

AN ACT requiring the reporting of children's sudden cardiac events and supplementing Title 26 of the Revised Statutes.

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

1. This act shall be known and may be cited as the "Children's Sudden Cardiac Events Reporting Act."

2. The Legislature finds and declares that:

a. A great deal of information is needed by schools and communities throughout New Jersey in order to improve the survival of children who experience sudden cardiac events;

b. The collection of relevant data and the documentation of sudden cardiac event outcomes are essential for policymakers and health care professionals to determine the most effective allocation of personnel, training, equipment, and resources to save the greatest number of lives; and

c. It is in the public interest to implement such measures as are necessary to provide for the collection of children's sudden cardiac event data and to establish a Statewide database that will inform the efforts of schools, families, policymakers, and health care professionals to improve children's sudden cardiac event prevention and survival.

3. As used in this act:

"Child" means a child who is at least 12 years of age and no more than 19 years of age.

"Commissioner" means the Commissioner of Health and Senior Services.

"Department" means the Department of Health and Senior Services.

"Health care professional" means a physician or registered professional nurse licensed to practice in this State.

"Registry" means the Children's Sudden Cardiac Events Registry established pursuant to this act.

"Sudden cardiac event" means a death or near death due to hypertrophic cardiomyopathy, sudden cardiac arrest, or other life-threatening cardiac condition as specified by regulation of the commissioner.

4. a. A health care professional who makes the diagnosis of a sudden cardiac event in a child, or who makes the actual determination and pronouncement of death for a child, as applicable, shall report the sudden cardiac event to the department on a form and in a manner prescribed by the commissioner.

b. The report shall be in writing and shall include the name and address of the health care professional submitting the report, the name, age, and address of the child, and other pertinent information as may be required by the commissioner; except that, if the child's

parent or guardian objects to the reporting of the child's condition for any reason, the report shall not include any information that could be used to identify the child.

c. The commissioner shall specify procedures for the health care professional to inform the child's parent or guardian of the requirements of subsections a. and b. of this section and the purpose served by including this information in the registry, as well as the parent's or guardian's right to refuse to permit the reporting of any information that could be used to identify the child.

5. a. The department shall establish and maintain an up-to-date Children's Sudden Cardiac Events Registry, which shall include a record of all sudden cardiac events that are reported pursuant to this act and any other information that the department deems relevant and appropriate in order to effectuate the purposes of this act.

b. The reports made pursuant to this act shall be used only by the department and other agencies as may be designated by the commissioner, and shall not otherwise be divulged or made public so as to disclose the identity of any person to whom they relate. To that end, the reports shall not be included under materials available to public inspections pursuant to P.L.1963, c.73 (C.47:1A-1 et seq.) or P.L.2001, c.404 (C.47:1A-5 et al.).

c. A health care professional providing information to the department pursuant to this act shall not be deemed to be, or held liable for, divulging confidential information.

d. Nothing in this act shall be construed to compel a child to submit to medical or health examination or supervision by the department.

6. a. The commissioner shall establish the Children's Sudden Cardiac Events Review Board in the department.

(1) The purpose of the board shall be to review and evaluate the information reported to the department pursuant to this act, and to study any other data, which the board shall seek and as may be made available to it to supplement the reported information, with respect to children diagnosed with cardiac conditions or reported to have had a sudden cardiac event in this State.

(2) The board shall make note of such factors as the age, gender, and ethnicity of each child, and the location of each sudden cardiac event, in its review of any information received by the board.

(3) The board may share its findings with other recognized entities that collect nationwide data on sudden cardiac events, except that the board shall not disclose to any person or entity outside the department any information that could be used to identify a child.

b. The board shall consist of nine members as follows:

(1) the commissioner and the Commissioners of Children and Families and Education, or their designees, who shall serve ex officio; and

(2) six public members to be appointed by the commissioner as follows: one person who represents the American Heart Association; one person who represents the American Academy of Pediatrics, New Jersey Chapter; one person who represents the American College of Cardiology; one person who represents the New Jersey State School Nurses Association; one person who represents the New Jersey State Interscholastic Athletic Association; and one person who represents the New Jersey Academy of Family Physicians.

c. The public members of the board shall serve for a term of three years, except that of the public members first appointed, three shall serve for a term of two years, and three shall serve for a term of three years. The public members shall serve without compensation but shall be eligible for reimbursement for the necessary and reasonable expenses incurred in the performance of their official duties, within the limits of funds appropriated or otherwise made available for this purpose. Vacancies in the membership of the board shall be filled in the same manner as the original appointments were made.

d. The public members shall select from among themselves an individual to serve as chairperson of the board, who shall be responsible for the coordination of all activities of the board and shall provide the technical assistance needed to execute the duties of the board.

e. The board shall be entitled to call to its assistance and avail itself of the services of employees of any State, county, or municipal department, board, bureau, commission, or agency as it may require and as may be available for the purposes of carrying out its responsibilities.

7. The commissioner, pursuant to the "Administrative Procedure Act," P.L.1968, c.410 (C.52:14B-1 et seq.), shall adopt rules and regulations to effectuate the purposes of this act.

8. This act shall take effect on the first day of the seventh month next following the date of enactment, but the commissioner 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 as the "Children's Sudden Cardiac Events Reporting Act," requires the reporting of children's sudden cardiac events and establishes a Statewide database as a repository for the reported information.

The bill provides specifically as follows:

- A health care professional (a physician or registered professional nurse licensed in New Jersey) who makes the diagnosis of a

sudden cardiac event in a child 12-19 years of age or who makes the actual determination and pronouncement of death for a child, as applicable, is to report the sudden cardiac event to the Department of Health and Senior Services (DHSS) on a form and in a manner prescribed by the Commissioner of Health and Senior Services.

- The bill defines “sudden cardiac event” to mean a death or near death due to hypertrophic cardiomyopathy, sudden cardiac arrest, or other life-threatening cardiac condition as specified by regulation of the commissioner.
- The report is to be in writing and include the name and address of the health care professional submitting the report, the name, age, and address of the child, and other pertinent information as may be required by the commissioner; except that, if the child’s parent or guardian objects to the reporting of the child’s condition for any reason, the report is not to include any information that could be used to identify the child.
- The commissioner is to specify procedures for the health care professional to inform the child’s parent or guardian of the requirements of the bill and the purpose served by including this information in the registry, as well as the parent’s or guardian’s right to refuse to permit the reporting of any information that could be used to identify the child.
- The bill establishes the Children’s Sudden Cardiac Events Registry in DHSS, which is to include a record of all sudden cardiac events reported pursuant to the bill and any other information that DHSS deems relevant and appropriate. The reports made pursuant to the bill are to be used only by DHSS and other agencies as may be designated by the commissioner, and are not to otherwise be divulged or made public so as to disclose the identity of any person to whom they relate.
- A health care professional providing information to DHSS pursuant to the bill is not liable for divulging confidential information.
- The commissioner is to establish a nine-member Children’s Sudden Cardiac Events Review Board in DHSS. The purpose of the board is to review and evaluate the information reported to DHSS, and to study any other data, which the board is to seek and as may be made available to it to supplement the reported information, with respect to children diagnosed with cardiac conditions or reported to have had a sudden cardiac event. The board is to make note of such factors as the age, gender, and ethnicity of each child, and the location of each sudden cardiac event, in its review of any information received by the board. The board may share its findings with other recognized entities that collect nationwide data on sudden cardiac events, but is prohibited from disclosing to any person or entity outside DHSS any information that could be used to identify a child.

- The members of the board will be: the commissioner and the Commissioners of Children and Families and Education, or their designees, as ex officio members; and six public members appointed by the commissioner who represent the American Heart Association, the New Jersey Chapter of the American Academy of Pediatrics, the American College of Cardiology, the New Jersey State School Nurses Association, the New Jersey State Interscholastic Athletic Association, and the New Jersey Academy of Family Physicians.
- The public members of the board are to serve for a term of three years, but of the public members first appointed, three are to serve for a term of two years and three for a term of three years. The public members are to serve without compensation but may be reimbursed for expenses from any available funds. The public members are to select a board chairperson from among themselves.

The bill takes effect on the first day of the seventh month after enactment, but authorizes the Commissioner of Health and Senior Services to take prior administrative action as necessary for implementation.

“Children’s Sudden Cardiac Events Reporting Act.”