



NEW YORK STATE SENATOR

Joseph A. Griffo

Legislature passes bill sponsored by Griffo that would help better understand epilepsy-related deaths

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ALBANY – The New York State Senate and Assembly on Monday passed legislation sponsored by Senator Joseph Griffo and Assemblyman Anthony Brindisi that would require death certificates to include whether someone suffered a sudden, unexpected death in epilepsy.

Sudden, Unexpected Death in Epilepsy – also called SUDEP – is a mysterious and rare condition in which young and middle-aged adults with epilepsy die without a clear cause determined during an autopsy. SUDEP is estimated to account for nearly 17 percent of deaths in people with epilepsy, particularly people whose seizures are poorly controlled. More than 1 out of every 1,000 people with epilepsy die from SUDEP each year, with poorly-controlled epilepsy increasing the odds to 1 out of 150 people. Also, SUDEP takes more lives annually in the U.S. than Sudden Infant Death Syndrome (SIDS).

But the Institute of Medicine has concluded that Sudden, Unexpected Death in Epilepsy is underreported, and so very little information has been collected about people who have died from this disorder. By requiring that these deaths are reported categorically, this bipartisan legislation will help raise more awareness and understanding about SUPED so that people can better try to prevent this unpredictable loss of life.

This legislation ([S1789](#) / [A2359](#)) was prompted, in large part, by the death of [Christopher Donalty](#) on Feb. 21, 2002. Christopher, born and raised in Utica as the son of Jeanne and Barry Donalty, was 21 years when he died of Sudden, Unexpected Death in Epilepsy. 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.

Senator Joseph Griffo, R-Rome, said: “Sudden, Unexpected Death in Epilepsy claims the lives of too many people ahead of their time, leaving too many families to suffer the loss of a loved one without ever having the chance to say goodbye. If there is a way to better understand what causes SUDEP, then we need to obtain that knowledge. If there is a means to prevent these unforeseen tragedies from shattering any other families, then we must do whatever it takes to one day achieve that cure.”

Assemblyman Anthony Brindisi, D-Utica, said: “I want to thank Jeanne Donalty for her strong advocacy on behalf of improving medical research on SUDEP. She provided us with important information that was used in preparing this legislation. Her work on this and other aspects of epilepsy research is very commendable, and is truly making a difference in our knowledge about this condition.”

Since Christopher Donalty's death, his mother, Jeanne, has served on the Board of Directors for [Citizens United for Research in Epilepsy, or CURE](#), and has founded a regular [CURE benefit](#) in her son's memory to raise funds to support further epilepsy research. Current research into the possible causes of SUDEP focuses on problems with breathing, heart rhythm and brain function that occur with a seizure, according to the [Epilepsy Foundation](#).

Christopher's parents, Jeanne and Barry Donalty, said: “Our family's heartfelt thanks go out to both Senator Griffo and Assemblyman Brindisi for their tireless efforts in getting this significant legislation passed, which will provide critical data for ongoing research into the

cause(s) of SUDEP and, ultimately, how to prevent it from happening. After losing our son, Christopher, to SUDEP, our family has been committed to increasing awareness of this tragic and devastating occurrence and raising funds in support of SUDEP research. In addition to their sponsorship of this bill, Senator Griffo and Assemblyman Brindisi have demonstrated their willingness to speak out on behalf of the epilepsy community – for individuals and their families, who look forward to the day when a cure is found.”

The Epilepsy Foundation of Northeastern N.Y. was the driving force in promoting this legislation. Also part of this effort were Dr. Michael Gruenthal, Chair of the Department of Neurology at Albany Medical Center, and Dr. Orrin Devinsky, Director of NYU Langone’s Comprehensive Epilepsy Center.

The bill will now be sent to the Governor for his approval.

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