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FOR IMMEDIATE RELEASE:

Governor Quinn Signs Danny Stanton SUDEP Act Into Law

Legislation mandates reporting of sudden deaths from epilepsy to national registry

August 12, 2013 – Chicago, Ill. – Illinois Governor Pat Quinn today signed Illinois Senate Bill 1226 – a.k.a. the Danny Stanton SUDEP Act - into law. The Danny Did Foundation worked with State Senator Dan Kotowski (D-Park Ridge) to create the legislation. The law requires medical examiners and coroners to include an inquiry about a history of epilepsy and seizures as part of a standard autopsy, and, if an instance of Sudden Unexpected Death in Epilepsy (SUDEP) is determined, to report it to a national registry.

"Coroners and medical examiners can play a critical role in recording instances of SUDEP. This data will help to educate the public on its causes and to provide a more accurate measure of how often it occurs," said Kotowski, a member of the Danny Did Foundation's board of directors and a person living with epilepsy. "We expect that this law will serve as a national model in combating SUDEP."

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. SUDEP is the most common cause of death in epilepsy and accounts for more deaths annually than from fires and sudden infant death syndrome (SIDS) combined.

"I am proud to have worked with the Danny Did Foundation on this important piece of legislation," said Rep. John D'Amico (D-Chicago), the chief sponsor of the bill in the Illinois House. "It is my hope that this law will play a significant role in raising awareness about SUDEP and produce tangible research that leads to its prevention."

The legislation has the support of the Illinois Coroners and Medical Examiners Association as well as numerous epilepsy organizations, including the Epilepsy Foundation of America and its Chicago chapter. Illinois joins New Jersey as the first two states to have legislation of this kind. Under the law, cases of SUDEP will be reported to the North American SUDEP Registry at New York University. It becomes effective January 1, 2014. The namesake of the legislation, Danny Stanton, died from SUDEP on December 12, 2009, shortly before his fifth birthday. His life inspired the nonprofit foundation that has helped families across 41 states and three countries.



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About Danny Did Foundation

Founded by Chicagoans Mike and Mariann Stanton in January 2010 after the death of their four-year-old son Danny, the Danny Did Foundation works toward its mission to prevent deaths caused by seizures with these main goals in mind: advancing public awareness of Sudden Unexpected Death in Epilepsy (SUDEP), enhancing the SUDEP communication model between medical professionals and families afflicted by seizures, and the mainstreaming of seizure detection and prediction devices that may assist in preventing seizure-related deaths. We view these devices as complimentary to medicinal, surgical and dietary measures that are used to treat seizures. Epilepsy impacts nearly three million people in the United States and 65 million people worldwide. One in 26 Americans will develop epilepsy over their lifetime. Seizures can sometimes be fatal from a range of causes; more people die as a result of seizures than from fires and sudden infant death syndrome (SIDS) combined. Thousands of deaths occur annually from SUDEP, status epilepticus (prolonged seizures), and other seizure-related causes such as drowning and other accidents. Find more information at www.dannydid.org, www.facebook.com/DannyDid and www.twitter.com/dannydidorg. The name of the foundation originates from the last line of Danny's obituary, written by his dad: "Please go and enjoy your life. Danny did."