



May 3, 2017

Fighting Epilepsy & SUDEP

A community response: Advocates embrace new AAN/AES SUDEP guideline while urging for expanded surveillance, research and education



The release of new practice guidelines co-developed by the American Academy of Neurology (AAN) and the American Epilepsy Society (AES) on the issue of Sudden Unexpected Death in Epilepsy (SUDEP) is a benchmark moment for everyone impacted by epilepsy. Historically, the communication between medical professionals and their patients about SUDEP risk has been unacceptably low. Too often, family members have learned about SUDEP only after they have lost a loved one. A change in practice is long overdue.



For the first time, the AAN and AES are issuing a definitive and public recommendation for neurologists to inform all populations suffering from epilepsy about the risk of SUDEP, the most common cause of mortality for people with epilepsy. Every patient and parent deserves and needs to be educated about the range of risks that accompany epilepsy, including one as serious as SUDEP.



The guidelines send the critical message that anyone who suffers generalized tonic-clonic seizures is at risk for SUDEP. The frequency of these seizures elevates the risk, and people who have three or more convulsive seizures per year face a 15-fold increased threat. Minimizing seizures through specialized medical care and strategies to reduce breakthrough seizures are the best methods to reduce risk. Since SUDEP happens more often in sleep, nighttime supervision or monitoring may also help and should be part of the patient/provider conversation. While the report assigns a blanket SUDEP risk ratio to children, it is important to note that certain pediatric populations - children with Dravet syndrome, Dup15q syndrome, and others – face a significantly higher risk ratio.



We hope these recommendations lead to increased disclosure rates and better standards of care. Yet much more remains to be done to advance our understanding of SUDEP and its prevention. This report underscores a systemic and ongoing failure to conduct necessary surveillance and prevention trials, and to adequately educate medical examiners, doctors and patients about SUDEP. Major progress is crucial, and will require increased collaboration among medical professionals, public health experts, families, researchers and advocates.



We urge all medical professionals to use these recommendations to initiate an honest and ongoing conversation that is tailored to their patient’s risk level. Furthermore, we urgently call for expanded research to better our understanding of SUDEP incidence, risk factors and to identify additional prevention strategies that could save lives.





ABOUT EPILEPSY AND SUDEP

Epilepsy is a neurological condition that is typically diagnosed after two or more unprovoked seizures. The disease affects nearly 3 million Americans - more people than multiple sclerosis, cerebral palsy, muscular dystrophy and Parkinson's combined – yet receives fewer federal dollars per patient than each. A death is referred to as SUDEP when a seemingly healthy person with epilepsy dies unexpectedly and no clear reason for the death can be determined. SUDEP takes more lives annually than house fires and SIDS combined.



Signed,

Danny Did Foundation
CURE, Citizens United for Research in Epilepsy
Epilepsy Foundation
NASR: North American SUDEP Registry
Autism Speaks
FACES: Finding a Cure for Epilepsy and Seizures
Tuberous Sclerosis Alliance
Dup15q Alliance
Dravet Syndrome Foundation
Autism Science Foundation
SUDEP Action

