



**FLOOR AMENDMENT STATEMENT:** No

**LEGISLATIVE FISCAL ESTIMATE:** Yes

**VETO MESSAGE:** No

**GOVERNOR'S PRESS RELEASE ON SIGNING:** No

**FOLLOWING WERE PRINTED:**

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**REPORTS:** No

**HEARINGS:** No

**NEWSPAPER ARTICLES:** Yes

"Chris Christie Signs Cardiac Kids Bill into Law," New Jersey 101.5, 8-20-13

LAW/KR

Title 26.  
Chapter 2H.  
Part VIII. (New)  
Children's Sudden  
Cardiac Events  
Reporting Act.  
§§1-7 -  
C.26:2H-141 to  
26:2H-147  
§8 - Note

P.L.2013, CHAPTER 143, *approved August 19, 2013*  
Senate, No. 1911 (*Second Reprint*)

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

3

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

6

7 1. This act shall be known and may be cited as the “Children’s  
8 Sudden Cardiac Events Reporting Act.”

9

10 2. The Legislature finds and declares that:

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

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

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

25

26 3. As used in this act:

27 “Child” means a child who is <sup>1</sup>**[at least 12 years of age and no**  
28 **more than] under<sup>1</sup> 19 years of age.**

29 “Commissioner” means the Commissioner of Health <sup>2</sup>**[and**  
30 **Senior Services] <sup>2</sup>.**

**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:**

<sup>1</sup>**Senate SHH committee amendments adopted June 18, 2012.**

<sup>2</sup>**Senate SBA committee amendments adopted October 1, 2012.**

1 “Department” means the Department of Health <sup>2</sup>and Senior  
2 Services<sup>2</sup>.

3 “Health care professional” means a physician or registered  
4 professional nurse licensed to practice in this State.

5 “Registry” means the Children’s Sudden Cardiac Events Registry  
6 established pursuant to this act.

7 “Sudden cardiac event” means a death or <sup>1</sup>near death due to  
8 hypertrophic cardiomyopathy, sudden cardiac arrest, or other life-  
9 threatening cardiac condition as specified by regulation of the  
10 commissioner] aborted death due to a cardiac arrhythmia resulting  
11 in loss of consciousness requiring cardiopulmonary resuscitation,  
12 defibrillation, or other advanced life support measures to regain  
13 normal heart function<sup>1</sup>.

14

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

20 b. The report shall be in writing and shall include the name and  
21 address of the health care professional submitting the report, the  
22 name, age, and address of the child, and other pertinent information  
23 as may be required by the commissioner; except that, if the child’s  
24 parent or guardian objects to the reporting of the child’s condition  
25 for any reason, the report shall not include any information that  
26 could be used to identify the child.

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

33

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

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

- 1 c. A health care professional providing information to the  
2 department pursuant to this act shall not be deemed to be, or held  
3 liable for, divulging confidential information.
- 4 d. Nothing in this act shall be construed to compel a child to  
5 submit to medical or health examination or supervision by the  
6 department.  
7
- 8 6. a. The commissioner shall establish the Children's Sudden  
9 Cardiac Events Review Board in the department.
- 10 (1) The purpose of the board shall be to review and evaluate the  
11 information reported to the department pursuant to this act, and to  
12 study any other data, which the board shall seek and as may be  
13 made available to it to supplement the reported information, with  
14 respect to children diagnosed with cardiac conditions or reported to  
15 have had a sudden cardiac event in this State.
- 16 (2) The board shall make note of such factors as the age, gender,  
17 and ethnicity of each child, and the location of each sudden cardiac  
18 event, in its review of any information received by the board.
- 19 (3) The board may share its findings with other recognized  
20 entities that collect nationwide data on sudden cardiac events,  
21 except that the board shall not disclose to any person or entity  
22 outside the department any information that could be used to  
23 identify a child.
- 24 b. The board shall consist of <sup>1</sup>~~nine~~ 11<sup>1</sup> members as follows:
- 25 (1) the commissioner and the Commissioners of Children and  
26 Families and Education, or their designees, who shall serve ex  
27 officio; and
- 28 (2) <sup>1</sup>~~six~~ eight<sup>1</sup> public members to be appointed by the  
29 commissioner as follows: one person who represents the American  
30 Heart Association; one person who represents the American  
31 Academy of Pediatrics, New Jersey Chapter; one person who  
32 represents the American College of Cardiology; one person who  
33 represents the New Jersey State School Nurses Association; one  
34 person who represents the New Jersey State Interscholastic Athletic  
35 Association; one person who represents the Hypertrophic  
36 Cardiomyopathy Association; one person who represents the  
37 Athletic Trainers' Society of New Jersey;<sup>1</sup> and one person who  
38 represents the New Jersey Academy of Family Physicians.
- 39 c. The public members of the board shall serve for a term of  
40 three years, except that of the public members first appointed,  
41 <sup>1</sup>~~three~~ four<sup>1</sup> shall serve for a term of two years, and <sup>1</sup>~~three~~  
42 four<sup>1</sup> shall serve for a term of three years. The public members  
43 shall serve without compensation but shall be eligible for  
44 reimbursement for the necessary and reasonable expenses incurred  
45 in the performance of their official duties, within the limits of funds  
46 appropriated or otherwise made available for this purpose.

1 Vacancies in the membership of the board shall be filled in the  
2 same manner as the original appointments were made.

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

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

13

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

17

18 8. This act shall take effect on the first day of the seventh  
19 month next following the date of enactment, but the commissioner  
20 may take such anticipatory administrative action in advance thereof  
21 as shall be necessary for the implementation of this act.

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“Children’s Sudden Cardiac Events Reporting Act.”

**SENATE, No. 1911**

**STATE OF NEW JERSEY**  
**215th LEGISLATURE**

INTRODUCED MAY 14, 2012

**Sponsored by:**

**Senator FRED H. MADDEN, JR.**

**District 4 (Camden and Gloucester)**

**SYNOPSIS**

“Children’s Sudden Cardiac Events Reporting Act.”

**CURRENT VERSION OF TEXT**

As introduced.



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2

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

3

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

6

7 1. This act shall be known and may be cited as the “Children’s  
8 Sudden Cardiac Events Reporting Act.”

9

10 2. The Legislature finds and declares that:

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

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

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

25

26 3. As used in this act:

27 “Child” means a child who is at least 12 years of age and no  
28 more than 19 years of age.

29 “Commissioner” means the Commissioner of Health and Senior  
30 Services.

31 “Department” means the Department of Health and Senior  
32 Services.

33 “Health care professional” means a physician or registered  
34 professional nurse licensed to practice in this State.

35 “Registry” means the Children’s Sudden Cardiac Events Registry  
36 established pursuant to this act.

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

41

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

47 b. The report shall be in writing and shall include the name and  
48 address of the health care professional submitting the report, the



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1 name, age, and address of the child, and other pertinent information  
2 as may be required by the commissioner; except that, if the child's  
3 parent or guardian objects to the reporting of the child's condition  
4 for any reason, the report shall not include any information that  
5 could be used to identify the child.

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

12

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

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

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

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

32

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

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

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

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

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

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

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

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

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

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

34

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

38

39       8. This act shall take effect on the first day of the seventh  
40 month next following the date of enactment, but the commissioner  
41 may take such anticipatory administrative action in advance thereof  
42 as shall be necessary for the implementation of this act.

43

44

45

**STATEMENT**

46

47       This bill, which is designated as the “Children’s Sudden Cardiac  
48 Events Reporting Act,” requires the reporting of children’s sudden

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5

1 cardiac events and establishes a Statewide database as a repository  
2 for the reported information.

3 The bill provides specifically as follows:

- 4 • A health care professional (a physician or registered professional  
5 nurse licensed in New Jersey) who makes the diagnosis of a  
6 sudden cardiac event in a child 12-19 years of age or who makes  
7 the actual determination and pronouncement of death for a  
8 child, as applicable, is to report the sudden cardiac event to the  
9 Department of Health and Senior Services (DHSS) on a form  
10 and in a manner prescribed by the Commissioner of Health and  
11 Senior Services.
- 12 • The bill defines “sudden cardiac event” to mean a death or near  
13 death due to hypertrophic cardiomyopathy, sudden cardiac  
14 arrest, or other life-threatening cardiac condition as specified by  
15 regulation of the commissioner.
- 16 • The report is to be in writing and include the name and address  
17 of the health care professional submitting the report, the name,  
18 age, and address of the child, and other pertinent information as  
19 may be required by the commissioner; except that, if the child’s  
20 parent or guardian objects to the reporting of the child’s  
21 condition for any reason, the report is not to include any  
22 information that could be used to identify the child.
- 23 • The commissioner is to specify procedures for the health care  
24 professional to inform the child’s parent or guardian of the  
25 requirements of the bill and the purpose served by including this  
26 information in the registry, as well as the parent’s or guardian’s  
27 right to refuse to permit the reporting of any information that  
28 could be used to identify the child.
- 29 • The bill establishes the Children’s Sudden Cardiac Events  
30 Registry in DHSS, which is to include a record of all sudden  
31 cardiac events reported pursuant to the bill and any other  
32 information that DHSS deems relevant and appropriate. The  
33 reports made pursuant to the bill are to be used only by DHSS  
34 and other agencies as may be designated by the commissioner,  
35 and are not to otherwise be divulged or made public so as to  
36 disclose the identity of any person to whom they relate.
- 37 • A health care professional providing information to DHSS  
38 pursuant to the bill is not liable for divulging confidential  
39 information.
- 40 • The commissioner is to establish a nine-member Children’s  
41 Sudden Cardiac Events Review Board in DHSS. The purpose of  
42 the board is to review and evaluate the information reported to  
43 DHSS, and to study any other data, which the board is to seek  
44 and as may be made available to it to supplement the reported  
45 information, with respect to children diagnosed with cardiac  
46 conditions or reported to have had a sudden cardiac event. The  
47 board is to make note of such factors as the age, gender, and  
48 ethnicity of each child, and the location of each sudden cardiac

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- 1 event, in its review of any information received by the board.  
2 The board may share its findings with other recognized entities  
3 that collect nationwide data on sudden cardiac events, but is  
4 prohibited from disclosing to any person or entity outside DHSS  
5 any information that could be used to identify a child.
- 6 • The members of the board will be: the commissioner and the  
7 Commissioners of Children and Families and Education, or their  
8 designees, as ex officio members; and six public members  
9 appointed by the commissioner who represent the American  
10 Heart Association, the New Jersey Chapter of the American  
11 Academy of Pediatrics, the American College of Cardiology, the  
12 New Jersey State School Nurses Association, the New Jersey  
13 State Interscholastic Athletic Association, and the New Jersey  
14 Academy of Family Physicians.
  - 15 • The public members of the board are to serve for a term of three  
16 years, but of the public members first appointed, three are to  
17 serve for a term of two years and three for a term of three years.  
18 The public members are to serve without compensation but may  
19 be reimbursed for expenses from any available funds. The  
20 public members are to select a board chairperson from among  
21 themselves.
- 22 The bill takes effect on the first day of the seventh month after  
23 enactment, but authorizes the Commissioner of Health and Senior  
24 Services to take prior administrative action as necessary for  
25 implementation.

SENATE HEALTH, HUMAN SERVICES AND SENIOR  
CITIZENS COMMITTEE

STATEMENT TO

**SENATE, No. 1911**

with committee amendments

**STATE OF NEW JERSEY**

DATED: JUNE 18, 2012

The Senate Health, Human Services and Senior Citizens Committee reports favorably and with committee amendments Senate Bill No. 1911.

As reported, this bill, which is designated as the “Children’s Sudden Cardiac Events Reporting Act,” requires the reporting of children’s sudden cardiac events, establishes a Statewide database as a repository for the reported information, and requires the Commissioner of Health and Senior Services to establish a board to review the information.

Specifically, the bill requires that a physician or registered professional nurse licensed in New Jersey who makes the diagnosis of a sudden cardiac event in a child under 19 years of age or who makes the actual determination and pronouncement of death for a child, report that event to the Department of Health and Senior Services (DHSS) on a form and in a manner prescribed by the commissioner. The information is to include the name, age, and address of the child, unless the child’s parent or guardian objects, in which case no information is to be included that could be used to identify the child. The bill provides that a health care professional providing this information would not be liable for divulging confidential information.

The bill defines “sudden cardiac event” to mean a death or aborted death due to a cardiac arrhythmia resulting in loss of consciousness requiring cardiopulmonary resuscitation, defibrillation, or other advanced life support measures to regain normal heart function.

The bill also establishes the Children’s Sudden Cardiac Events Registry in DHSS. The registry would include a record of all sudden cardiac events reported to DHSS pursuant to the bill and other relevant information determined by DHSS. The reports are to be used only by DHSS and other agencies 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.

In addition, the bill directs the commissioner to establish an 11-member Children’s Sudden Cardiac Events Review Board in DHSS. The board is to review and evaluate the information reported to it, and

study any other relevant data respecting children diagnosed with cardiac conditions or reported to have had a sudden cardiac event. Membership of the board is to include: the commissioner and the Commissioners of Children and Families and Education, or their designees, as ex officio members; and eight 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; the Hypertrophic Cardiomyopathy Association; the Athletic Trainers' Society of New Jersey; and the New Jersey Academy of Family Physicians.

The bill takes effect on the first day of the seventh month after enactment.

The committee amendments change the definition of "child" to mean a child under 19 years of age and change the definition of "sudden cardiac event" to mean a death or aborted death due to a cardiac arrhythmia resulting in loss of consciousness requiring cardiopulmonary resuscitation, defibrillation, or other advanced life support measures to regain normal heart function. In addition, the amendments add two members to the Children's Sudden Cardiac Events Review Board: one person who represents the Hypertrophic Cardiomyopathy Association; and one person who represents the Athletic Trainers' Society of New Jersey.

# LEGISLATIVE FISCAL ESTIMATE

[First Reprint]

## SENATE, No. 1911 STATE OF NEW JERSEY 215th LEGISLATURE

DATED: SEPTEMBER 28, 2012

### SUMMARY

- Synopsis:** “Children’s Sudden Cardiac Events Reporting Act.”
- Type of Impact:** An expenditure increase.
- Agencies Affected:** Department of Health (DOH); possible costs to other State, county, and municipal agencies.

#### Office of Legislative Services Estimate

<b>Fiscal Impact</b>	<b><u>Year 1</u></b>
<b>State Cost</b>	Indeterminate Increase

- The bill will cause the Department of Health (DOH) to incur indeterminate costs in establishing and maintaining a Children’s Sudden Cardiac Events Registry.

### BILL DESCRIPTION

Senate Bill No 1911 (1R) of 2012, which is designated as the “Children’s Sudden Cardiac Events Reporting Act,” requires the reporting of children’s sudden cardiac events, establishes a Statewide database as a repository for the reported information, and requires the Commissioner of Health to establish a board to review the reported information.

Specifically, the bill requires that a physician or registered professional nurse licensed in New Jersey who makes the diagnosis of a sudden cardiac event in a child under 19 years of age, or who makes the actual determination and pronouncement of death for a child related to a sudden cardiac event, report that event to DOH on a form and in a manner prescribed by the commissioner. The information is to include the name, age, and address of the child, unless the child’s parent or guardian objects, in which case no information is to be included that could be used to identify the child.

The bill also establishes the Children’s Sudden Cardiac Events Registry in DOH. The registry would include a record of all sudden cardiac events reported to DOH pursuant to the bill

and other relevant information determined by DOH. The reports are to be used only by DOH and other agencies designated by the commissioner, and are otherwise not to be divulged or made public so as to disclose the identity of any person to whom they relate.

In addition, the bill directs the commissioner to establish an 11-member Children's Sudden Cardiac Events Review Board in DOH. The board is to review and evaluate the information reported to it, and study any other relevant data respecting children diagnosed with cardiac conditions or reported to have had a sudden cardiac event. The public members are to serve without compensation but are 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. The bill authorizes the board 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.

## **FISCAL ANALYSIS**

### ***EXECUTIVE BRANCH***

None received.

### ***OFFICE OF LEGISLATIVE SERVICES***

The most significant costs associated with the bill would be incurred by the DOH in establishing and maintaining the Children's Sudden Cardiac Events Registry required by the bill. It is expected that the DOH will bid for a private contractor to develop the registry, producing significant up-front costs. Out-year costs of maintaining the registry and keeping its information up-to-date may be modest in comparison to other State registries, because the registry is required to track a relatively small amount of information (name, age, and address of the child, and other information required by the commissioner) about a small number of events (approximately one to two sudden cardiac deaths per 100,000 children, plus an unknown number of additional nonfatal sudden cardiac events). Without information from the Executive, the Office of Legislative Services is unable to provide specific estimates of these costs.

The bill establishes a Children's Sudden Cardiac Events Review Board, whose members are to serve without compensation, but would be eligible for reimbursement for necessary and reasonable expenses incurred in the performance of their duties. These costs would likely be minimal, and are restricted to the limits of funds appropriated or made available for this purpose. The bill authorizes the board 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. The language of the bill suggests that the entity providing assistance would do so voluntarily and at its own cost. These costs are unlikely to be significant.

*Section:* Human Services

*Analyst:* David Drescher  
Assistant 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.).

# LEGISLATIVE FISCAL ESTIMATE

[Second Reprint]

## SENATE, No. 1911 STATE OF NEW JERSEY 215th LEGISLATURE

DATED: NOVEMBER 1, 2012

### SUMMARY

- Synopsis:** “Children’s Sudden Cardiac Events Reporting Act.”
- Type of Impact:** An expenditure increase.
- Agencies Affected:** Department of Health (DOH); possible costs to other State, county, and municipal agencies.

#### Office of Legislative Services Estimate

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

- The bill will cause the Department of Health (DOH) to incur indeterminate costs in establishing and maintaining a Children’s Sudden Cardiac Events Registry.

### BILL DESCRIPTION

Senate Bill No. 1911 (2R) of 2012, which is designated as the “Children’s Sudden Cardiac Events Reporting Act,” requires the reporting of children’s sudden cardiac events, establishes a Statewide database as a repository for the reported information, and requires the Commissioner of Health to establish a board to review the reported information.

Specifically, the bill requires that a physician or registered professional nurse licensed in New Jersey who makes the diagnosis of a sudden cardiac event in a child under 19 years of age, or who makes the actual determination and pronouncement of death for a child related to a sudden cardiac event, report that event to DOH on a form and in a manner prescribed by the commissioner. The information is to include the name, age, and address of the child, unless the child’s parent or guardian objects, in which case no information is to be included that could be used to identify the child.

The bill also establishes the Children’s Sudden Cardiac Events Registry in DOH. The registry would include a record of all sudden cardiac events reported to DOH pursuant to the bill

and other relevant information determined by DOH. The reports are to be used only by DOH and other agencies designated by the commissioner, and are otherwise not to be divulged or made public so as to disclose the identity of any person to whom they relate.

In addition, the bill directs the commissioner to establish an 11-member Children's Sudden Cardiac Events Review Board in DOH. The board is to review and evaluate the information reported to it, and study any other relevant data respecting children diagnosed with cardiac conditions or reported to have had a sudden cardiac event. The public members are to serve without compensation but are 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. The bill authorizes the board 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.

## **FISCAL ANALYSIS**

### ***EXECUTIVE BRANCH***

None received.

### ***OFFICE OF LEGISLATIVE SERVICES***

The most significant costs associated with the bill would be incurred by the DOH in establishing and maintaining the Children's Sudden Cardiac Events Registry required by the bill. It is expected that the DOH will bid for a private contractor to develop the registry, producing significant up-front costs. Out-year costs of maintaining the registry and keeping its information up-to-date may be modest in comparison to other State registries, because the registry is required to track a relatively small amount of information (name, age, and address of the child, and other information required by the commissioner) about a small number of events (approximately one to two sudden cardiac deaths per 100,000 children, plus an unknown number of additional nonfatal sudden cardiac events). Without information from the Executive, the Office of Legislative Services (OLS) is unable to provide specific estimates of these costs.

The bill establishes a Children's Sudden Cardiac Events Review Board, whose members are to serve without compensation, but would be eligible for reimbursement for necessary and reasonable expenses incurred in the performance of their duties. These costs would likely be minimal, and are restricted to the limits of funds appropriated or made available for this purpose. The bill authorizes the board 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. The language of the bill suggests that the entity providing assistance would do so voluntarily and at its own cost. These costs are unlikely to be significant.

*Section:* Human Services

*Analyst:* David Drescher  
Assistant Fiscal Analyst

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

This legislative fiscal estimate has been produced by the OLS 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 HEALTH AND SENIOR SERVICES COMMITTEE

## STATEMENT TO

[Second Reprint]  
**SENATE, No. 1911**

# STATE OF NEW JERSEY

DATED: MARCH 7, 2013

The Assembly Health and Senior Services Committee reports favorably Senate Bill No. 1911 (2R).

This bill, which is designated as the “Children’s Sudden Cardiac Events Reporting Act,” requires the reporting of children’s sudden cardiac events, establishes a Statewide database as a repository for the reported information, and requires the Commissioner of Health to establish a board to review the information.

Specifically, the bill requires that a physician or registered professional nurse licensed in New Jersey who makes the diagnosis of a sudden cardiac event in a child under 19 years of age or who makes the actual determination and pronouncement of death for a child, report that event to the Department of Health (DOH) on a form and in a manner prescribed by the Commissioner of Health. The information is to include the name, age, and address of the child, unless the child’s parent or guardian objects, in which case no information is to be included that could be used to identify the child. The bill provides that a health care professional providing this information would not be liable for divulging confidential information.

The bill defines “sudden cardiac event” to mean a death or aborted death due to a cardiac arrhythmia resulting in loss of consciousness requiring cardiopulmonary resuscitation, defibrillation, or other advanced life support measures to regain normal heart function.

The bill also establishes the Children’s Sudden Cardiac Events Registry in DOH. The registry would include a record of all sudden cardiac events reported to DOH pursuant to the bill and other relevant information determined by DOH. The reports are to be used only by DOH and other agencies designated by the Commissioner of Health, and are not to otherwise be divulged or made public so as to disclose the identity of any person to whom they relate.

In addition, the bill directs the Commissioner of Health to establish an 11-member Children’s Sudden Cardiac Events Review Board in DOH. The board is to review and evaluate the information reported to it, and study any other relevant data respecting children diagnosed with cardiac conditions or reported to have had a sudden cardiac event. The board is to include the Commissioners of Health, Children and

Families, and Education, or their designees, as ex officio members, and eight 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; the Hypertrophic Cardiomyopathy Association; the Athletic Trainers' Society of New Jersey; and the New Jersey Academy of Family Physicians.

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

This bill is identical to Assembly Bill No. 3047 ACA (Diegnan/Lampitt/Egan/Quijano), which the committee also reported on this date.

# ASSEMBLY APPROPRIATIONS COMMITTEE

## STATEMENT TO

[Second Reprint]  
**SENATE, No. 1911**

# STATE OF NEW JERSEY

DATED: JUNE 6, 2013

The Assembly Appropriations Committee reports favorably Senate Bill No. 1911 (2R).

The bill, the “Children’s Sudden Cardiac Events Reporting Act,” requires the occurrence of a sudden cardiac event in a child to be reported to the Department of Health, establishes a State registry as a central repository for information on reported sudden cardiac events in children, and directs the Commissioner of Health to establish a board to review and evaluate the information.

MANDATORY REPORTING - The bill requires a health care professional who makes a diagnosis of a sudden cardiac event in a child, or who makes the actual determination and pronouncement of death for a child, to report the event to the Department of Health. The bill specifies that the report must be provided in writing, and must include the name and address of the health care professional submitting the report; the name, age, and address of the child; and certain other information required by the Commissioner of Health.

The bill permits the parent or guardian of a child who experienced a sudden cardiac event to object to the reporting of personal information identifying the child. The bill provides that if a parent or guardian objects to the reporting of a child’s condition (for any reason), the report of the sudden cardiac event to the Department of Health will not include any information that could be used to identify the child.

STATE REGISTRY - The bill establishes the Children’s Sudden Cardiac Events Registry in the Department of Health. The bill requires the registry to include a record of all sudden cardiac events occurring in children that are reported to the department by health care professionals and any other information deemed relevant and appropriate by the department.

The bill provides that reports of sudden cardiac events occurring in children made by health care professionals will only be used by the Department of Health and other agencies as may be designated by the Commissioner of Health, and will not otherwise be divulged or made public. The bill provides that health care professionals providing information to the department will not be deemed to be, or held liable for, divulging confidential information, and stipulates that nothing in

the bill will be construed to compel a child to submit to medical or health examination or supervision by the department.

REVIEW BOARD - The bill directs the Commissioner of Health to establish the Children's Sudden Cardiac Events Review Board in the Department of Health. The bill provides that the board will review and evaluate all sudden cardiac event information reported to the department by health care professionals, and study any other relevant data respecting children diagnosed with cardiac conditions or reported to have had a sudden cardiac event in this State.

The bill provides that the board will consist of 11 members, including: the Commissioners of Health, Children and Families, and Education, or their designees, who shall serve ex officio, and eight public members appointed by the Commissioner of Health in accordance with the bill. The bill stipulates that the public members will serve without compensation, but may be reimbursed for expenses incurred in the performance of their duties.

DEFINITIONS - For purposes of the bill, a "sudden cardiac event" is defined as a death or aborted death due to cardiac arrhythmia resulting in loss of consciousness requiring cardiopulmonary resuscitation, defibrillation, or other advanced life support measures to regain normal heart function. The bill defines a "health care professional" as a physician or registered professional nurse who is licensed to practice in this State. The bill defines a "child" as a child who is under 19 years of age.

RULES AND REGULATIONS - The bill authorizes the Commissioner of Health to adopt, pursuant to the "Administrative Procedures Act," P.L.1968, c.410 (C.52:14B-1 et seq.), rules and regulations necessary to effectuate the purposes of the bill.

EFFECTIVE DATE - The bill takes effect on the first day of the seventh month next following the date of enactment, but permits the Commissioner of Health to take anticipatory administrative actions prior to the bill's effective date.

As reported, this bill is identical to Assembly Bill No. 3047 (1R), as also reported by the committee.

FISCAL IMPACT:

The Office of Legislative Services (OLS) expects the State to incur some additional costs as a result of the bill. These additional costs are comprised of certain up-front costs to establish the Children's Sudden Cardiac Events Registry, and certain recurring, out-year costs associated with maintaining the registry and keeping the information on sudden cardiac events up-to-date.

The OLS notes that the up-front costs may be significant if the Department of Health contracts with a private entity to develop the registry, and notes that the out-year costs of maintaining the registry may be modest in comparison to the cost of maintaining other State registries. The registry established by the bill is required to track a

relatively limited amount of information about a small number of events (approximately one to two sudden cardiac deaths per 100,000 children, plus an unknown number of additional nonfatal sudden cardiac events).



# ASSEMBLY, No. 3047

## STATE OF NEW JERSEY 215th LEGISLATURE

INTRODUCED JUNE 7, 2012

**Sponsored by:**

**Assemblyman PATRICK J. DIEGNAN, JR.**

**District 18 (Middlesex)**

**Assemblywoman PAMELA R. LAMPITT**

**District 6 (Burlington and Camden)**

**Assemblyman JOSEPH V. EGAN**

**District 17 (Middlesex and Somerset)**

**Assemblywoman ANNETTE QUIJANO**

**District 20 (Union)**

**Co-Sponsored by:**

**Assemblymen Coughlin, Albano, Schroeder, Giblin and Webber**

**SYNOPSIS**

“Children’s Sudden Cardiac Events Reporting Act.”

**CURRENT VERSION OF TEXT**

As introduced.



**(Sponsorship Updated As Of: 2/22/2013)**

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

3

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

6

7 1. This act shall be known and may be cited as the “Children’s  
8 Sudden Cardiac Events Reporting Act.”

9

10 2. The Legislature finds and declares that:

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

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

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

25

26 3. As used in this act:

27 “Child” means a child who is at least 12 years of age and no  
28 more than 19 years of age.

29 “Commissioner” means the Commissioner of Health and Senior  
30 Services.

31 “Department” means the Department of Health and Senior  
32 Services.

33 “Health care professional” means a physician or registered  
34 professional nurse licensed to practice in this State.

35 “Registry” means the Children’s Sudden Cardiac Events Registry  
36 established pursuant to this act.

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

41

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

47 b. The report shall be in writing and shall include the name and  
48 address of the health care professional submitting the report, the

1 name, age, and address of the child, and other pertinent information  
2 as may be required by the commissioner; except that, if the child's  
3 parent or guardian objects to the reporting of the child's condition  
4 for any reason, the report shall not include any information that  
5 could be used to identify the child.

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

12

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

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

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

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

31

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

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

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

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

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

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

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

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

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

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

33

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

37

38 8. This act shall take effect on the first day of the seventh  
39 month next following the date of enactment, but the commissioner  
40 may take such anticipatory administrative action in advance thereof  
41 as shall be necessary for the implementation of this act.

42

43

44

#### STATEMENT

45

46 This bill, which is designated as the "Children's Sudden Cardiac  
47 Events Reporting Act," requires the reporting of children's sudden

1 cardiac events and establishes a Statewide database as a repository  
2 for the reported information.

3 The bill provides specifically as follows:

- 4 • A health care professional (a physician or registered professional  
5 nurse licensed in New Jersey) who makes the diagnosis of a  
6 sudden cardiac event in a child 12-19 years of age or who makes  
7 the actual determination and pronouncement of death for a  
8 child, as applicable, is to report the sudden cardiac event to the  
9 Department of Health and Senior Services (DHSS) on a form  
10 and in a manner prescribed by the Commissioner of Health and  
11 Senior Services.
- 12 • The bill defines “sudden cardiac event” to mean a death or near  
13 death due to hypertrophic cardiomyopathy, sudden cardiac  
14 arrest, or other life-threatening cardiac condition as specified by  
15 regulation of the commissioner.
- 16 • The report is to be in writing and include the name and address  
17 of the health care professional submitting the report, the name,  
18 age, and address of the child, and other pertinent information as  
19 may be required by the commissioner; except that, if the child’s  
20 parent or guardian objects to the reporting of the child’s  
21 condition for any reason, the report is not to include any  
22 information that could be used to identify the child.
- 23 • The commissioner is to specify procedures for the health care  
24 professional to inform the child’s parent or guardian of the  
25 requirements of the bill and the purpose served by including this  
26 information in the registry, as well as the parent’s or guardian’s  
27 right to refuse to permit the reporting of any information that  
28 could be used to identify the child.
- 29 • The bill establishes the Children’s Sudden Cardiac Events  
30 Registry in DHSS, which is to include a record of all sudden  
31 cardiac events reported pursuant to the bill and any other  
32 information that DHSS deems relevant and appropriate. The  
33 reports made pursuant to the bill are to be used only by DHSS  
34 and other agencies as may be designated by the commissioner,  
35 and are not to otherwise be divulged or made public so as to  
36 disclose the identity of any person to whom they relate.
- 37 • A health care professional providing information to DHSS  
38 pursuant to the bill is not liable for divulging confidential  
39 information.
- 40 • The commissioner is to establish a nine-member Children’s  
41 Sudden Cardiac Events Review Board in DHSS. The purpose of  
42 the board is to review and evaluate the information reported to  
43 DHSS, and to study any other data, which the board is to seek  
44 and as may be made available to it to supplement the reported  
45 information, with respect to children diagnosed with cardiac  
46 conditions or reported to have had a sudden cardiac event. The  
47 board is to make note of such factors as the age, gender, and  
48 ethnicity of each child, and the location of each sudden cardiac

- 1 event, in its review of any information received by the board.  
2 The board may share its findings with other recognized entities  
3 that collect nationwide data on sudden cardiac events, but is  
4 prohibited from disclosing to any person or entity outside DHSS  
5 any information that could be used to identify a child.
- 6 • The members of the board will be: the commissioner and the  
7 Commissioners of Children and Families and Education, or their  
8 designees, as ex officio members; and six public members  
9 appointed by the commissioner who represent the American  
10 Heart Association, the New Jersey Chapter of the American  
11 Academy of Pediatrics, the American College of Cardiology, the  
12 New Jersey State School Nurses Association, the New Jersey  
13 State Interscholastic Athletic Association, and the New Jersey  
14 Academy of Family Physicians.
  - 15 • The public members of the board are to serve for a term of three  
16 years, but of the public members first appointed, three are to  
17 serve for a term of two years and three for a term of three years.  
18 The public members are to serve without compensation but may  
19 be reimbursed for expenses from any available funds. The  
20 public members are to select a board chairperson from among  
21 themselves.
- 22 The bill takes effect on the first day of the seventh month after  
23 enactment, but authorizes the Commissioner of Health and Senior  
24 Services to take prior administrative action as necessary for  
25 implementation.

# ASSEMBLY HEALTH AND SENIOR SERVICES COMMITTEE

## STATEMENT TO

### **ASSEMBLY, No. 3047**

with committee amendments

# **STATE OF NEW JERSEY**

DATED: MARCH 7, 2013

The Assembly Health and Senior Services Committee reports favorably and with committee amendments Assembly Bill No. 3047.

As amended by the committee, this bill, which is designated as the “Children’s Sudden Cardiac Events Reporting Act,” requires the reporting of children’s sudden cardiac events, establishes a Statewide database as a repository for the reported information, and requires the Commissioner of Health to establish a board to review the information.

Specifically, the bill requires that a physician or registered professional nurse licensed in New Jersey who makes the diagnosis of a sudden cardiac event in a child under 19 years of age or who makes the actual determination and pronouncement of death for a child, report that event to the Department of Health (DOH) on a form and in a manner prescribed by the Commissioner of Health. The information is to include the name, age, and address of the child, unless the child’s parent or guardian objects, in which case no information is to be included that could be used to identify the child. The bill provides that a health care professional providing this information would not be liable for divulging confidential information.

The bill defines “sudden cardiac event” to mean a death or aborted death due to a cardiac arrhythmia resulting in loss of consciousness requiring cardiopulmonary resuscitation, defibrillation, or other advanced life support measures to regain normal heart function.

The bill also establishes the Children’s Sudden Cardiac Events Registry in DOH. The registry would include a record of all sudden cardiac events reported to DOH pursuant to the bill and other relevant information determined by DOH. The reports are to be used only by DOH and other agencies designated by the Commissioner of Health, and are not to otherwise be divulged or made public so as to disclose the identity of any person to whom they relate.

In addition, the bill directs the Commissioner of Health to establish an 11-member Children’s Sudden Cardiac Events Review Board in DOH. The board is to review and evaluate the information reported to it, and study any other relevant data respecting children diagnosed

with cardiac conditions or reported to have had a sudden cardiac event. The board is to include the Commissioners of Health, Children and Families, and Education, or their designees, as ex officio members, and eight 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; the Hypertrophic Cardiomyopathy Association; the Athletic Trainers' Society of New Jersey; and the New Jersey Academy of Family Physicians.

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

As reported by the committee, this bill is identical to Senate Bill No. 1911 (2R) (Madden/O'Toole), which the committee also reported on this date.

#### COMMITTEE AMENDMENTS

The committee amendments to the bill: (1) change the definition of "child" to mean a child under 19 years of age and the definition of "sudden cardiac event" to mean a death or aborted death due to a cardiac arrhythmia resulting in loss of consciousness requiring cardiopulmonary resuscitation, defibrillation, or other advanced life support measures to regain normal heart function; (2) add two members to the Children's Sudden Cardiac Events Review Board, to include one person who represents the Hypertrophic Cardiomyopathy Association and one person who represents the Athletic Trainers' Society of New Jersey; and (3) update references to the Department of Health and Senior Services as the Department of Health pursuant to section 93 of P.L.2012, c.17 (C.26:1A-2.1).



# ASSEMBLY APPROPRIATIONS COMMITTEE

## STATEMENT TO

[First Reprint]

**ASSEMBLY, No. 3047**

# **STATE OF NEW JERSEY**

DATED: JUNE 6, 2013

The Assembly Appropriations Committee reports favorably Assembly Bill No. 3047 (1R).

The bill, the “Children’s Sudden Cardiac Events Reporting Act,” requires the occurrence of a sudden cardiac event in a child to be reported to the Department of Health, establishes a State registry as a central repository for information on reported sudden cardiac events in children, and directs the Commissioner of Health to establish a board to review and evaluate the information.

MANDATORY REPORTING - The bill requires a health care professional who makes a diagnosis of a sudden cardiac event in a child, or who makes the actual determination and pronouncement of death for a child, to report the event to the Department of Health. The bill specifies that the report must be provided in writing, and must include the name and address of the health care professional submitting the report; the name, age, and address of the child; and certain other information required by the Commissioner of Health.

The bill permits the parent or guardian of a child who experienced a sudden cardiac event to object to the reporting of personal information identifying the child. The bill provides that if a parent or guardian objects to the reporting of a child’s condition (for any reason), the report of the sudden cardiac event to the Department of Health will not include any information that could be used to identify the child.

STATE REGISTRY - The bill establishes the Children’s Sudden Cardiac Events Registry in the Department of Health. The bill requires the registry to include a record of all sudden cardiac events occurring in children that are reported to the department by health care professionals and any other information deemed relevant and appropriate by the department.

The bill provides that reports of sudden cardiac events occurring in children made by health care professionals will only be used by the Department of Health and other agencies as may be designated by the Commissioner of Health, and will not otherwise be divulged or made public. The bill provides that health care professionals providing information to the department will not be deemed to be, or held liable

for, divulging confidential information, and stipulates that nothing in the bill will be construed to compel a child to submit to medical or health examination or supervision by the department.

REVIEW BOARD - The bill directs the Commissioner of Health to establish the Children's Sudden Cardiac Events Review Board in the Department of Health. The bill provides that the board will review and evaluate all sudden cardiac event information reported to the department by health care professionals, and study any other relevant data respecting children diagnosed with cardiac conditions or reported to have had a sudden cardiac event in this State.

The bill provides that the board will consist of 11 members, including: the Commissioners of Health, Children and Families, and Education, or their designees, who shall serve ex officio, and eight public members appointed by the Commissioner of Health in accordance with the bill. The bill stipulates that the public members will serve without compensation, but may be reimbursed for expenses incurred in the performance of their duties.

DEFINITIONS - For purposes of the bill, a "sudden cardiac event" is defined as a death or aborted death due to cardiac arrhythmia resulting in loss of consciousness requiring cardiopulmonary resuscitation, defibrillation, or other advanced life support measures to regain normal heart function. The bill defines a "health care professional" as a physician or registered professional nurse who is licensed to practice in this State. The bill defines a "child" as a child who is under 19 years of age.

RULES AND REGULATIONS - The bill authorizes the Commissioner of Health to adopt, pursuant to the "Administrative Procedures Act," P.L.1968, c.410 (C.52:14B-1 et seq.), rules and regulations necessary to effectuate the purposes of the bill.

EFFECTIVE DATE - The bill takes effect on the first day of the seventh month next following the date of enactment, but permits the Commissioner of Health to take anticipatory administrative actions prior to the bill's effective date.

As reported, this bill is identical to Senate Bill No. 1911 (2R), as also reported by the committee.

FISCAL IMPACT:

The Office of Legislative Services (OLS) expects the State to incur some additional costs as a result of the bill. These additional costs are comprised of certain up-front costs to establish the Children's Sudden Cardiac Events Registry, and certain recurring, out-year costs associated with maintaining the registry and keeping the information on sudden cardiac events up-to-date.

The OLS notes that the up-front costs may be significant if the Department of Health contracts with a private entity to develop the registry, and notes that the out-year costs of maintaining the registry may be modest in comparison to the cost of maintaining other State

registries. The registry established by the bill is required to track a relatively limited amount of information about a small number of events (approximately one to two sudden cardiac deaths per 100,000 children, plus an unknown number of additional nonfatal sudden cardiac events).

# LEGISLATIVE FISCAL ESTIMATE

[First Reprint]

**ASSEMBLY, No. 3047**

**STATE OF NEW JERSEY  
215th LEGISLATURE**

DATED: JUNE 10, 2013

## SUMMARY

**Synopsis:** “Children’s Sudden Cardiac Events Reporting Act.”

**Type of Impact:** An expenditure increase.

**Agencies Affected:** Department of Health (DOH).

### Office of Legislative Services Estimate

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

- The bill will cause the Department of Health (DOH) to incur indeterminate costs in establishing and maintaining a Children’s Sudden Cardiac Events Registry.

## BILL DESCRIPTION

Assembly Bill No. 3047 (1R) of 2012, which is designated as the “Children’s Sudden Cardiac Events Reporting Act,” requires the reporting of children’s sudden cardiac events, establishes a Statewide database as a repository for the reported information, and requires the Commissioner of Health to establish a board to review the reported information.

Specifically, the bill requires that a physician or registered professional nurse licensed in New Jersey who makes the diagnosis of a sudden cardiac event in a child under 19 years of age, or who makes the actual determination and pronouncement of death for a child related to a sudden cardiac event, report that event to DOH on a form and in a manner prescribed by the commissioner. The information is to include the name, age, and address of the child, unless the child’s parent or guardian objects, in which case no information is to be included that could be used to identify the child.

The bill also establishes the Children’s Sudden Cardiac Events Registry in DOH. The registry would include a record of all sudden cardiac events reported to DOH pursuant to the bill

and other relevant information determined by DOH. The reports are to be used only by DOH and other agencies designated by the commissioner, and are otherwise not to be divulged or made public so as to disclose the identity of any person to whom they relate.

In addition, the bill directs the commissioner to establish an 11-member Children's Sudden Cardiac Events Review Board in DOH. The board is to review and evaluate the information reported to it, and study any other relevant data respecting children diagnosed with cardiac conditions or reported to have had a sudden cardiac event. The public members are to serve without compensation but are 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. The bill authorizes the board 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.

## **FISCAL ANALYSIS**

### ***EXECUTIVE BRANCH***

None received.

### ***OFFICE OF LEGISLATIVE SERVICES***

The most significant costs associated with the bill would be incurred by the DOH in establishing and maintaining the Children's Sudden Cardiac Events Registry required by the bill. It is expected that the DOH will bid for a private contractor to develop the registry, producing significant up-front costs. Out-year costs of maintaining the registry and keeping its information up-to-date may be modest in comparison to other State registries, because the registry is required to track a relatively small amount of information (name, age, and address of the child, and other information required by the commissioner) about a small number of events (approximately one to two sudden cardiac deaths per 100,000 children, plus an unknown number of additional nonfatal sudden cardiac events). Without information from the Executive, the Office of Legislative Services is unable to provide specific estimates of these costs.

The bill establishes a Children's Sudden Cardiac Events Review Board, whose members are to serve without compensation, but would be eligible for reimbursement for necessary and reasonable expenses incurred in the performance of their duties. These costs would likely be minimal, and are restricted to the limits of funds appropriated or made available for this purpose. The bill authorizes the board 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. The language of the bill suggests that the entity providing assistance would do so voluntarily and at its own cost. These costs are unlikely to be significant.

*Section: Human Services*

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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.).