

A3298-A Epstein Same as S 67-A HOYLMAN

Public Health Law

TITLE. ...Relates to information provided to patients and health care practitioners regarding sudden unexpected death in epilepsy

01/22/21 referred to health
02/09/21 reported
02/11/21 advanced to third reading cal.110
03/25/21 passed assembly
03/25/21 delivered to senate
03/25/21 REFERRED TO HEALTH
01/05/22 DIED IN SENATE
01/05/22 RETURNED TO ASSEMBLY
01/05/22 ordered to third reading cal.121
01/26/22 passed assembly
01/26/22 delivered to senate
01/26/22 REFERRED TO HEALTH
05/18/22 recalled from senate
05/18/22 RETURNED TO ASSEMBLY
05/18/22 vote reconsidered - restored to third reading
05/18/22 amended on third reading 3298a
05/31/22 repassed assembly
05/31/22 returned to senate
05/31/22 RECOMMITTED TO HEALTH
06/02/22 SUBSTITUTED FOR S67A
06/02/22 3RD READING CAL.1832
06/02/22 REPASSED SENATE
06/02/22 RETURNED TO ASSEMBLY

EPSTEIN, SEAWRIGHT, SAYEGH, MCDONOUGH, ASHBY, GOTTFRIED, L. ROSENTHAL,
MCDONALD, SILLITTI, BARRON, DURSO, ZINERMAN, OTIS

Amd §2995, add §2997-f-1, Pub Health L

Requires that certain information be provided to patients and health care practitioners regarding sudden unexpected death in epilepsy.

STATE OF NEW YORK

3298--A

Cal. No. 121

2021-2022 Regular Sessions

IN ASSEMBLY

January 22, 2021

Introduced by M. of A. EPSTEIN, SEAWRIGHT, SAYEGH, McDONOUGH, ASHBY, GOTTFRIED, L. ROSENTHAL, McDONALD, SILLITTI, DURSO, ZINERMAN, OTIS -- read once and referred to the Committee on Health -- ordered to a third reading -- passed by Assembly and delivered to the Senate, recalled from the Senate, vote reconsidered, bill amended, ordered reprinted, retaining its place on the special order of third reading

AN ACT to amend the public health law, in relation to information provided to patients regarding sudden unexpected death in epilepsy

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

- 1 Section 1. This act shall be known and may be cited as the "Natasha
2 Gembka SUDEP Awareness Act."
- 3 § 2. Subdivision 2 of section 2995 of the public health law is amended
4 by adding two new paragraphs (f) and (g) to read as follows:
5 (f) "Health care practitioner" shall mean a physician, nurse practi-
6 itioner, or physician assistant licensed or certified pursuant to title
7 eight of the education law.
8 (g) "Sudden unexpected death in epilepsy" shall mean sudden, unex-
9 pected death in patients with epilepsy, with or without evidence of a
10 seizure.
- 11 § 3. The public health law is amended by adding a new section 2997-f-1
12 to read as follows:
13 § 2997-f-1. Provision of information relating to sudden unexpected
14 death in epilepsy. 1. Any health care practitioner who is treating a
15 patient diagnosed with epilepsy and at elevated risk for sudden unex-
16 pected death in epilepsy, who has primary responsibility for the treat-
17 ment and care of the patient for epilepsy, other than a health care
18 practitioner treating such patient in an emergency situation, shall
19 provide such patient with the following written information:
20 (a) current and evidence-based information about sudden unexpected
21 death in epilepsy risk factors and conditions reviewed and approved by

EXPLANATION--Matter in italics (underscored) is new; matter in brackets
[-] is old law to be omitted.

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1 one or more professional not-for-profit organizations with expertise in
2 neurology and epilepsy; and

3 (b) contact information for nonprofit organizations that provide
4 information and support services for epilepsy conditions.

5 2.(a) The commissioner shall provide written information to health
6 care practitioners necessary to implement subdivision one of this
7 section, and shall post such information on the department's website.

8 (b) The commissioner shall ensure that such information is culturally
9 and linguistically appropriate for all recipients.

10 (c) Any local or national organization that provides education or
11 services related to epilepsy conditions may request that the commission-
12 er include such organization's informational material and contact infor-
13 mation on the department's website. Once such a request is made, the
14 commissioner may add the information to the department's website at his
15 or her discretion.

16 (d) The commissioner shall, in consultation with local and national
17 organizations that provide education or services related to epilepsy
18 conditions, provide guidance to health care practitioners to assist
19 health care practitioners in determining whether a patient is at
20 elevated risk for sudden unexpected death in epilepsy, including but not
21 limited to, whether the patient has had convulsive seizures, the
22 frequency and recency of such seizures, and whether the patient's symp-
23 toms have subsided in response to medicinal or surgical treatment.

24 3. A health care practitioner found to be in violation of this section
25 shall be issued a warning and shall suffer no further civil penalty or
26 discipline on any first offense, provided such violation was not commit-
27 ted willfully and knowingly.

28 § 4. This act shall take effect on the ninetieth day after it shall
29 have become a law.

**NEW YORK STATE ASSEMBLY
MEMORANDUM IN SUPPORT OF LEGISLATION
submitted in accordance with Assembly Rule III, Sec 1(f)**

BILL NUMBER: A3298A

SPONSOR: Epstein

TITLE OF BILL:

An act to amend the public health law, in relation to information provided to patients regarding sudden unexpected death in epilepsy

PURPOSE OR GENERAL IDEA OF BILL:

The bill would require health care practitioners to provide patients with epilepsy and at elevated risk for sudden unexpected death in epilepsy (SUDEP) with current and evidence-based information about SUDEP risk factors and conditions, as well as contact information for non-profit organizations that provide support services for epilepsy conditions.

SUMMARY OF SPECIFIC PROVISIONS:

Section 1 names the bill the "Natasha Gembka SUDEP Awareness Act"

Section 2 amends section 2995 of the Public Health Law (Structure and definitions) by adding definitions for "health care practitioner" and "Sudden unexpected death in epilepsy."

Section 3 of the bill adds a new section 2997-f-1 to the Public Health Law (Provision of information relating to sudden unexpected death in epilepsy) to require health care practitioners who are treating patients for epilepsy that are at elevated risk for SUDEP to provide them with information regarding sudden unexpected death in epilepsy risk factors and conditions, and with contact information for nonprofit organizations that provide support for epilepsy conditions.

Section 3 also requires the Department of Health to provide culturally and linguistically appropriate written information to health care practitioners necessary to implement the above requirement, and to post such information on the Department's website. It would also allow nonprofit organizations to provide the Department with resources and contact information which may also be added to the website.

Section 4 of the bill is the effective date.

JUSTIFICATION:

According to the Centers for Disease Control (CDC), sudden unexpected death in epilepsy (SUDEP) is the cause of epilepsy-related mortality at an annual rate of 1.16 cases per every 1,000 people with epilepsy. Currently, SUDEP is not widely discussed between doctors and their patients, yet the best way to prevent SUDEP is to reduce the number of seizures suffered by a person with epilepsy as much as possible.

To be able to reduce their number of seizures, a person with epilepsy needs to know their triggers for seizures, take their medicine on time, and know the risk factors for SUDEP to better understand and plan for the future.

This legislation would require health care practitioners to provide patients they are treating for epilepsy that have an elevated risk for SUDEP with current and evidence-based information about SUDEP and to connect them with nonprofit organizations that can offer further assistance and support. It would also require the Department of Health to provide information to health care practitioners to assist with compliance and to post such information on its website.

LEGISLATIVE HISTORY:

S.5397-A of 2019-2020 (Hoylman): Advanced to Third Reading

A.7807-A of 2019-2020 (Epstein): Advanced to Third Reading Calendar

FISCAL IMPLICATIONS:

To be determined.

EFFECTIVE DATE:

This act shall take effect on the ninetieth day after it shall have become a law.