

HOUSE JOINT RESOLUTION NO. 98

Designating July 12, in 2014 and in each succeeding year, as Sudden Unexpected Death in Epilepsy Awareness Day in Virginia.

Agreed to by the House of Delegates, February 5, 2014

Agreed to by the Senate, March 4, 2014

WHEREAS, Sudden Unexpected Death in Epilepsy is a rare condition that kills nearly one in every thousand individuals with epilepsy per year; individuals affected by this condition will die suddenly and without apparent cause; and

WHEREAS, instances of Sudden Unexpected Death in Epilepsy (SUDEP) were not widely known until 1992, when the first major news article on the condition was published; and

WHEREAS, the causes of SUDEP are still not fully understood; while data on SUDEP is available from a variety of sources, there have been no large-scale studies conducted in the United States on the condition; and

WHEREAS, only a limited number of organizations focus exclusively on the research and study of SUDEP; organizations such as Citizens United for Research in Epilepsy in Chicago raise funds for SUDEP, while the North American SUDEP Registry, the Stop SUDEP Program, and SUDEP Aware in Toronto, Canada, conduct research; and

WHEREAS, SUDEP can happen to anyone with epilepsy, but the individuals at the highest risk for SUDEP are those with frequent, generalized tonic-clonic (grand mal) seizures; while there are methods for reducing the risk of SUDEP, these are unique to the individual and must be discussed with a doctor; and

WHEREAS, a joint report from the American Epilepsy Society and the Epilepsy Foundation states that, among individuals with poorly controlled seizures, the risk increases to one death in every hundred people with epilepsy in a year; and

WHEREAS, while certain people are at higher risk for SUDEP than others, not all risk factors are conclusively known and agreed upon; and

WHEREAS, due to a lack of awareness, the diagnosis of SUDEP is low and often does not appear on a death certificate, leading to incomplete statistics on the condition; and

WHEREAS, Khristin Elizabeth Kylo, a Vienna native, died on January 13, 2011, at Princeton University from SUDEP; and

WHEREAS, it is important to understand the nature and causes of SUDEP, seek to mitigate risk factors and prevent SUDEP, and increase awareness of SUDEP in the Commonwealth and throughout the United States; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the General Assembly designate July 12, in 2014 and in each succeeding year, as Sudden Unexpected Death in Epilepsy Awareness Day in Virginia; and, be it

RESOLVED FURTHER, That the Clerk of the House of Delegates transmit a copy of this resolution to the family of Khristin Elizabeth Kylo so that they may be apprised of the sense of the General Assembly of Virginia in this matter; and, be it

RESOLVED FINALLY, That the Clerk of the House of Delegates post the designation of this day on the General Assembly's website.

ENROLLED

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