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STATE OF NEW JERSEY

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Sponsored by:
Senator LORETTA WEINBERG
District 37 (Bergen)
Senator DAWN MARIE ADDIEGO
District 8 (Atlantic, Burlington and Camden)

Co-Sponsored by:
Senators Corrado, Ruiz, T.Kean and Pou

SYNOPSIS

Establishes “Stillbirth Resource Center” and regional Fetal and Infant Mortality Review Committee, and programs for the prevention and reduction of incidences of stillbirth; expands list of professionals authorized to provide stillbirth-related care.

CURRENT VERSION OF TEXT

As reported by the Senate Budget and Appropriations Committee on June 17, 2021, with amendments.

(Sponsorship Updated As Of: 6/21/2021)

AN ACT establishing the "Stillbirth Resource Center [2]**[**,**]**[2] " [2]and Fetal Infant Death Review Committee,[2] amending P.L.2013, c.217, [1]and[1] supplementing Title 26 of the Revised Statutes [1]**[**, and making an appropriation**]**[1] .

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 completed weeks of pregnancy, excluding induced terminations of pregnancies occurring after 20 weeks, or involve the unintended death of fetuses weighing 350 or more grams when no prenatal obstetric dating is available;

b. Stillbirths are not rare and are one of the most common adverse pregnancy outcomes experienced by pregnant [1]**[**women**]** persons[1] . **[**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 [1]**[**women**]** people[1] experience stillbirth at more than three times the rate of Caucasian [1]**[**women**]** people[1], 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.**]** f. 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 are 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**]** baby ;

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:
[1]Senate SHH committee amendments adopted May 6, 2021.
[2]Senate SBA committee amendments adopted June 17, 2021.

[d.**]** 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 evaluating and classifying stillbirths, and to decreasing autopsy rates;

[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

[f.**]** i. It is in the public interest to establish mandatory protocols for health care facilities in the State, so that each **[**child**]** baby 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. It is also in the public interest to establish a Stillbirth Resource Center, in collaboration with the Department of Health, to educate the public and health care professionals about stillbirths, to promote research on treatments options to eliminate the preventable causes of stillbirth, and provide supportive services to families experiencing a stillbirth.

(cf: P.L.2013, c.217, s.1)

2. Section 2 of P.L.2013, c.217 (C.26:8-40.28) is amended to 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, **[2]**, the regional Fetal and Infant Mortality Review Committee established pursuant to section 5 of P.L. , c. (C.) (pending before the Legislature as this bill),**[2]** 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 **[2]**labor, delivery, and**[2]** birthing **[2][**and newborn care**]**[2] 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 **[1][**mother**]** gestational parent**[1]** 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 ¹[mother] gestational parent¹ and family in a timely and compassionate 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 ¹[one-on-one nursing care] one designated nurse as the primary point of contact¹ for the duration of the ¹[mother's] gestational parent's¹ stay at the facility;

(5) training of physicians, nurses, psychologists, and social workers to ensure that information is provided to the ¹[mother] gestational parent¹ 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 ¹[mother] gestational parent¹ 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.

(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 4 of P.L. , c. (C.) (pending before the Legislature as this bill) [2], the Fetal and Infant Mortality Review Committee established pursuant to section 5 of P.L. , c. (C.) (pending before the Legislature as this bill),[2] [1]and The 2 Degrees Foundation[1] , shall develop a program, no later than 180 days after the effective date of [2][this act] P.L. , c. (C.) (pending before the Legislature as this bill)[2] , 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 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 [1][women] persons[1] to improve fetal and [1][maternal] gestational parent[1] outcomes; and

d. establish and administer an education [2][and training][2] 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, [1][maternal] gestational parental[1] health experts, and social workers. The education [2][and training][2] 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 [1][women] persons[1] and [1][women] persons[1] who may become pregnant with educational [1][material] materials[1] and other resources on how to improve fetal and [1][maternal] gestational parental[1] 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 [2][this act] P.L. , c. (C.) (pending before the Legislature as this bill)[2] . 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 experienced a stillbirth. The commissioner shall forward 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. [2]The center may work with the maternal health consortia or any other organization to fulfill the requirements of this section.[2]

b. The center shall:

(1) develop a voluntary stillbirth reporting process, pursuant to which the [1][mother] gestational parent[1] or family who has experienced a stillbirth, or the [1][mother's] gestational parent's[1] 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; **[2]**[and]**[2]**

(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;

(b) a peer-to-peer support program led by parents who have 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 **[2]**;

(5) work with the Governor's office to coordinate all efforts and strategies on research and interventions to eliminate the preventable causes of stillbirth, and to eliminate racial and ethnic disparities in the State related to the rates and causes of fetal and infant death; and

(6) collaborate and exchange data with the Fetal and Infant Mortality Review Committee established pursuant to section 5 of P.L. , c. (C.) (pending before the Legislature as this bill) to develop strategies, interventions, and initiatives to eliminate the preventable causes of stillbirth, and eliminate racial and ethnic disparities in the State related to the rates and causes of fetal and infant death**[2]** .

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. [2]The center shall employ an executive director, a program manager, and any other personnel as shall be authorized by the Commissioner of Health. The Department of Health shall provide such administrative staff support to the center as shall be necessary for the center to carry out its duties. The executive director shall be appointed by, and shall serve at the pleasure of, the Commissioner of Health during the commissioner's term of office and until the appointment and qualification of the executive director's successor.

f.[2] 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.

[2]5. (New section) a. (1) There is established in the Department of Health the regional Fetal and Infant Mortality Review Committee, which shall be tasked with annually reviewing and reporting on fetal and infant death rates and the causes of fetal and infant deaths in the State, and providing recommendations to improve fetal and infant outcomes and maternal care to reduce fetal and infant death rates in New Jersey.

(2) The Fetal and Infant Mortality Review Committee established pursuant to this section shall replace and supersede the Fetal Infant Mortality Review teams currently constituted within the Partnership for Maternal and Child Health of Northern New Jersey, the Central Jersey Family Health Consortium, and the Southern New Jersey Perinatal Cooperative.

b. The committee shall include a program manager, a clinical nurse case abstractor; a maternal child health epidemiologist, and a case abstraction manager, and shall also include one maternal child health epidemiologist to review cases of fetal and infant death in each of the northern, central, and southern regions of the State. For the purposes of this section:

(1) The northern region of the State shall include Bergen, Essex, Hudson, Morris, Sussex, Union, and Warren counties;

(2) The central region of the State shall include Hunterdon, Mercer, Middlesex, Monmouth, Ocean, and Somerset counties; and

(3) The southern region of the State shall include Atlantic, Camden, Cape May, Cumberland, Gloucester, and Salem counties.

c. The committee shall have the power to:

(1) carry out any power, duty, or responsibility expressly granted by sections 5 through 9 of P.L. , c. (C.) (pending before the Legislature as this bill);

(2) adopt, amend, or repeal suitable bylaws for the management of its affairs;

(3) maintain an office at such place or places as it may designate;

(4) 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 committee's authorized purposes, or that are made available to assist the committee in carrying out its powers, duties, and responsibilities under sections 5 through 9 of P.L. , c. (C.) (pending before the Legislature as this bill);

(5) enter into any and all agreements or contracts, execute any and all instruments, and do and perform any and all acts or things necessary, convenient, or desirable to further the purposes of the committee;

(6) call to its assistance, and avail itself of the services of, such employees of any State entity or local government unit as may be required and available for the committee's purposes;

(7) review and investigate reports of fetal and infant deaths, conduct witness interviews, hear testimony provided under oath at public or private hearings on any material matter, and request, or compel through the issuance of a subpoena, the attendance of relevant witnesses and the production of relevant documents, records, and papers;

(8) solicit and consider public input and comment on the committee's activities; and

(9) identify, and promote the use of, best practices in prenatal, postnatal, and general maternal care, and encourage and facilitate cooperation and collaboration among health care facilities, health care professionals, administrative agencies, and local government units for the purposes of ensuring the provision of the highest quality prenatal, postnatal, and general maternal care throughout the State.[2]

[2]6. (New section) a. The Fetal and Infant Mortality Review Committee shall develop a mandatory fetal death reporting process, pursuant to which health care practitioners, medical examiners, hospitals, prenatal care clinics and providers, birthing centers, and other relevant professional actors and health care facilities will be required to confidentially report to the Department of Health on individual cases of fetal or infant death.

b. The Department of Health shall maintain a record of all reports of fetal and infant deaths that are submitted to the department through the reporting processes that are established pursuant to subsection a. of this section. The department shall also

ensure that a copy of each such report of fetal or infant death is promptly forwarded to the Fetal and Infant Mortality Committee, so that the committee may properly execute its investigatory functions and other duties and responsibilities under sections 5 through 9 of P.L. , c. (C.) (pending before the Legislature as this bill).[2]

[2]7. (New section) a. Upon receipt of a report of a fetal or infant death that has been forwarded to the Fetal and Infant Mortality Review Committee pursuant to subsection b. of section 6 of P.L. , c. (C.) (pending before the Legislature as this bill), the committee shall investigate the reported case in accordance with the provisions of this section. In conducting the investigation, the committee shall consider:

(1) the information contained in the forwarded report of the fetal or infant death;

(2) any relevant information contained in the deceased fetus' or infant's autopsy report or death record, or in a certificate of fetal death for the deceased fetus or infant, or in any other vital records pertaining to the deceased fetus or infant or the gestational parent;

(3) any relevant information contained in the medical records of the gestational parent experiencing the fetal or infant death, including:

(a) records related to the health care that was provided to the gestational parent prior to becoming pregnant;

(b) records related to the gestational parent's prenatal and postnatal care, labor and delivery care, emergency room care, care provided to the deceased fetus or infant, and any other care delivered up until the time of the fetal or infant death; and

(c) the gestational parent's hospital discharge records and all hospital records related to the deceased fetus or infant, including all emergency room and outpatient records for the gestational parent from the one-year period following the end of the pregnancy;

(4) information obtained through the oral and written interviews of individuals who were directly involved in the care of the gestational parent either during, or immediately following, the pregnancy and the fetal or infant death, including interviews with relevant health care practitioners, mental health care practitioners, and social service providers, and, as deemed to be appropriate and necessary, interviews with the gestational parent's family members;

(5) background information about the gestational parent who experienced the fetal or infant death, including, but not limited to, information regarding the gestational parent's age, race, and socioeconomic status; and

(6) any other information that may shed light on the fetal or infant death, including, but not limited to, reports from social service or child welfare agencies.

b. At the conclusion of an investigation conducted pursuant to this section, the committee shall prepare a case summary, which

shall include the committee's findings with regard to the cause of, or the factors that contributed to, the fetal or infant death, and recommendations for actions that should be undertaken, or policies that should be implemented, to mitigate or eliminate those factors and causes in the future. Any case summary prepared pursuant to this subsection shall omit the identifying information of the deceased fetus or infant and the family members of the gestational parent and the deceased fetus or infant, the health care providers who provided care, and the hospitals where care was provided.

c. The committee may present its findings and recommendations on each individual case, or on groups of individual cases, as the committee deems appropriate, to the health care facility or facilities where relevant care was provided, and to the individual health care practitioners who provided such care, or to any relevant professional organization, for the purposes of instituting or facilitating policy changes, educational activities, or improvements in the quality of care provided; or for the purposes of exploring, facilitating, or establishing regional projects or other collaborative projects that are designed to reduce instances of fetal and infant death.[2]

[2]8. (New section) a. (1) Except as otherwise provided by subsection b. of this section, all proceedings and activities of the Fetal Infant Death Review Committee; all opinions of the members of the committee which are formed as a result of the committee's proceedings and activities; and all records obtained, created, or maintained by the committee, including written reports and records of interviews or oral statements, shall be confidential, and shall not be subject to public inspection, discovery, subpoena, or introduction into evidence in any civil, criminal, legislative, or other proceeding.

(2) In no case shall the committee disclose any personally identifiable information to the public, or include any personally identifiable information in a case summary or report that is prepared pursuant to P.L. , c. (C.) (pending before the Legislature as this bill).

(3) Members of the committee shall not be questioned in any civil, criminal, legislative, or other proceeding regarding information that has been presented in, or opinions that have been formed as a result of, a meeting or communication of the committee; however, nothing in this paragraph shall prohibit a committee member from being questioned, or from testifying, in relation to publicly available information or information that was obtained independent of the member's participation on the committee.

b. Nothing in this section shall be deemed to prohibit the committee from publishing, or from otherwise making available for public inspection, statistical compilations or reports that are based on confidential information, provided that those compilations and

reports do not contain personally identifying information or other information that could be used to identify the individuals concerned.[2]

[2]9. (New section) a. On an annual basis, and using the death records that have been filed during the preceding year, the Fetal Infant Death Review Committee shall work collaboratively with the Still Birth Resource Center established pursuant to section 4 of P.L. , c. (C.) (pending before the Legislature as this bill), and any research university, Department of Health epidemiologist, or other appropriate Department of Health staff, to identify:

(1) the total number of fetal and infant deaths that have occurred in the State during the year, and during each quarter of the year;

(2) the average Statewide rate of fetal and deaths occurring during the year;

(3) the number and percentage of fetal and infant deaths that occurred during the year in each of the northern, central, and southern regions of the State;

(4) the areas of the State where the rates of fetal and infant death are significantly higher than the Statewide average; and

(5) the rate of racial disparities in fetal and infant deaths occurring on a Statewide and regional basis.

b. The results of the annual analysis that is conducted pursuant to subsection a. of this section shall be posted at a publicly accessible location on the Internet website of the Department of Health, and shall also be promptly forwarded to the Stillbirth Resource Center.[2]

[1][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).][1]

[1][6.][2][5.[1]] 10.[2] 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.

[1][7.][2][6.[1]] 11.[2] 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.