

First Regular Session
Sixty-ninth General Assembly
STATE OF COLORADO

INTRODUCED

LLS NO. 13-0879.01 Kristen Forrestal x4217

HOUSE BILL 13-1256

HOUSE SPONSORSHIP

Joshi,

SENATE SPONSORSHIP

Aguilar,

House Committees
Public Health Care & Human Services

Senate Committees

A BILL FOR AN ACT

101 CONCERNING THE CREATION OF "THE SUDDEN UNEXPECTED DEATH
102 IN EPILEPSY REPORTING REQUIREMENT ACT OF 2013", AND, IN
103 CONNECTION THEREWITH, RAISING AWARENESS ABOUT AND
104 REQUIRING REPORTING OF EPILEPSY-RELATED DEATHS.

Bill Summary

(Note: This summary applies to this bill as introduced and does not reflect any amendments that may be subsequently adopted. If this bill passes third reading in the house of introduction, a bill summary that applies to the reengrossed version of this bill will be available at <http://www.leg.state.co.us/billsummaries>.)

The bill requires the state's chief medical officer to establish a sudden unexpected death in epilepsy (SUDEP) awareness program to

Shading denotes HOUSE amendment. Double underlining denotes SENATE amendment.
Capital letters indicate new material to be added to existing statute.
Dashes through the words indicate deletions from existing statute.

educate medical examiners and coroners about SUDEP. The bill requires all postmortem examinations to determine whether the death was a result of SUDEP. If the findings are consistent with the definition of SUDEP, the medical examiner or coroner is required to indicate this cause of death on the death certificate, request that the individual's medical information be forwarded to a SUDEP registry, and request that the individual's brain be donated to a brain bank for research purposes.

1 *Be it enacted by the General Assembly of the State of Colorado:*

2 **SECTION 1.** In Colorado Revised Statutes, **add** 25-2-123 as
3 follows:

4 **25-2-123. Sudden unexpected death in epilepsy reporting**
5 **requirement - awareness program - short title - legislative**
6 **declaration.** (1) THIS SECTION SHALL BE KNOWN AND MAY BE CITED AS
7 "THE SUDDEN UNEXPECTED DEATH IN EPILEPSY REPORTING
8 REQUIREMENT ACT OF 2013".

9 (2) THE GENERAL ASSEMBLY FINDS AND DECLARES THAT:

10 (a) SUDDEN, UNEXPECTED DEATH IN EPILEPSY, REFERRED TO IN
11 THIS SECTION AS SUDEP, IS AN UNSOLVED, RARE CONDITION BY WHICH
12 TYPICALLY YOUNG OR MIDDLE-AGED PEOPLE WITH EPILEPSY DIE WITHOUT
13 A CLEAR CAUSE, AND IS GENERALLY DEFINED BY THE MEDICAL
14 COMMUNITY AS A SUDDEN, UNEXPECTED, NONTRAUMATIC, NONDROWNING
15 DEATH IN AN OTHERWISE HEALTHY INDIVIDUAL WITH EPILEPSY, WHERE
16 THE POSTMORTEM EXAMINATION DOES NOT REVEAL AN ANATOMIC OR
17 TOXICOLOGIC CAUSE FOR THE DEATH;

18 (b) SUDEP IS BELIEVED TO ACCOUNT FOR UP TO THIRTY-EIGHT
19 PERCENT OF DEATHS IN PEOPLE WITH EPILEPSY;

20 (c) AUTOPSY PLAYS A KEY ROLE IN DETERMINING THE DIAGNOSIS
21 OF SUDEP, YET THE INSTITUTE OF MEDICINE HAS FOUND THAT SUDEP
22 MAY BE UNDER-REPORTED FOR SEVERAL REASONS, INCLUDING A LACK OF

1 AWARENESS ABOUT SUDEP AMONG MEDICAL EXAMINERS AND CORONERS;

2 (d) THE CAUSE OF SUDEP IS NOT KNOWN, AND OPPORTUNITIES
3 FOR ITS PREVENTION HAVE BEEN HINDERED BY THE LACK OF A SYSTEMATIC
4 EFFORT TO COLLECT INFORMATION ABOUT PERSONS WHO HAVE DIED FROM
5 SUDEP, AS HAS BEEN DONE WITH MANY OTHER DISORDERS; AND

6 (e) IT IS APPROPRIATE TO RAISE AWARENESS OF SUDEP AMONG
7 MEDICAL EXAMINERS AND CORONERS BY DEVELOPING A SUDEP
8 AWARENESS PROGRAM AND TO FACILITATE RESEARCH INTO THE CAUSES
9 AND PREVENTION OF SUDEP BY REQUIRING THAT MEDICAL EXAMINERS
10 AND CORONERS IN THIS STATE WHO DETERMINE THAT AN INDIVIDUAL'S
11 CAUSE OF DEATH IS SUDEP WORK WITH RELEVANT ORGANIZATIONS IN
12 THE STATE TO ASSIST IN REQUESTING FROM THE NEXT OF KIN THAT AN
13 INDIVIDUAL'S RELEVANT MEDICAL INFORMATION BE SENT TO A SUDEP
14 REGISTRY AND THAT THE INDIVIDUAL'S BRAIN BE DONATED FOR RESEARCH
15 PURPOSES.

16 (3) THE CHIEF MEDICAL OFFICER SHALL ESTABLISH A SUDDEN
17 UNEXPECTED DEATH IN EPILEPSY AWARENESS PROGRAM TO EDUCATE
18 MEDICAL EXAMINERS AND CORONERS IN THE STATE ABOUT SUDEP.

19 (4) ALL POSTMORTEM EXAMINATIONS CONDUCTED MUST INCLUDE
20 AN INQUIRY TO DETERMINE WHETHER THE DEATH WAS A DIRECT RESULT
21 OF A SEIZURE OR EPILEPSY. THE CHIEF MEDICAL OFFICER, IN
22 CONSULTATION WITH THE COUNTY MEDICAL EXAMINERS, CORONERS, AND
23 ORGANIZATIONS WITH EXPERTISE IN SUDEP, SHALL ESTABLISH A
24 STANDARD PROTOCOL GOVERNING MEDICOLEGAL DEATH INVESTIGATIONS
25 INVOLVING SEIZURE DISORDERS IN ORDER TO IDENTIFY THE DEATHS. IF A
26 MEDICAL EXAMINER'S OR CORONER'S FINDINGS IN AN AUTOPSY ARE
27 CONSISTENT WITH THE DEFINITION OF KNOWN OR SUSPECTED SUDEP, THE

1 MEDICAL EXAMINER OR CORONER SHALL:

2 (a) INDICATE ON THE DEATH CERTIFICATE THAT SUDEP IS THE
3 CAUSE OR SUSPECTED CAUSE OF DEATH;

4 (b) RETAIN AND TRACK THE INFORMATION AND MAKE DATA
5 CONCERNING SEIZURE-RELATED DEATHS, WITH INDIVIDUALLY
6 IDENTIFIABLE INFORMATION REDACTED, PUBLICLY AVAILABLE UPON
7 REQUEST;

8 (c) WORK WITH RELEVANT ORGANIZATIONS IN THE STATE TO
9 ASSIST IN REQUESTING FROM THE AUTHORIZED SURVIVORS OF THE
10 DECEASED INDIVIDUALS THAT THEIR RELEVANT MEDICAL INFORMATION,
11 CONSISTENT WITH THE FEDERAL HEALTH PRIVACY RULES SET FORTH AT 45
12 CFR PARTS 160 AND 164, BE FORWARDED TO A SUDEP REGISTRY FOR
13 PURPOSES OF RESEARCH; AND

14 (d) WORK WITH RELEVANT ORGANIZATIONS IN THE STATE TO
15 ASSIST IN REQUESTING FROM THE AUTHORIZED SURVIVORS OF INDIVIDUALS
16 WITH EPILEPSY DETERMINED OR SUSPECTED TO HAVE DIED AS A RESULT OF
17 SUDEP THAT A DONATION OF THE INDIVIDUAL'S BRAIN BE MADE FOR
18 RESEARCH PURPOSES TO A BRAIN BANK. THE DONATION SHOULD
19 OPTIMALLY BE CARRIED OUT WITHIN TWENTY-FOUR HOURS OF DEATH,
20 WITH SHIPPING MATERIALS AND SHIPPING COSTS PAID BY THE BRAIN BANK.

21 **SECTION 2. Act subject to petition - effective date.** This act
22 takes effect at 12:01 a.m. on the day following the expiration of the
23 ninety-day period after final adjournment of the general assembly (August
24 7, 2013, if adjournment sine die is on May 8, 2013); except that, if a
25 referendum petition is filed pursuant to section 1 (3) of article V of the
26 state constitution against this act or an item, section, or part of this act
27 within such period, then the act, item, section, or part will not take effect

1 unless approved by the people at the general election to be held in
2 November 2014 and, in such case, will take effect on the date of the
3 official declaration of the vote thereon by the governor.