ABOUT THE EPILEPSY FOUNDATION

The Epilepsy Foundation, a national nonprofit with more than 45 network partners throughout the U.S., has led the fight against seizures since 1968. The Foundation is an unwavering ally for individuals and families impacted by epilepsy and seizures.

The mission of the Epilepsy Foundation is to lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives. The Foundation works to ensure that people with seizures have the opportunity to live their lives to their fullest potential.

For additional information, please visit epilepsy.com/sudep.

CONTACT US
800.332.1000
(en Español 1-866-748-8008)
SUDEP@efa.org

KNOW THE SUEDEP FACTS

More than 1 out of 1,000 with epilepsy die from SUEDEP each year.

SUEDEP is the leading cause of death among young adults with poorly controlled seizures.

For people with poorly controlled seizures, the risk of SUEDEP is much higher:
1 out of 150 each year

The best way to prevent SUEDEP is to work with your health care team to have as few seizures as possible.

BE AN AMBASSADOR FOR THE SUEDEP INSTITUTE

Have you been affected by SUEDEP or are you living with epilepsy and want to make a difference by raising awareness about death in epilepsy? Do you want to share your journey? If so, join us as an Ambassador for the SUEDEP Institute. Contact us at SUDEP@efa.org.

The exact causes of SUEDEP are not well understood but it is likely due to problems with consciousness, breathing and heart function following a seizure. Many but not all instances of SUEDEP occur at night, when seizures are not witnessed.
In a 2016 survey, almost all caregivers and nearly 2 in 3 people with epilepsy said they worry about death from epilepsy or seizures. Almost half of respondents said learning more about SUDEP could make a difference in how they approach seizure control. People know about the dangers of fire and Sudden Infant Death Syndrome (SIDS), but there is very little awareness about the risk of death from epilepsy. And unfortunately, SUDEP kills more Americans than either of these.

WHAT IS THE SUDEP INSTITUTE?

The Epilepsy Foundation is dedicated to helping people living with epilepsy. The SUDEP Institute empowers people living with epilepsy with information and education about SUDEP. We also urge medical professionals to openly discuss reducing risk with their patients. We accomplish this by:

• Conducting SUDEP education and awareness for people living with epilepsy, their families, and medical professionals
• Driving and supporting research into the causes of and ways to prevent SUDEP
• Offering bereavement support services via phone, email, text or an online community for those affected by loss from epilepsy
• Working collaboratively with other organizations involved with epilepsy to support and find the answers to SUDEP

WHY IS IT IMPORTANT TO DISCUSS MORTALITY IN EPILEPSY?

In a 2016 survey, almost all caregivers and nearly 2 in 3 people with epilepsy said they worry about death from epilepsy or seizures. Almost half of respondents said learning more about SUDEP could make a difference in how they approach seizure control. People know about the dangers of fire and Sudden Infant Death Syndrome (SIDS), but there is very little awareness about the risk of death from epilepsy. And unfortunately, SUDEP kills more Americans than either of these.

Epilepsy-related mortality should be a public health priority. There are at least 2,750 U.S. cases of SUDEP every year. In comparison, in 2013, sudden infant death syndrome (SIDS) caused 1,575 deaths, and accidental exposure to smoke, fire, and flames caused 2,760 deaths.”

- Orrin Devinsky, MD, director of the New York University Langone Comprehensive Epilepsy Center and SUDEP Advisory Board member

Each person with epilepsy is different. While many people with epilepsy can achieve seizure control with available treatments, some cannot. However, with information, people living with epilepsy can feel empowered to have the information they need to minimize their risk for SUDEP.