

# 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 tioner, 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.