



Epilepsy Deaths Highlighted in Minneapolis Event

Epilepsy organizations, families, scientists and doctors gather June 19-22

Minneapolis, May 5, 2014 -- One in 26 Americans will develop epilepsy over the course of a lifetime¹ leading to nearly three million Americans now living with epilepsy. For nearly one-third of them, their seizures are uncontrolled by medicine and other common forms of treatment. People who have uncontrolled seizures are at heightened risk for Sudden Unexpected Death in Epilepsy (SUDEP), which takes more lives annually in the United States than fires and sudden infant death syndrome (SIDS) combined.

To address SUDEP, epilepsy experts, people with epilepsy, bereaved families and advocacy organizations have come together for the Partners Against Mortality in Epilepsy (PAME) Conference -- a four-day educational event devoted predominately to SUDEP. This meeting aims to foster knowledge, heighten awareness and to hasten action around epilepsy mortality. Top researchers from around the world will be presenting the latest discoveries and findings on SUDEP and discussing the latest developments in devices and treatments to prevent epilepsy mortality.

According to the National Institutes of Health, SUDEP is the most common epilepsy-related cause of death. Yet, for many families facing epilepsy, information regarding SUDEP is not provided by their doctors, creating a communication gap that impacts a patient's ability to take steps to minimize their risk.

“There is a growing need for communications between researchers, clinicians, families and the public in order to identify approaches which may be useful to all people involved in caring for someone with epilepsy,” said Elson So, president, American Epilepsy Society. “The goal of this conference is to build cross-fertilization of information so that clinical interactions can be better informed by patients and families and so that clinicians can better recognize risk factors and involve families in timely discussion of these risks.”

The PAME Conference will be held June 19-22 at the Hyatt Regency Minneapolis. To learn more visit aesnet.org/pame

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¹ Institute of Medicine March 2012