

GENERAL ASSEMBLY OF NORTH CAROLINA
SESSION 2015

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SENATE DRS35133-MG-100 (03/13)

Short Title: Track Sudden Unexplained Death in Epilepsy. (Public)

Sponsors: Senator Gunn (Primary Sponsor).

Referred to:

A BILL TO BE ENTITLED

AN ACT REQUIRING THE OFFICE OF THE CHIEF MEDICAL EXAMINER TO TRAIN MEDICAL EXAMINERS HOW TO RECOGNIZE SUDDEN UNEXPLAINED DEATH IN EPILEPSY (SUDEP) AND TO INVESTIGATE WHETHER SUDEP IS A KNOWN OR SUSPECTED CAUSE OF DEATH IN EACH CASE UNDER ITS JURISDICTION.

Whereas, sudden unexplained death in epilepsy (SUDEP) is a mysterious, rare condition in which typically young or middle-aged individuals with epilepsy die without a clear cause; and

Whereas, SUDEP is generally defined by the medical community as a sudden, unexplained, nontraumatic, nondrowning death in an otherwise healthy individual with epilepsy, where the postmortem examination does not reveal an anatomical or toxicological cause for the death; and

Whereas, SUDEP is believed to account for up to seventeen percent (17%) of deaths in people with epilepsy; and

Whereas, autopsy plays a key role in determining the diagnosis of SUDEP, yet the Institute of Medicine has found that SUDEP may be underreported for several reasons, including a lack of awareness about SUDEP among medical examiners; and

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

Whereas, it is appropriate to raise awareness of SUDEP among medical examiners by developing a SUDEP awareness program and to facilitate research into the causes and prevention of SUDEP by requiring that medical examiners in this State who determine that an individual's cause of death is SUDEP request from the individual's survivors that the individual's relevant medical information be sent to a SUDEP registry and that the individual's brain be donated for research purposes; Now, therefore, The General Assembly of North Carolina enacts:

SECTION 1. G.S. 130A-379 reads as rewritten:

"§ 130A-379. Duties-Powers and duties of the Chief Medical Examiner.

(a) The Chief Medical Examiner shall ~~perform~~do all of the following:

(1) Perform postmortem medicolegal examinations as provided in this Part.

(2) Establish a sudden unexplained death in epilepsy (SUDEP) awareness training program to educate all medical examiners in this State about SUDEP and how to investigate whether SUDEP is a known or suspected cause of death.



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1 **(b)** The Chief Medical Examiner may, upon request, provide instruction in health
2 science, legal medicine and other subjects related to his duties at The University of North
3 Carolina, the North Carolina Justice Academy and other institutions of higher learning."

4 **SECTION 2.** G.S. 130A-385 reads as rewritten:

5 **"§ 130A-385. Duties of medical examiner upon receipt of notice; reports; copies.**

6 **(a)** Upon receipt of a notification under G.S. 130A-383, the medical examiner shall take
7 charge of the body, make inquiries regarding the cause and manner of death, reduce the
8 findings to writing and promptly make a full report to the Chief Medical Examiner on forms
9 prescribed for that purpose.

10 **(a1)** For each death under investigation, the Chief Medical Examiner's inquiries
11 regarding the cause and manner of death shall include an inquiry to determine whether the
12 death was a direct result of a seizure or epilepsy. If the findings of an autopsy are consistent
13 with the definition of known or suspected sudden unexplained death in epilepsy, the Chief
14 Medical Examiner shall do all of the following:

15 **(1)** Indicate on the death certificate that sudden unexplained death in epilepsy is
16 the cause or suspected cause of death.

17 **(2)** Request that the decedent's authorized representative submit relevant
18 medical information about the decedent, consistent with the federal Health
19 Insurance Portability and Accountability Act, Privacy Rule and Security
20 Rule, 45 C.F.R. §§ 160, 164, to a sudden unexplained death in epilepsy
21 registry for research purposes.

22 **(3)** Request that a person authorized to make an anatomical gift of the decedent's
23 body or body part under G.S. 130A-412.11 consider making an anatomical
24 gift of the decedent's brain to maximize the opportunity for research or
25 education on sudden unexplained death in epilepsy.

26 **(a2)** The Chief Medical Examiner or the county medical examiner is authorized to
27 inspect and copy the medical records of the decedent whose death is under investigation. In
28 addition, in an investigation conducted pursuant to this Article, the Chief Medical Examiner or
29 the county medical examiner is authorized to inspect all physical evidence and documents
30 which may be relevant to determining the cause and manner of death of the person whose death
31 is under investigation, including decedent's personal possessions associated with the death,
32 clothing, weapons, tissue and blood samples, cultures, medical equipment, X rays and other
33 medical images. The Chief Medical Examiner or county medical examiner is further authorized
34 to seek an administrative search warrant pursuant to G.S. 15-27.2 for the purpose of carrying
35 out the duties imposed under this Article. In addition to the requirements of G.S. 15-27.2, no
36 administrative search warrant shall be issued pursuant to this section unless the Chief Medical
37 Examiner or county medical examiner submits an affidavit from the office of the district
38 attorney in the district in which death occurred stating that the death in question is not under
39 criminal investigation.

40 **(a3)** The Chief Medical Examiner shall provide directions as to the nature, character and
41 extent of an investigation and appropriate forms for the required reports. The facilities of the
42 central and district offices and their staff services shall be available to the medical examiners
43 and designated pathologists in their investigations.

44 **(b)** The medical examiner shall complete a certificate of death, stating the name of the
45 disease which in ~~his~~ the medical examiner's opinion caused death. If the death was from
46 external causes, the medical examiner shall state on the certificate of death the means of death,
47 and whether, in the medical examiner's opinion, the manner of death was accident, suicide,
48 homicide, execution by the State, or undetermined. The medical examiner shall also furnish any
49 information as may be required by the State Registrar of Vital Statistics in order to properly
50 classify the death.

1 (c) The Chief Medical Examiner shall have authority to amend a medical examiner
2 death certificate.

3 (d) A copy of the report of the medical examiner investigation may be forwarded to the
4 appropriate district attorney.

5 (e) In cases where death occurred due to an injury received in the course of the
6 decedent's employment, the Chief Medical Examiner shall forward to the Commissioner of
7 Labor a copy of the medical examiner's report of the investigation, including the location of the
8 fatal injury and the name and address of the decedent's employer at the time of the fatal injury.
9 The Chief Medical Examiner shall forward this report within 30 days of receipt of the
10 information from the medical examiner.

11 (f) If a death occurred in a facility licensed subject to Article 2 or Article 3 of Chapter
12 122C of the General Statutes, or Articles 1 or 1A of Chapter 131D of the General Statutes, and
13 the deceased was a client or resident of the facility or a recipient of facility services at the time
14 of death, then the Chief Medical Examiner shall forward a copy of the medical examiner's
15 report to the Secretary of Health and Human Services within 30 days of receipt of the report
16 from the medical examiner."

17 **SECTION 3.** This act becomes effective October 1, 2015.