

For Immediate Release

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Few Answers in Understanding Death from Epilepsy

Unique conference joins physicians, scientists with patients and families to spur action around an overlooked and underfunded public health issue

washington, D.C.—Epilepsy-related deaths are a significant public health problem, yet are poorly understood and often overlooked. People with epilepsy are two to three times more likely to die prematurely than people without the disease. The greatest cause of epilepsy-related deaths, Sudden Unexpected Death in Epilepsy (SUDEP), kills more than 1 out of 1,000 people with epilepsy each year in the U.S. When seizures are uncontrolled, the risk of SUDEP increases to more than 1 out of 150.

To increase understanding of mortality in epilepsy, including SUDEP, Partners Against Mortality in Epilepsy (PAME) unites physicians, scientists, health care professionals, people with epilepsy, caregivers and bereaved family members for a unique conference that facilitates collaboration and spurs action. The 2016 PAME Conference will be held June 23-26, in Alexandria, Va. To learn more about the PAME conference or to register, please visit http://pame.aesnet.org.

PAME Conference highlights include:

- Mortality in people with epilepsy improving epidemiology and surveillance
- How SUDEP is different in children
- Factors that predispose people to die from epilepsy
- Gene analysis and discovery in SUDEP
- Autoimmune diseases and non-SUDEP causes
- Events during and after seizures that cause SUDEP
- How to support families in their grief
- Future direction of research and prevention

The PAME Conference offers the latest research in epilepsy mortality through scientific posters and educational sessions presented by leading U.S. and international experts and discussions that are designed to close the gaps in knowledge and understanding. In addition to diverse educational courses, the PAME meeting offers advocacy opportunities to advance research and raise public awareness.

This conference has been conceived and planned by a large and diverse group of professionals, advocates and family members. Major contributing organizations include the <u>American Epilepsy Society (AES)</u>, <u>Citizens United for Research in Epilepsy (CURE)</u>, <u>Epilepsy Foundation (EF)</u>, <u>the Danny Did Foundation</u>, and <u>the Patrick Ring Foundation</u>. To learn more about the PAME conference, visit http://pame.aesnet.org.