

NEWS RELEASE

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Kotowski's proposal creates national model to prevent sudden unexpected deaths in epilepsy

SPRINGFIELD—A measure to improve awareness and gather research concerning sudden unexpected deaths in epilepsy (SUDEP) passed the Senate on Tuesday.

State Senator Dan Kotowski (D-Park Ridge) worked with Tom Stanton, the executive director of the Danny Did Foundation, to put together this proposal. Mr. Stanton's 4 year-old nephew, Danny, lived with epilepsy before dying from SUDEP following a seizure that occurred during his sleep. His family was never made aware of the possibility of SUDEP, a seizure-related risk that is not often discussed between doctors and patients.

"Coroners and medical examiners can play a key role in recording instances of SUDEP, and this data will help to educate the public on its causes and signs," Kotowski said.

The definition of 'Sudden Unexpected Death in Epilepsy' (SUDEP) is accepted as an unexpected death in a person with epilepsy, with no clear causes for death. It is a baffling condition that brings sorrow and bereavement to many families every year. Little is known about the precise causes of SUDEP, although it is now accepted that it is likely to be triggered by a seizure as, almost invariably, SUDEP seems to happen in the aftermath of a seizure. SUDEP is the most common cause of death in epilepsy and accounts for an estimated 20,000 of deaths in people with epilepsy every year.

"This legislation will create a national model to further SUDEP research," Kotowski continued. "It will help save lives by providing accurate data that furthers research and hopefully one day can prevent sudden death for those with epilepsy."

"Providing data to a national SUDEP registry is a key factor in discovering the causes behind this devastating occurrence," said Stanton. "It is critical that an autopsy includes inquiries about a history of seizures and epilepsy and that the process includes the opportunity for a bereaved family to further epilepsy research. This bill will make Illinois a national leader in fighting SUDEP."

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