



## 98TH GENERAL ASSEMBLY

### State of Illinois

2013 and 2014

SB1226

Introduced 1/30/2013, by Sen. Dan Kotowski

#### SYNOPSIS AS INTRODUCED:

20 ILCS 2310/2310-665 new

Amends the Department of Public Health Powers and Duties Law of the Civil Administrative Code of Illinois. Sets forth the General Assembly's findings and declarations concerning sudden, unexpected death in epilepsy (SUDEP). Provides that the Department shall establish a SUDEP awareness program to educate medical examiners, examining physicians, and coroners in this State about SUDEP. Provides that all autopsies conducted in this State shall include an inquiry to determine whether the death was a direct result of a seizure or epilepsy. Provides that if a medical examiner's, examining physician's, or coroner's findings in an autopsy are consistent with the definition of known or suspected SUDEP, then the medical examiner, examining physician, or coroner shall take certain action.

LRB098 04241 RPM 34266 b

FISCAL NOTE ACT  
MAY APPLY

A BILL FOR

1 AN ACT concerning health.

2 **Be it enacted by the People of the State of Illinois,**  
3 **represented in the General Assembly:**

4 Section 5. The Department of Public Health Powers and  
5 Duties Law of the Civil Administrative Code of Illinois is  
6 amended by adding Section 2310-665 as follows:

7 (20 ILCS 2310/2310-665 new)

8 Sec. 2310-665. Sudden, unexpected death in epilepsy  
9 awareness program.

10 (a) The General Assembly finds and declares that:

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

19 (2) SUDEP is believed to account for up to 17% of  
20 deaths in people with epilepsy.

21 (3) Autopsy plays a key role in determining the  
22 diagnosis of SUDEP, yet the Institute of Medicine has found  
23 that SUDEP may be underreported for several reasons,

1 including a lack of awareness about SUDEP among medical  
2 examiners.

3 (4) The cause of SUDEP is not known, and opportunities  
4 for its prevention have been hindered by the lack of a  
5 systematic effort to collect information about persons who  
6 have died from SUDEP, as is done with many other disorders.

7 (5) It is appropriate to raise awareness of SUDEP among  
8 medical examiners by developing a SUDEP awareness program  
9 and to facilitate research into the causes and prevention  
10 of SUDEP by requiring that medical examiners, examining  
11 physicians, and coroners in this State who determine that  
12 an individual's cause of death is SUDEP request from the  
13 individual's survivors that the individual's relevant  
14 medical information be sent to a SUDEP registry and that  
15 the individual's brain be donated for research purposes.

16 (b) The Department shall establish a sudden, unexpected  
17 death in epilepsy (SUDEP) awareness program to educate medical  
18 examiners, examining physicians, and coroners in this State  
19 about SUDEP.

20 (c) All autopsies conducted in this State shall include an  
21 inquiry to determine whether the death was a direct result of a  
22 seizure or epilepsy. If a medical examiner's, examining  
23 physician's, or coroner's findings in an autopsy are consistent  
24 with the definition of known or suspected SUDEP, then the  
25 medical examiner, examining physician, or coroner shall:

26 (1) cause to be indicated on the death certificate that

1       SUDEP is the cause or suspected cause of death;  
2       (2) request from the authorized survivors of that  
3       individual that the individual's relevant medical  
4       information, consistent with the federal health privacy  
5       rules set forth at 45 CFR Parts 160 and 164, be forwarded  
6       to a SUDEP registry for purposes of research; and  
7       (3) request from the authorized survivors of  
8       individuals with epilepsy and individuals determined or  
9       suspected to have died as a result of SUDEP that a donation  
10      of the individual's brain be made for research purposes to  
11      a brain bank, if such a gift has not already been  
12      established.