Dear Health Care Professional,

The care and information you provide people with epilepsy is critical. As a medical provider, you are viewed as the most reliable source of information on epilepsy. We want to share our story with you, in the hopes that it will give you a perspective on why it is important to discuss the risk of **Sudden Unexpected Death in Epilepsy**, known as SUDEP, and the importance of aiming for complete seizure control in conversations you have with people with epilepsy.

[Insert your family story and why you wish you had discussed SUDEP with your medical provider]

In the October 2014 issue of *Epilepsia*, Drs. Donner and Buchhalter explained that “sharing accurate information about SUDEP can optimize epilepsy self management and engage the person with epilepsy as a partner in their own care. Information about SUDEP must be part of the comprehensive education given to all people with epilepsy.”

We hope as a health care professional you will help us by making your patients, other health care professionals, and the community aware of SUDEP. It is critical we increase awareness of SUDEP so families like ours can do everything we can to protect the people we love. Awareness may also drive patients’ behavior change and treatment compliance and will also help accelerate important research so we can one day learn how to prevent this tragic outcome.

Thank you for your help and support to build awareness of SUDEP.

Sincerely,

**Facts about SUDEP**

* SUDEP is sudden unexpected death of a person with epilepsy.
* Each year, more than 1 out of 1,000 people with epilepsy die from SUDEP. If seizures are poorly controlled, the risk increases to 1 out of 150.
* SUDEP is less common in children, but it is a leading cause of death in young adults with uncontrolled seizures.
* The best way to prevent SUDEP is to have as few seizures as possible.

**Who is at Risk for SUDEP?**

The greatest risk factor for SUDEP is frequent seizures, especially generalized tonic-clonic (grand mal) seizures. Other risk factors may include:

* Epilepsy beginning at an early age
* Having epilepsy for a long time
* Not taking medications regularly or as prescribed
* Young adult age (20-40 years old)
* Seizures occurring at night

**What can you tell your patients about SUDEP?**

Provide answers to these questions:

* What is their risk of SUDEP?
* What should they do if they have another seizure?
* How can they prevent future seizures?
* What can they do if they are having difficulty taking medications as prescribed?
* What additional treatments could you explore together to stop their seizures and lower their risk of SUDEP?
* What should they do to reduce their risk of SUDEP if they have seizures at night?
* What should they do if they are not getting enough sleep at night?
* What is the impact of alcohol on their treatment plan?
* Should they consider using a device to warn someone that they are having a seizure?
* Should they consider sharing a room?

Urge people living with epilepsy to have regularly scheduled medical evaluations by their primary care physician to make sure there are no other health conditions that may increase their risk from dying or getting injured following a seizure.

The Epilepsy Foundation SUDEP Institute and the American Epilepsy Society developed [a two-part CME and CNE webinar series](http://www.epilepsy.com/learn/impact/mortality/sudep/sudep-webinars-and-presentations#SUDEP) to help medical providers learn how to determine risk levels and know how to have discussions about SUDEP risk.

**For more information:**

Contact the Epilepsy Foundation SUDEP Institute at [SUDEP@efa.org](mailto:sudep@efa.org?subject=Information%20about%20SUDEP). Learn more about SUDEP at [epilepsy.com/SUDEP](http://www.epilepsy.com/get-help/about-sudep-institute)