

NEW YORK STATE SENATOR

Joseph A. Griffo

Governor signs Griffo's SUDEP bill to prevent epilepsy deaths

JOSEPH A. GRIFFO August 28, 2017

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## SUDEP Action 🕃 Making every epilepsy death count

**UTICA** – State Senator Joseph Griffo and Assemblyman Anthony Brindisi announced today that Governor Cuomo has signed into law legislation they sponsored (A.2380/S.2422) that would require death certificates to list if someone suffered a Sudden, Unexpected Death in Epilepsy (SUDEP).

SUDEP is a condition in which people with epilepsy die unexpectedly without a clear cause being determined. This condition is estimated to account for nearly 17 percent of deaths in people with epilepsy, particularly those with poorly controlled seizures, and represents about 1 in every 1,000 people with epilepsy who die each year. In the case of people with poorly controlled epilepsy, it results in about 1 in every 150 annually.

The Institute of Medicine characterizes SUDEP as an underreported condition, with little documented information on it available. The new law sponsored by Brindisi and Griffo that has now been signed will help researchers understand more about the condition, and hopefully prevent unexpected deaths from SUDEP.

This legislation was prompted, in large part, by the death of Christopher Donalty on Feb. 21, 2002. Christopher, born and raised in Utica, the son of Jeanne and Barry Donalty, was 21 years old when he died of SUDEP. Christopher's parents had no idea at the time that their son – and thousands of others like him each year – could potentially die from this poorly understood condition.

"The loss of a loved one is tragic for any family to endure, but it is even more heartbreaking when so little is known about their cause of death," **said Senator Joseph Griffo, of Rome**. "But with the unrelenting commitment of Jeanne and Barry Donalty to better understand the SUDEP condition that took their son and many others like him, I am encouraged that our new legislation will now provide more hope and clarity toward preventing these epilepsyrelated deaths.

"Without the advocacy of Jeanne Donalty of Utica, this bill would not have been signed into law," **said Assemblyman Anthony Brindisi, of Utica.** "The tragic loss of her 21-year-old son Christopher to SUDEP in 2002 resulted in her tireless work for more research on it. She provided us with valuable information to write this legislation, and the work she continues to do for epilepsy research is clearly making a big difference in our understanding of it." "We appreciate all that Senator Griffo and Assemblyman Brindisi have done to see this important effort finally become reality," **said Christopher's parents, Jeanne and Barry Donalty.** "This law is going to provide much-needed data, so that we can hopefully find ways to prevent these unfortunate and tragic deaths. We'd also like to thank Governor Cuomo for recognizing the significance of this bill by signing it into law. After losing our son Christopher to SUDEP, our family remains committed to increasing awareness of this devastating condition and raising funds to research it. We are grateful to Senator Griffo and Assemblyman Brindisi for their determination to address this critical issue on behalf of the epilepsy community, and we all look forward to the day when a cure can finally be found."

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## RELATED LEGISLATION

## 2017-S2422

• Introduced

• • In Committee Assembly

- In Committee Senate
- • On Floor Calendar Assembly
  - On Floor Calendar Senate
- • Passed Assembly
  - Passed Senate
- Delivered to Governor
- Signed By Governor
- •

## Relates to the reporting of sudden, unexpected death in epilepsy

January 13, 2017

Senate Floor Calendar

Sponsored by Joseph A. Griffo

Do you support this bill?