

CHAPTER 91

AN ACT concerning sudden death in epilepsy and supplementing Title 52 of the Revised Statutes.

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

C.52:17B-88.12 Findings, declarations relative to sudden death in epilepsy.

1. The Legislature finds and declares that:
 - a. Sudden, unexpected 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 is generally defined by the medical community as a sudden, unexpected, non-traumatic, non-drowning death in an otherwise healthy individual with epilepsy, where the postmortem examination does not reveal an anatomic or toxicologic cause for the death;
 - b. SUDEP is believed to account for up to 17 percent of deaths in people with epilepsy;
 - c. 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, but not limited to, a lack of awareness about SUDEP among medical examiners;
 - d. 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
 - e. 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 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 that the individual's brain be donated for research purposes.

C.52:17B-88.13 SUDEP awareness program.

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

C.52:17B-88.14 Standard protocol governing medicolegal death investigations.

3. The office of the State Medical Examiner, in consultation with the county medical examiners and organizations with expertise in SUDEP, shall establish a standard protocol governing medicolegal death investigations involving seizure disorders in order to identify such deaths. If a medical examiner's findings in an autopsy are consistent with the definition of known or suspected SUDEP, the medical examiner shall:

- (1) retain and track that information and make unidentifiable data concerning seizure-related deaths available upon request to the public;
- (2) work with relevant organizations in the State to assist in requesting from the authorized survivors of deceased individuals that their relevant medical information, consistent with the federal health privacy rules set forth at 45 CFR Parts 160 and 164, be forwarded to a SUDEP registry for purposes of research; and
- (3) 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 that is registered pursuant to P.L.2008, c.49 (C.26:6-68 et seq.), if such a gift has not already been established pursuant to the provisions of P.L.2008, c.50 (C.26:6-77 et al.).

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

Approved August 7, 2013.