



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 2017, 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.

Progress in the U.S. is supported by a multiday event devoted to epilepsy mortality known as Partners Against Mortality in Epilepsy (PAME). The fourth PAME meeting will be held June 14-16, 2018 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 fourth time that we will celebrate SUDEP Action Day, which includes the opportunity to honor the special relationship with bereaved families both in the UK and in the U.S. The SUDEP movement takes daily action 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 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,

“The special relationship we have with PAME and with many of the U.S. organizations has meant that distance has not been a barrier. The opportunities to share and for the SUDEP movements in both countries to support each other means we can make faster progress together. The SUDEP movement is a success story so far only because we have not let geography get in the way.”

To learn about how to get involved with SUDEP Action Day, visit <http://sudepactionday.org/get-involved-2017/campaigners/>.

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.”*