

52:17B-88.2 to 52:17B-88.14

LEGISLATIVE HISTORY CHECKLIST

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LAWS OF: 2013 **CHAPTER:** 91

NJSA: 52:17B-88.2 to 52:17B-88.14 (Requires medical examiner training about sudden unexpected death in epilepsy and requesting decedent's medical information and brain donation for research)

BILL NO: S2227 (Substituted for A3387)

SPONSOR(S) Codey and others

DATE INTRODUCED: October 4, 2012

COMMITTEE: **ASSEMBLY:** Health and Senior Services
 SENATE: Health, Human Services and Senior Citizens

AMENDED DURING PASSAGE: Yes

DATE OF PASSAGE: **ASSEMBLY:** June 20, 2013
 SENATE: March 18, 2013

DATE OF APPROVAL: August 7, 2013

FOLLOWING ARE ATTACHED IF AVAILABLE:

FINAL TEXT OF BILL (First reprint enacted)

S2227

SPONSOR'S STATEMENT: (Begins on page 3 of introduced bill) Yes

COMMITTEE STATEMENT: **ASSEMBLY:** Yes
 SENATE: Yes

. (Audio archived recordings of the committee meetings, corresponding to the date of the committee statement, *may possibly* be found at www.njleg.state.nj.us)

FLOOR AMENDMENT STATEMENT: No

LEGISLATIVE FISCAL ESTIMATE: No

A3387

SPONSOR'S STATEMENT (Begins on page 3 of introduced bill) Yes

COMMITTEE STATEMENT: **ASSEMBLY:** Yes
 SENATE: No

FLOOR AMENDMENT STATEMENT: No

LEGISLATIVE FISCAL ESTIMATE: No

(continued)

VETO MESSAGE: No

GOVERNOR'S PRESS RELEASE ON SIGNING: No

FOLLOWING WERE PRINTED:

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REPORTS: No

HEARINGS: No

NEWSPAPER ARTICLES: No

LAW/KR

P.L.2013, CHAPTER 91, *approved August 7, 2013*
Senate, No. 2227 (*First Reprint*)

1 **AN ACT** concerning sudden death in epilepsy and supplementing
2 Title 52 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. The Legislature finds and declares that:

8 a. Sudden, unexpected death in epilepsy (SUDEP) is a
9 mysterious, rare condition in which typically young or middle-aged
10 individuals with epilepsy die without a clear cause, and is generally
11 defined by the medical community as a sudden, unexpected, non-
12 traumatic, non-drowning death in an otherwise healthy individual
13 with epilepsy, where the postmortem examination does not reveal
14 an anatomic or toxicologic cause for the death;

15 b. SUDEP is believed to account for up to 17 percent of deaths
16 in people with epilepsy;

17 c. Autopsy plays a key role in determining the diagnosis of
18 SUDEP, yet the Institute of Medicine has found that SUDEP may
19 be underreported for several reasons, including ¹, but not limited
20 to,¹ a lack of awareness about SUDEP among medical examiners;

21 d. The cause of SUDEP is not known and opportunities for its
22 prevention have been hindered by the lack of a systematic effort to
23 collect information about persons who have died from SUDEP, as is
24 done with many other disorders; and

25 e. It is appropriate to raise awareness of SUDEP among
26 medical examiners by developing a SUDEP awareness program and
27 to facilitate research into the causes and prevention of SUDEP by
28 requiring that medical examiners in this State who determine that an
29 individual's cause of death is SUDEP ¹**request from the**
30 **individual's survivors that the** work with relevant organizations in
31 the State to assist in requesting from next-of-kin that an¹
32 individual's relevant medical information be sent to a SUDEP
33 registry and that the individual's brain be donated for research
34 purposes.

35
36 2. The State Medical Examiner, in consultation with the
37 Commissioner of Health and the State Board of Medical Examiners,

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:

¹Senate SHH committee amendments adopted December 17, 2012.

1 shall establish a sudden unexpected death in epilepsy (SUDEP)
2 awareness program to educate medical examiners in the State about
3 SUDEP.

4
5 3. ¹**【All investigations conducted pursuant to section 9 of**
6 **P.L.1967, c.234 (C.52:17B-86) shall include an inquiry to**
7 **determine whether the death was a direct result of a seizure or**
8 **epilepsy.】** a. The office of the Sate Medical Examiner, in
9 consultation with the county medical examiners and organizations
10 with expertise in SUDEP, shall establish a standard protocol
11 governing medicolegal death investigations involving seizure
12 disorders in order to identify such deaths.¹ If a medical examiner's
13 findings in an autopsy are consistent with the definition of known
14 or suspected SUDEP, the medical examiner shall:

15 ¹**【a indicate on the death certificate that SUDEP is the cause or**
16 **suspected cause of death;**

17 **b.】** (1) retain and track that information and make unidentifiable
18 data concerning seizure-related deaths available upon request to the
19 public;

20 (2) work with relevant organizations in the State to assist in
21 requesting¹ from the authorized survivors of ¹**【that individual】**
22 **deceased individuals'**¹ that ¹**【the individual's】** their¹ relevant
23 medical information, consistent with the federal health privacy rules
24 set forth at 45 CFR Parts 160 and 164, be forwarded to a SUDEP
25 registry for purposes of research; and

26 ¹**【c. request】** (3) work with relevant organizations in the State to
27 assist in requesting¹ from the authorized survivors of individuals
28 with epilepsy ¹**【and individuals】**¹ determined or suspected to have
29 died as a result of SUDEP that a donation of the individual's brain
30 be made for research purposes to a brain bank that is registered
31 pursuant to P.L.2008, c.49 (C.26:6-68 et seq.), if such a gift has not
32 already been established pursuant to the provisions of P.L.2008,
33 c.50 (C.26:6-77 et al.).

34
35 4. This act shall take effect on the first day of the fourth month
36 next following the date of enactment.

37
38
39

40
41 _____
42 Requires medical examiner training about sudden unexpected
43 death in epilepsy and requesting decedent's medical information
and brain donation for research.

SENATE, No. 2227

STATE OF NEW JERSEY
215th LEGISLATURE

INTRODUCED OCTOBER 4, 2012

Sponsored by:

Senator RICHARD J. CODEY

District 27 (Essex and Morris)

Senator SANDRA B. CUNNINGHAM

District 31 (Hudson)

SYNOPSIS

Requires medical examiner training about sudden unexpected death in epilepsy and requesting decedent's medical information and brain donation for research.

CURRENT VERSION OF TEXT

As introduced.



1 AN ACT concerning sudden death in epilepsy and supplementing
2 Title 52 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. The Legislature finds and declares that:

8 a. Sudden, unexpected death in epilepsy (SUDEP) is a
9 mysterious, rare condition in which typically young or middle-aged
10 individuals with epilepsy die without a clear cause, and is generally
11 defined by the medical community as a sudden, unexpected, non-
12 traumatic, non-drowning death in an otherwise healthy individual
13 with epilepsy, where the postmortem examination does not reveal
14 an anatomic or toxicologic cause for the death;

15 b. SUDEP is believed to account for up to 17 percent of deaths
16 in people with epilepsy;

17 c. Autopsy plays a key role in determining the diagnosis of
18 SUDEP, yet the Institute of Medicine has found that SUDEP may
19 be underreported for several reasons, including a lack of awareness
20 about SUDEP among medical examiners;

21 d. The cause of SUDEP is not known and opportunities for its
22 prevention have been hindered by the lack of a systematic effort to
23 collect information about persons who have died from SUDEP, as is
24 done with many other disorders; and

25 e. It is appropriate to raise awareness of SUDEP among
26 medical examiners by developing a SUDEP awareness program and
27 to facilitate research into the causes and prevention of SUDEP by
28 requiring that medical examiners in this State who determine that an
29 individual's cause of death is SUDEP request from the individual's
30 survivors that the individual's relevant medical information be sent
31 to a SUDEP registry and that the individual's brain be donated for
32 research purposes.

33
34 2. The State Medical Examiner, in consultation with the
35 Commissioner of Health and the State Board of Medical Examiners,
36 shall establish a sudden unexpected death in epilepsy (SUDEP)
37 awareness program to educate medical examiners in the State about
38 SUDEP.

39
40 3. All investigations conducted pursuant to section 9 of
41 P.L.1967, c.234 (C.52:17B-86) shall include an inquiry to
42 determine whether the death was a direct result of a seizure or
43 epilepsy. If a medical examiner's findings in an autopsy are
44 consistent with the definition of known or suspected SUDEP, the
45 medical examiner shall:

46 a. indicate on the death certificate that SUDEP is the cause or
47 suspected cause of death;

48 b. request from the authorized survivors of that individual that
49 the individual's relevant medical information, consistent with the

1 federal health privacy rules set forth at 45 CFR Parts 160 and 164,
2 be forwarded to a SUDEP registry for purposes of research; and
3 c. request from the authorized survivors of individuals with
4 epilepsy and individuals determined or suspected to have died as a
5 result of SUDEP that a donation of the individual's brain be made
6 for research purposes to a brain bank that is registered pursuant to
7 P.L.2008, c.49 (C.26:6-68 et seq.), if such a gift has not already
8 been established pursuant to the provisions of P.L.2008, c.50
9 (C.26:6-77 et al.).

10

11 4. This act shall take effect on the first day of the fourth month
12 next following the date of enactment.

13

14

15

STATEMENT

16

17 This bill requires that the State Medical Examiner establish a
18 program to educate medical examiners in the State about sudden,
19 unexpected death in epilepsy (SUDEP), which is a mysterious
20 condition in which typically young or middle-aged individuals with
21 epilepsy die without a clear cause and is believed to account for up
22 to 17 percent of deaths in people with epilepsy.

23 In addition to receiving training about SUDEP, medical
24 examiners would be required to include in their investigations
25 questions to determine if a decedent had epilepsy and request from
26 the authorized survivors of decedents with epilepsy and decedents
27 determined or suspected to have died as a result of SUDEP that the
28 decedent's relevant medical information be sent to a SUDEP
29 registry and the decedent's brain be donated to a brain bank to
30 facilitate research.

31 Research to help prevent SUDEP has been hindered by the lack
32 of a systematic collection of medical information and brain tissue of
33 individuals who have died from SUDEP. Medical examiners can
34 serve a key role in diagnosing SUDEP, but currently medical
35 examiners often do not recognize that a death may be the result of
36 SUDEP.

SENATE HEALTH, HUMAN SERVICES AND SENIOR
CITIZENS COMMITTEE

STATEMENT TO

SENATE, No. 2227

with committee amendments

STATE OF NEW JERSEY

DATED: DECEMBER 17, 2012

The Senate Health, Human Services and Senior Citizens Committee reports favorably and with amendments the Senate Bill No. 2227.

This bill concerns sudden, unexpected death in epilepsy (SUDEP), which is a mysterious, rare condition in which typically young or middle-aged individuals with epilepsy die without a clear cause, and which is underreported for various reasons, including lack of awareness among medical examiners.

As amended, the bill requires that the State Medical Examiner, in consultation with the Commissioner of Health and the State Board of Medical Examiners, establish a SUDEP awareness program to educate medical examiners about SUDEP. The bill further requires that the office of the State Medical Examiner, in consultation with the county medical examiners and organizations with expertise in SUDEP, establish standard protocol governing investigations of deaths involving seizure disorders in order to enable medical examiners to better identify SUDEP, and to work with these organizations to reach out to next-of-kin to encourage the donation of medical information and brain tissue of individuals who have died from SUDEP for research purposes, consistent with health privacy laws.

The committee amendments: revise the legislative findings to state that it is appropriate that medical examiners work with relevant organizations in the State to assist in requesting from next-of-kin that an individual's relevant medical information be sent to a SUDEP registry and brain be donated for research purposes. The amendments also require that if a medical examiner's findings in an autopsy are consistent with the definition of known or suspected SUDEP, the medical examiner is to: retain and track that information and make unidentifiable data concerning seizure-related deaths available upon request to the public; work with relevant organizations in the State to assist in requesting from the authorized survivors of deceased individuals' that their relevant medical information be forwarded to a SUDEP registry for purposes of research; and work with relevant organizations in the State to assist in requesting from the authorized

survivors of individuals with epilepsy determined or suspected to have died as a result of SUDEP that a donation of the individual's brain be made for research purposes to a brain bank.

ASSEMBLY HEALTH AND SENIOR SERVICES COMMITTEE

STATEMENT TO

[First Reprint]

SENATE, No. 2227

STATE OF NEW JERSEY

DATED: MAY 6, 2013

The Assembly Health and Senior Services Committee reports favorably Senate Bill No. 2227 (1R).

This bill concerns sudden, unexpected death in epilepsy (SUDEP), which is a mysterious, rare condition in which typically young or middle-aged individuals with epilepsy die without a clear cause, and which is underreported for various reasons, including lack of awareness among medical examiners.

The bill requires that the State Medical Examiner, in consultation with the Commissioner of Health and the State Board of Medical Examiners, establish a SUDEP awareness program to educate medical examiners about SUDEP. The bill further requires that the office of the State Medical Examiner, in consultation with the county medical examiners and organizations with expertise in SUDEP, establish a standard protocol governing investigations of deaths involving seizure disorders in order to enable medical examiners to better identify SUDEP, and to work with these organizations to reach out to next-of-kin to encourage the donation of medical information and brain tissue of individuals who have died from SUDEP for research purposes, consistent with health privacy laws.

This bill is identical to Assembly Bill No. 3387 ACA (Jasey/Conaway), which the committee also reported on this date.

ASSEMBLY, No. 3387

STATE OF NEW JERSEY 215th LEGISLATURE

INTRODUCED OCTOBER 15, 2012

Sponsored by:

Assemblywoman MILA M. JASEY

District 27 (Essex and Morris)

Assemblyman HERB CONAWAY, JR.

District 7 (Burlington)

SYNOPSIS

Requires medical examiner training about sudden unexpected death in epilepsy and requesting decedent's medical information and brain donation for research.

CURRENT VERSION OF TEXT

As introduced.



(Sponsorship Updated As Of: 4/5/2013)

1 AN ACT concerning sudden death in epilepsy and supplementing
2 Title 52 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. The Legislature finds and declares that:

8 a. Sudden, unexpected death in epilepsy (SUDEP) is a
9 mysterious, rare condition in which typically young or middle-aged
10 individuals with epilepsy die without a clear cause, and is generally
11 defined by the medical community as a sudden, unexpected, non-
12 traumatic, non-drowning death in an otherwise healthy individual
13 with epilepsy, where the postmortem examination does not reveal
14 an anatomic or toxicologic cause for the death;

15 b. SUDEP is believed to account for up to 17 percent of deaths
16 in people with epilepsy;

17 c. Autopsy plays a key role in determining the diagnosis of
18 SUDEP, yet the Institute of Medicine has found that SUDEP may
19 be underreported for several reasons, including a lack of awareness
20 about SUDEP among medical examiners;

21 d. The cause of SUDEP is not known and opportunities for its
22 prevention have been hindered by the lack of a systematic effort to
23 collect information about persons who have died from SUDEP, as is
24 done with many other disorders; and

25 e. It is appropriate to raise awareness of SUDEP among
26 medical examiners by developing a SUDEP awareness program and
27 to facilitate research into the causes and prevention of SUDEP by
28 requiring that medical examiners in this State who determine that an
29 individual's cause of death is SUDEP request from the individual's
30 survivors that the individual's relevant medical information be sent
31 to a SUDEP registry and that the individual's brain be donated for
32 research purposes.

33

34 2. The State Medical Examiner, in consultation with the
35 Commissioner of Health and the State Board of Medical Examiners,
36 shall establish a sudden unexpected death in epilepsy (SUDEP)
37 awareness program to educate medical examiners in the State about
38 SUDEP.

39

40 3. All investigations conducted pursuant to section 9 of
41 P.L.1967, c.234 (C.52:17B-86) shall include an inquiry to
42 determine whether the death was a direct result of a seizure or
43 epilepsy. If a medical examiner's findings in an autopsy are
44 consistent with the definition of known or suspected SUDEP, the
45 medical examiner shall:

46 a. indicate on the death certificate that SUDEP is the cause or
47 suspected cause of death;

1 b. request from the authorized survivors of that individual that
2 the individual's relevant medical information, consistent with the
3 federal health privacy rules set forth at 45 CFR Parts 160 and 164,
4 be forwarded to a SUDEP registry for purposes of research; and

5 c. request from the authorized survivors of individuals with
6 epilepsy and individuals determined or suspected to have died as a
7 result of SUDEP that a donation of the individual's brain be made
8 for research purposes to a brain bank that is registered pursuant to
9 P.L.2008, c.49 (C.26:6-68 et seq.), if such a gift has not already
10 been established pursuant to the provisions of P.L.2008, c.50
11 (C.26:6-77 et al.).

12
13 4. This act shall take effect on the first day of the fourth month
14 next following the date of enactment.

15
16
17 STATEMENT

18
19
20 This bill requires that the State Medical Examiner establish a
21 program to educate medical examiners in the State about sudden,
22 unexpected death in epilepsy (SUDEP), which is a mysterious
23 condition in which typically young or middle-aged individuals with
24 epilepsy die without a clear cause and is believed to account for up
25 to 17 percent of deaths in people with epilepsy.

26 In addition to receiving training about SUDEP, medical
27 examiners would be required to include in their investigations
28 questions to determine if a decedent had epilepsy and request from
29 the authorized survivors of decedents with epilepsy and decedents
30 determined or suspected to have died as a result of SUDEP that the
31 decedent's relevant medical information be sent to a SUDEP
32 registry and the decedent's brain be donated to a brain bank to
33 facilitate research.

34 Research to help prevent SUDEP has been hindered by the lack
35 of a systematic collection of medical information and brain tissue of
36 individuals who have died from SUDEP. Medical examiners can
37 serve a key role in diagnosing SUDEP, but currently medical
38 examiners often do not recognize that a death may be the result of
39 SUDEP.

ASSEMBLY HEALTH AND SENIOR SERVICES COMMITTEE

STATEMENT TO

ASSEMBLY, No. 3387

with committee amendments

STATE OF NEW JERSEY

DATED: MAY 6, 2013

The Assembly Health and Senior Services Committee reports favorably and with committee amendments Assembly Bill No. 3387.

This bill concerns sudden, unexpected death in epilepsy (SUDEP), which is a mysterious, rare condition in which typically young or middle-aged individuals with epilepsy die without a clear cause, and which is underreported for various reasons, including lack of awareness among medical examiners.

As amended by the committee, the bill requires that the State Medical Examiner, in consultation with the Commissioner of Health and the State Board of Medical Examiners, establish a SUDEP awareness program to educate medical examiners about SUDEP. The bill further requires that the office of the State Medical Examiner, in consultation with the county medical examiners and organizations with expertise in SUDEP, establish a standard protocol governing investigations of deaths involving seizure disorders in order to enable medical examiners to better identify SUDEP, and to work with these organizations to reach out to next-of-kin to encourage the donation of medical information and brain tissue of individuals who have died from SUDEP for research purposes, consistent with health privacy laws.

As reported by the committee, this bill is identical to Senate Bill No. 2227 (1R) (Codey/Cunningham), which the committee also reported on this date.

COMMITTEE AMENDMENTS

The committee amendments revise the legislative findings to state that it is appropriate that medical examiners work with relevant organizations in the State to assist in requesting from next-of-kin that an individual's relevant medical information be sent to a SUDEP registry and the brain be donated for research purposes.

The amendments also require the office of the State Medical Examiner to establish a standard protocol governing investigations of deaths involving seizure disorders.

The amendments further require that if a medical examiner's findings in an autopsy are consistent with the definition of known or

suspected SUDEP, the medical examiner is to: retain and track that information and make unidentifiable data concerning seizure-related deaths available upon request to the public; work with relevant organizations in the State to assist in requesting from the authorized survivors of deceased individuals that their relevant medical information be forwarded to a SUDEP registry for purposes of research; and work with relevant organizations in the State to assist in requesting from the authorized survivors of individuals with epilepsy determined or suspected to have died as a result of SUDEP that a donation of the individual's brain be made for research purposes to a brain bank.