



Danny Did[®]
F O U N D A T I O N

October 23rd Marks International Day of SUDEP Action

The **Danny Did Foundation** has joined epilepsy organizations in the United States, Europe, Australia and around the world to recognize October 23rd as a global awareness day for Sudden Unexpected Death in Epilepsy, or SUDEP. The goals are to advance awareness about SUDEP, to encourage people with epilepsy to learn about SUDEP and their individual risk, and to honor the lives lost to the most common form of death in epilepsy.

This international collaboration has grown strong since 2008, and now in 2018, there is a multi-faceted movement to understand and prevent SUDEP. Initiated by families and advocates who were desperate for answers, this movement now includes scientists, clinicians, medical examiners, non-profit organizations, and governmental agencies. This broad group of stakeholders has rallied to end sudden death in epilepsy by launching innovative research projects, awareness and educational campaigns, and bereavement support services.

Earlier this year, action in the U.S. featured a multiday event devoted to epilepsy mortality known as **Partners Against Mortality in Epilepsy (PAME)**. The fourth PAME meeting took place June 14-16th in Alexandria, Virginia. Details about PAME are at <http://pame.aesnet.org/>.

UK-based nonprofit **SUDEP Action** – which created SUDEP Action Day - has participated in PAME meeting since 2012, enabling a deepening of the relationships across the pond and the opportunities to advocate together. The **Epilepsy Foundation of America** is among the nonprofits supporting SUDEP Action Day on October 23rd.

Tom Stanton, Executive Director of the Danny Did Foundation and Co-Chair of PAME said,

“This is the 5th time that we will celebrate SUDEP Action Day, which includes the opportunity to honor the special relationship with bereaved families in the UK and in the U.S and around the world. The SUDEP movement requires action and advocacy daily to bring us closer to prevention, but October 23rd is an especially powerful day when we can all share common messages and raise our voices together. We lose thousands of people like Danny every year, and we urgently need funding and progress. We are grateful to SUDEP Action for taking the lead to engage all advocates around the world to take part.”

Jane Hanna, CEO of SUDEP Action said,

“It is great to have PAME’s support for this global initiative which is now in its fifth year. As it gathers momentum, it is so important that the international community rallies behind this cause; and to have such close relationships helps to drive this forward.”

To learn about how to get involved with SUDEP Action Day, visit <http://sudepactionday.org>.

To find and share social media content tied to SUDEP Action Day, search for #SUDEPActionDay2018.

FOR MORE INFORMATION:

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About Danny Did Foundation

Founded by Chicago parents Mike and Mariann Stanton in 2010 after the sudden death of their four-year-old son Danny, the Danny Did Foundation’s primary mission is to prevent deaths caused by seizures. The Foundation advances public awareness of epilepsy and Sudden Unexpected Death in Epilepsy (SUDEP), strives to improve communication about SUDEP between medical professionals and families affected by seizures, and advocates for the mainstream acceptance and use of seizure detection and prediction devices that may assist in preventing seizure-related deaths.

Epilepsy affects 3.4 million people in the United States and 65 million people worldwide. One in 26 Americans will develop epilepsy during their lifetime. But what few people understand, including many people with the disorder, is that seizures can be fatal. More people die as a result of seizures than from fires and sudden infant death syndrome (SIDS) combined. The causes of death can vary and include drowning, other accidents and status epilepticus (prolonged seizures). In addition, thousands of deaths occur annually from SUDEP, a fact that is little known and too rarely addressed in public and in medical circles. The name of the Danny Did Foundation originates from the last line of Danny Stanton’s obituary, written by his dad: *“Please go and enjoy your life. Danny did.”*