



Stronger Together

**Policy Statement: The epilepsy community and organizations listed strongly support increased awareness of Sudden Unexpected Death in Epilepsy (SUDEP) and expansion of scientific efforts to understand SUDEP.** We advocate for programs to educate medical examiners and coroners about SUDEP with mandatory reporting of SUDEP on death certificates and opportunities for families of individuals who suffered SUDEP to provide tissue to brain banks and medical information to registries for research to combat this major cause of mortality in people with epilepsy.

Epilepsy is associated with substantially higher rates of mortality than experienced in the population as a whole, with SUDEP being the most common cause of epilepsy-related deaths. SUDEP applies to a sudden death in someone known to have epilepsy, in the absence of another cause for the death. As noted in the 2012 Institute of Medicine report *Epilepsy Across the Spectrum*<sup>i</sup> people with epilepsy succumb to sudden death at a rate over 20 times higher than the general population.<sup>ii</sup> Premature death occurs in people with epilepsy: it is estimated that 10 years of life are lost for people whose epilepsy has a known cause and 2 years are lost for people with epilepsy from an unknown cause. Overall the deaths of 40% of people with severe epilepsy and 4% of those with all types of epilepsy are due to SUDEP.<sup>iii</sup>

Despite the importance of the problem and the implications for intervention, SUDEP has not previously received widespread professional attention or patient education and awareness. The IOM report stressed recognition and prevention of SUDEP and identified lack of awareness of SUDEP by coroners and medical examiners as a significant problem. To accurately count the number and distribution of SUDEP cases, determine its cause, and—ultimately—seek opportunities for prevention, more accurate forensic data are needed. **States have a critical leadership role to increase awareness and education about SUDEP in their medical communities, to better assist those families impacted, and to advance data collection and public health research on SUDEP.**

**State Leaders are urged to support legislation that:**

- 1. Supports programs to educate medical examiners and coroners about SUDEP.** By appreciating the nature of SUDEP and its relatively common occurrence in the epilepsy population, coroners and medical examiners, whose responsibility it is to identify the cause of death, will be able to accurately report SUDEP as a cause of death. Accurate reporting is an important step towards research into this poorly understood condition.
- 2. Provides for mandatory reporting on death certificates of victims of SUDEP.** Accurate prevalence data can further the assessment of the public health significance of SUDEP. Furthermore, this reporting is essential for identification of individuals affected for future research.

- 3. Increases awareness about organ donation & expands research on SUDEP.** A critical component of research is the availability of tissue. Families of those impacted by SUDEP should have the opportunity to provide medical information to a SUDEP registry and allow the tissue of the individuals who died of SUDEP to be incorporated into brain banks. These measures are crucial for research to determine the causes of SUDEP and the development of preventative measures for SUDEP.

**Magnitude of Epilepsy:** There are over 2.2 million people in the United States and more than 65 million people worldwide who have epilepsy;<sup>iv</sup> 150,000 new cases of epilepsy are diagnosed in the United States annually; **1 in 26 people in the United States will develop epilepsy at some point in their lifetime;** children and older adults are the fastest growing segments of the population with new onset epilepsy. **Epilepsy is one of the most common neurological disorders;** in the United States the prevalence of epilepsy is greater than autism spectrum disorder, cerebral palsy, multiple sclerosis, and Parkinson's disease combined.

### **Background on the organizations:**

The American Epilepsy Society (AES) is the main professional organization in the United States representing multi-specialty members including physicians, psychologists, nurses, social workers, and research scientists that provide care to people with epilepsy. The Society promotes research, interdisciplinary communication, and education for professionals dedicated to the prevention, optimal treatment, and cure of epilepsy.

The Epilepsy Foundation, a national nonprofit with affiliated organizations throughout the United States, has led the fight against epilepsy since 1968. The Foundation's mission is to stop seizures, find cures and overcome the challenges created by epilepsy. The Epilepsy Therapy Project was founded in 2002 by a group of parents, distinguished physicians, and researchers to support the commercialization of new therapies through direct grants and investments in promising academic and commercial projects. Effective January 1, 2013 the Epilepsy Foundation and the Epilepsy Therapy Project merged to form one organization known as the Epilepsy Foundation.

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<sup>i</sup> National Academies, Institute of Medicine, *Highlights from Epilepsy Across the Spectrum: Promoting Health and Understanding A Focus on Mortality and Sudden Unexpected Death in Epilepsy, 2012*. Accessed at: <http://www.iom.edu/~media/Files/Report%20Files/2012/Epilepsy/IOM%20Report%20Highlights%20for%20PAME%20Conference.pdf>

<sup>ii</sup> Ficker DE, So EL, Shen WK, et al. "Population-based study of the incidence of sudden unexplained death in epilepsy." *Neurology* 1998;51:1270-1274.

<sup>iii</sup> Tellez-Zenteno JF, Ronquillo LH, Weibe S. "Sudden unexpected death in epilepsy: Evidence-based analysis of incidence and risk factors." *Epilepsy Research* 2005;65(1-2):101-115.

<sup>iv</sup> National Academies, Institute of Medicine, *Epilepsy Across the Spectrum: Promoting Health and Understanding, 2012*. Accessed at: <http://www.iom.edu/Reports/2012/Epilepsy-Across-the-Spectrum.aspx>