

Families, doctors, advocates urgently seeking answers in epilepsy deaths

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Generalized 3 Hz spike and wave discharges in a child with childhood absence epilepsy. Credit: Wikipedia.

One in 26 Americans will develop epilepsy over the course of a lifetime. In advance of the June 23-26 Partners Against Mortality in Epilepsy (PAME) Conference, epilepsy experts and people who face seizures are sounding the alarm on a greatly underestimated problem - epilepsy-related deaths. Although epilepsy affects 3 million Americans, communication and understanding around the risk of mortality remains low, creating a blind spot for caregivers that can prove devastating.

The most common cause of death in [epilepsy](#) is Sudden Unexpected Death in Epilepsy (SUDEP), which takes more lives annually in the United States than fires and sudden infant death syndrome combined. Cases of SUDEP occur without warning in otherwise healthy people living with epilepsy, and when no other cause of death is found.

"No words can describe the horror and devastation of unexpectedly losing a child or loved one to epilepsy. SUDEP has been a silent killer for far too long. PAME, a unique and dynamic collaboration of families and professional, is calling on the medical community to confront and disclose all risks of epilepsy, including SUDEP, so that individuals and families are empowered with information to make safe and informed decisions," says Gardiner Lapham, bereaved mother, PAME Co-Chair, and Citizens United for Research in Epilepsy (CURE) board member.

Beyond SUDEP, epilepsy-related deaths also occur from status epilepticus (prolonged seizures), suicide and fatal accidents that occur during a seizure, such as drowning, burning, choking, or falling. Yet, epilepsy is often not listed as a cause of death on death certificates, making it difficult for [public health officials](#) to quantify and draw attention to the problem.

Without accurate, systematic data to count epilepsy deaths, doctors and researchers are hampered in their goal of understanding what circumstances make someone more vulnerable. The lack of data also

challenges clinicians in deciding what to disclose to patients and families about their level of risk and in advising them on how best to prevent SUDEP.

To increase understanding of mortality in epilepsy, the PAME conference will unite physicians, scientists, [health care professionals](#), people with epilepsy, caregivers and bereaved family members from around the world 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>.

Now in its third meeting, PAME offers more than 50 presentations on the latest research in epilepsy mortality through panels and educational sessions designed to close the gaps in knowledge and understanding including:

- Mortality in people with epilepsy - Studies suggest that epilepsy-related deaths are under-reported. A panel will explore ways to improve epidemiology and surveillance, increase data collection and explore populations that aren't typically counted.
- Factors that predispose people to die from epilepsy - The risk factors and SUDEP remain unclear. Researchers have proposed explanations including irregular heart rhythm and genetic predisposition to accidental suffocation during sleep. A panel of leading genetic and epilepsy experts explores what we know and don't know about the biomarkers and other risk factors of death in epilepsy.
- Genetic analysis and discovery in SUDEP - Much of the research into the genetic risks of SUDEP has focused on single gene mutations that cause both epilepsy and sudden death. New research is emerging linking these genes to SUDEP.
- Options for prevention - Though much remains to be discovered

about underlying causal mechanisms of mortality, there are prevention strategies available to us now that we can and should employ. Areas to be explored include the latest in device research, upcoming practice guidelines and patient education needs.

Major contributing organizations include the American Epilepsy Society, CURE, the Epilepsy Foundation, the Danny Did Foundation, and the Patrick Ring Foundation. Discounted rates for early registration end on May 16.

Provided by American Epilepsy Society

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