 14 (Mercer and Middlesex)
Assemblywoman VALERIE VAINIERI HUTTLE
District 37 (Bergen)

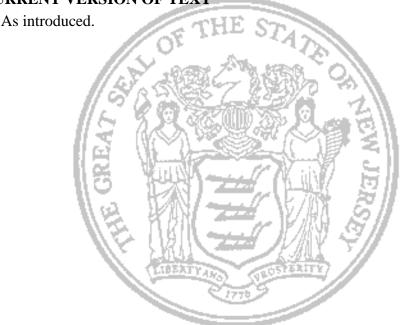
Co-Sponsored by:

Assemblyman Conaway, Assemblywomen Jasey and McKnight

### **SYNOPSIS**

Establishes "Stillbirth Resource Center" and programs for the prevention and reduction of incidences of stillbirth; expands list of professionals authorized to provide stillbirth-related care; appropriates \$2.5 million.

#### **CURRENT VERSION OF TEXT**



(Sponsorship Updated As Of: 6/9/2021)

AN ACT establishing the "Stillbirth Resource Center," amending P.L.2013, c.217, supplementing Title 26 of the Revised Statutes, and making an appropriation.

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

- 1. Section 1 of P.L.2013, c.217 (C.26:8-40.27) is amended to read as follows:
  - 1. The Legislature finds and declares that:
- a. Stillbirths are unintended fetal deaths and are traditionally identified as those which occur after 20 <u>completed</u> weeks of pregnancy, <u>excluding induced terminations of pregnancies occurring after 20 weeks</u>, or involve the unintended death of fetuses weighing 350 or more grams <u>when no prenatal obstetric dating is available</u>;
- b. Stillbirths are not rare and are one of the most common adverse pregnancy outcomes experienced by pregnant women.

  [Approximately] Every year, roughly 25,000 babies are stillborn in the United States, and 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. As with most adverse health outcomes, there are longstanding and persistent racial, ethnic, age, and educational disparities for stillbirth in New Jersey. Statewide, African American women experience stillbirth at more than three times the rate of Caucasian women, and at more than twice the rate of other racial and ethnic groups;
- d. Many factors, including genetics, environment, stress, social issues, access to and quality of medical care, and behavior, contribute to racial disparities in stillbirth. Research on stillbirth has not been afforded the same attention as other areas of medical research. As a result, the reasons for racial disparities in, and the causes of, stillbirth remain unknown;
- e. Stillbirth is a traumatic event and its impact on families, who often need counseling and other support services after experiencing a stillbirth, has not be adequately researched;
- [c.] <u>f.</u> 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 <u>are</u> 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 stillborn [child] <u>baby</u>;
- Id. g. 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 2 evaluating and classifying stillbirths, and to decreasing autopsy

- [e.] h. 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 the risk factors and causes of stillbirths, and thus more effectively inform strategies for their prevention; and
- 9 [f.] <u>i.</u> It is in the public interest to establish mandatory 10 protocols for health care facilities in the State, so that each [child] baby who is stillborn and each family experiencing a stillbirth in the 11 12 State is treated with dignity, each family experiencing a stillbirth 13 receives appropriate follow-up care provided in a sensitive manner, 14 and comprehensive data related to stillbirths are consistently 15 collected by the State and made available to researchers seeking to 16 prevent and reduce the incidence of stillbirths. It is also in the 17 public interest to establish a Stillbirth Resource Center, in 18 collaboration with the Department of Health, to educate the public 19 and health care professionals about stillbirths, to promote research 20 on treatments options to eliminate the preventable causes of 21 stillbirth, and provide supportive services to families experiencing a 22 stillbirth.
  - (cf: P.L.2013, c.217, s.1)

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- 25 2. Section 2 of P.L.2013, c.217 (C.26:8-40.28) is amended to 26 read as follows:
  - 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 the 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 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 or certified nurse midwife, per shift, who shall communicate the condition of the fetus to the mother and family, and inform and coordinate staff to assist with labor, delivery, postpartum, and postmortem procedures; provided that primary responsibility may be transferred to another licensed or certified health care professional, if the transfer is necessary to ensure that labor, delivery, postpartum, and postmortem care services are provided to the mother and family in a timely and compassionate
- 48 manner;

(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 stillborn [child] baby;
- (6) best practices to provide psychological and emotional support to the mother and family following a stillbirth, including referring to the stillborn [child] baby by name, and offering the family the opportunity to cut the umbilical cord, hold the stillborn [child] 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, and provisions for retaining the keepsakes for one year if the family chooses not to take them at discharge;
- (7) protocols to ensure that the physician or certified nurse midwife, per shift, assigned primary responsibility for communicating with the family, or, if primary responsibility is transferred to another health care professional pursuant to paragraph (1) of this subsection, the health care professional to whom primary responsibility is transferred, 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 member who is 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.
- c. The State Board of Medical Examiners and the New Jersey
  Board of Nursing shall require physicians and nurses, respectively,
  to adhere to the policies and procedures prescribed in subsection a.
  of this section.
- 47 (cf: P.L.2013, c.217, s.2)

3. (New section) The Commissioner of Health, in consultation with the "Stillbirth Resource Center" established pursuant to section , c. (C. ) (pending before the Legislature as this bill), shall develop a program, no later than 180 days after the effective date of this act, to educate the public and health care professionals about stillbirths and to promote research on treatment options to eliminate the preventable causes of stillbirth. program shall:

- a. include a toll-free, peer support telephone helpline to respond to calls from families experiencing a stillbirth, and refer such families to, and provide informational resources on, bereavement support and counseling services, including, but not limited to, information on national organizations that advocate for and provide support to families experiencing a stillbirth, funeral homes, photographers, and other businesses and organizations that provide financial assistance to families throughout the bereavement process;
- b. study common trends associated with, and conduct research studies focusing on, the risk factors and causes of stillbirth;
- c. identify and promote the use of evidence-based best practices and standards in providing prenatal care to pregnant women to improve fetal and maternal outcomes; and
- d. establish and administer an education and training program, which shall include the preparation and dissemination of literature on techniques to prevent and reduce the incidence of stillbirth, targeted to specific groups of persons who interact with families experiencing a stillbirth, including, but not limited to, public health nurses, emergency room physicians and nurses, emergency medical services personnel, forensic pathologists, hospital pathologists, obstetricians, gynecologists, neonatologists, registered nurses, practical nurses, advanced practice nurses, family physicians, midwives, maternal health experts, and social workers. The education and training program shall include:
- (1) training on the nature and causes of stillbirth, how to respond to families experiencing a stillbirth, including during the bereavement process; the protocols used by hospitals and health care professionals during labor, delivery, postpartum, and postmortem when a stillbirth occurs; the importance of autopsy records and placental and postmortem evaluations; and best practices in providing care to families prior to and during subsequent pregnancies after a stillbirth; and
- (2) a risk reduction and prevention education component to inform the public on the causes, and ways to prevent and reduce the incidence of, stillbirth, and to provide pregnant women and women who may become pregnant with educational material and other resources on how to improve fetal and maternal outcomes after a stillbirth.

- 4. (New section) a. The Commissioner of Health shall establish a "Stillbirth Resource Center" within a State medical school no later than 180 days after the effective date of this act. The Stillbirth Resource Center shall, in coordination with the Department of Health, serve as a technical advisory center, administer the program educating the public and health care professionals about stillbirths developed pursuant to section 3 of P.L. (C. , c. ) (pending before the Legislature as this bill), and offer other supportive services that may be necessary to assist families who have The commissioner shall forward experienced a stillbirth. information collected under the fetal death evaluation protocol established pursuant to section 3 of P.L.2013, c.217 (C.26:8-40.29) to the center, on a bi-monthly basis, so that the center may provide bereavement support services and conduct research on stillbirth pursuant to the provisions of this act.
  - b. The center shall:

- (1) develop a voluntary stillbirth reporting process, pursuant to which the mother or family who has experienced a stillbirth, or the mother's designee, will be permitted, but not required, to report to the center on individual cases of stillbirth. At a minimum, the process developed pursuant to this paragraph shall require the center to:
- (a) ask the department to post on its Internet website a hyperlink, a toll-free telephone number, and an email address, each of which may be used for the voluntary submission of public reports of stillbirths; and
- (b) publicize the availability of these resources to professional organizations, community organizations, social service agencies, health care facilities, and members of the public;
- (2) develop a process, in consultation with the Department of Health, pursuant to which the center will contact the family of a stillborn baby, if consent is obtained from the family, to offer information on the bereavement support services it provides pursuant to paragraph (4) of this subsection;
- (3) maintain a list of bereavement support groups, bereavement therapists, and counseling services, by location and county, and make the list available to the public through the Department of Health's Internet website; and
- (4) provide bereavement support services to families who have experienced a stillbirth. The support services shall include, but shall not be limited to:
- (a) the development of an informational pamphlet to be given to a family experiencing a stillbirth that includes information about the toll-free telephone helpline established pursuant to subsection a. of section 3 of P.L. , c. (C. ) (pending before this Legislature as this bill) and the list maintained by the center pursuant to paragraph (3) of this subsection;
- 48 (b) a peer-to-peer support program led by parents who have 49 experienced a stillbirth, are familiar with the psychosocial needs of

- a family experiencing a stillbirth, and can provide support immediately after a stillbirth and guidance during the bereavement process; and
  - (c) the organization of events and activities that provide support to families who have experienced a stillbirth.
  - c. The center shall maintain a record of all reports of stillbirths that are forwarded by the department pursuant to subsection a. of this section or that are submitted thereto through the reporting process established by the center pursuant to paragraph (1) of subsection b. of this section, so that the center may:
  - (1) provide bereavement support services pursuant to paragraph(4) of subsection b. of this section;
    - (2) conduct research on stillbirth and its effects on families; and
  - (3) propose and assist in the implementation of policies and procedures to improve the delivery of health care and other support services to women experiencing stillbirth and their families.
  - d. The center may access information from certificates of fetal death and certificates of birth resulting in stillbirth contained in the New Jersey Vital Information Platform maintained by the Department of Health, for the purpose of research on, and to identify current trends in the incidence of, stillbirth.
  - e. The center shall apply for, receive, and accept, from any federal, State, or other public or private source, grants, loans, or other moneys that are made available for, or in aid of, the center's authorized purposes, or that are made available to assist the center in carrying out its duties and responsibilities under this act.
  - 5. There is appropriated annually \$2,500,000 from the General Fund to the Department of Health to support the creation of the center and fund the database established or updated pursuant to the provisions of section 4 of P.L.2013, c217 (C.26:8-40.30).
  - 6. The Commissioner of Health shall adopt, pursuant to the provisions of the "Administrative Procedure Act," P.L.1968, c.410 (C.52:14B-1 et seq.), rules and regulations necessary to effectuate the purposes of this act.
  - 7. This act shall take effect on the first day of the sixth month next following the date of enactment, except that the Commissioner of Health may take any anticipatory administrative action in advance as shall be necessary for the implementation of this act.

#### STATEMENT

This bill amends the "Autumn Joy Stillbirth Research and Dignity Act," P.L.2013, c.217 (C.26:8-40.27 et seq.), to expand the list of health care professionals who may be assigned primary responsibility for communicating with a mother and family

concerning the status of a fetus when a stillbirth occurs, as well as primary responsibility for informing and coordinating staff to assist with labor, delivery, and postpartum procedures.

 Current law requires that a physician be assigned primary responsibility to provide these services and carry out these duties. This bill provides that a certified nurse midwife may also be assigned this primary responsibility, and that the physician or nurse midwife may transfer these responsibilities to another licensed or certified health care professional, if the transfer is necessary to ensure that labor, delivery, postpartum, and postmortem care services are provided to the mother and family in a timely and compassionate manner.

The bill also amends the "Autumn Joy Stillbirth Research and Dignity Act," to require the Department of Health (DOH), in consultation with the "Stillbirth Resource Center" established under the bill, to develop a program to educate the public and health care professionals about stillbirths and to promote research on treatment options to eliminate the preventable causes of stillbirth. The program would be developed no later than 180 after the effective date of the bill.

Under the bill's provisions, the program would: include a toll-free, peer support telephone helpline to respond to calls from families experiencing a stillbirth and refer such families to, and provide informational resources on, bereavement support and counseling services; study the risk factors and causes associated with stillbirth; identify and promote the effectiveness of evidence-based best practices and standards in providing prenatal care to pregnant women to improve fetal and maternal outcome; and establish and administer a stillbirth education and training program, including the preparation and dissemination of literature on techniques to prevent and reduce the incidence of stillbirth.

The training and education program would be targeted to specific groups of persons who interact with families experiencing a stillbirth, including certain health care professionals, as outlined in the bill, midwives, maternal health experts, and social workers, and would include: training on the nature and causes of stillbirth; how to respond to families experiencing a stillbirth; the protocols used by hospitals and health care professionals during labor, delivery, postpartum, and postmortem when a stillbirth occurs; the importance of autopsy records and placental and postmortem evaluations; best practices in providing care to families prior to and during subsequent pregnancies after a stillbirth; and a risk reduction and prevention education component to inform the public and pregnant women on the causes, and ways to prevent and reduce the incidence, of stillbirth, and how to improve fetal and maternal outcomes after a stillbirth.

The bill also requires the Commissioner of Health to establish the "Stillbirth Resource Center" in a State medical school selected by the commissioner no later than 180 days after the effective date of the bill. The center would, in coordination with DOH, serve as a technical advisory center, administer the program established under the bill to educate the public and health care professionals about stillbirths, and offer other supportive services that may be necessary to assist families who have experienced a stillbirth.

The commissioner is required to forward to the center the information collected under the fetal death evaluation protocol established pursuant to section 3 of P.L.2013, c.217 (C.26:8-40.29) on a bi-monthly basis so the center can provide bereavement support services and conduct research pursuant to the bill.

The provisions of the bill stipulate that the center would: develop a voluntary stillbirth reporting process that would allow a mother, family member, or the mother's designee, to report on individual cases of stillbirth; take appropriate action to ensure that any certificate of fetal death is prepared in accordance with, and contains information that satisfies the provisions of, P.L.2013, c.217 (C.26:8-40.27 et seq.); ask the DOH to post on its Internet website a hyperlink, a toll-free telephone number, and an email address, each of which would be used for the voluntary submission of public reports of stillbirths; publicize the availability of these resources to professional organizations, community organizations, social service agencies, health care facilities, and members of the public; develop a process, in consultation with DOH, allowing the center to contact families who have experienced a stillbirth to offer information on the bereavement support services provided by the center; maintain a list of bereavement support groups and counseling services, by location and county, and make the information available to the public; and provide bereavement support services to families who have experienced a stillbirth.

The center is required to keep a record of all reports of stillbirths that are forwarded by DOH or submitted through the reporting process established by the center, so that it can: provide bereavement support services; conduct research on stillbirth and its effects on families; and propose and assist in the implementation of policies and procedures to improve the delivery of health care and other support services to women experiencing stillbirth and their families.

The center will be authorized to access information from certificates of fetal death and certificates of birth resulting in stillbirth contained in the DOH's New Jersey Vital Information Platform for the purpose of research on, and to identify current trends in the incidence of, stillbirth.

The center would apply for, receive, and accept, from any federal, State, or other public or private source, grants, loans, or other moneys that are made available for, or in aid of, the center's authorized purposes, or that are made available to assist the center in carrying out its duties and responsibilities

The bill also provides for an annual appropriation of \$2,500,000, from the General Fund to DOH to support the creation of the center

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- and fund the database established or updated pursuant to the
- 2 provisions of section 4 of P.L.2013, c217 (C.26:8-40.30).