

Sudden Unexpected Death in Epilepsy (SUDEP)

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Issue

This report answers several questions related to Sudden Unexpected Death in Epilepsy (SUDEP).

What is SUDEP?

According to the [Centers for Disease Control and Prevention](#) (CDC), SUDEP refers to deaths in people with epilepsy that are not caused by injury, drowning, or other known causes. The [Epilepsy Foundation](#) reports that annually, about one in 1,000 people with epilepsy die from SUDEP, and SUDEP is the leading cause of death in people with uncontrolled seizures.

Most SUDEP cases occur during or immediately after a seizure. According to the Epilepsy Foundation, research into the possible causes of SUDEP has focused on seizures leading to changes in (1) breathing (e.g., dangerously low oxygen levels brought on by interrupted breathing), (2) heart rhythm (e.g., cardiac arrest), or (3) brain function (e.g., seizures interfering with vital areas of the brainstem).

The Epilepsy Foundation reports that the greatest risk factor for SUDEP is having tonic-clonic (formerly “grand mal”) seizures. Nighttime seizures may put people at higher risk, as may failure to take medication as prescribed (which could lead to increased seizures).

For more information on SUDEP, see the [Epilepsy Foundation](#) and [CDC](#) websites.

How does the SUDEP Registry operate?

The [North American SUDEP Registry](#) (NASR) describes itself as “an international group of collaborating researchers . . . dedicated to uncovering the risk factors, causes, and mechanisms of SUDEP so that we may improve future epilepsy treatment and SUDEP prevention.” NASR includes a seven-member executive board and an advisory committee of over 20 members. The registry was launched in 2011 by New York University Langone Health’s Comprehensive Epilepsy Center.

Through voluntary participation by family members of individuals who died, NASR collects and analyzes data on possible SUDEP cases. NASR collects both clinical information and donated brain and tissue samples (such donation is not necessary to participate).

While medical professionals may refer families to the registry, such referral is not required for families to participate. If a family member chooses to participate, he or she must complete a 45 to 60 minute screening interview by phone about the deceased person’s epilepsy and seizure history and the circumstances of his or her death. NASR then requests permission to access the deceased person’s medical records; all medical information remains confidential. If the death occurred within the past 72 hours, the family has the option of donating tissue for research.

A recent study reviewed information concerning all individuals added to NASR between October 2011 and June 2018. The study found that among the 530 records, there were 237 definite and probable cases of SUDEP. Of the SUDEP cases, decedents had a median age of 26 and 38% were female. Among other things, the study found that (1) 93% of the SUDEP deaths were unwitnessed; (2) SUDEP affected the full spectrum of epilepsies; and (3) among the decedents who had been prescribed anti-seizure medications, 37% had taken their last dose of medication as prescribed before their death. For more information, see this *Neurology* article by Verducci, C. et al., “[SUDEP in the North American SUDEP Registry](#)” (July 16, 2019).

How do state SUDEP reporting laws work? How do those laws compare to Connecticut law on Sudden Infant Death Syndrome (SIDS)?

Both New York and Illinois require identified SUDEP cases to be reported to NASR. (Families may still choose not to participate in the study.)

In New York, when an autopsy is conducted on a deceased person who had epilepsy or a history of seizures, it must include an investigation and determination as to whether the person suffered a SUDEP. If so, that information must be noted on the death certificate and reported to NASR ([N.Y. Public Health Law § 4210](#)).

In Illinois, all autopsies must include an inquiry to determine whether the death was a direct result of a seizure or epilepsy. If the findings are consistent with known or suspected SUDEP, then the medical examiner, examining physician, or coroner must (1) ensure SUDEP is indicated on the death certificate as the cause or suspected cause of death and (2) forward a copy of the death certificate to NASR within 30 days ([55 Ill. Comp. Stat. § 5/3-3016.5](#)).

A few other states have SUDEP-specific laws (see below).

Connecticut law does not contain reporting requirements comparable to those in New York and Illinois. Connecticut law requires the chief medical examiner to investigate all deaths in certain categories, including sudden or unexpected deaths not caused by readily recognizable disease. The chief medical examiner may require autopsies in connection with these deaths if appropriate for a proper investigation and the chief medical examiner or a deputy, associate, or assistant medical examiner deems it necessary ([CGS § 19a-406](#)).

Connecticut's law on autopsies does not reference SUDEP or SIDS specifically. But according to the Office of the Chief Medical Examiner (OCME), in practice, autopsies are conducted for all suspected SIDS cases. Autopsies are conducted for suspected epilepsy deaths that occur outside of a hospital. If a person with epilepsy is hospitalized following a seizure and later dies in the hospital, that death is considered natural and typically not reported to OCME.

Are there other SUDEP-specific state laws?

Both New Jersey and North Carolina also have SUDEP-specific laws.

New Jersey. New Jersey first passed a SUDEP law in 2013; it has since been significantly amended. Under the original law, if a medical examiner's autopsy findings were consistent with known or suspected SUDEP, the examiner was required to (1) track that information and (2) work with relevant organizations to assist in requesting that the authorized survivors (A) forward the deceased person's medical information to a SUDEP registry for research purposes, consistent with federal health privacy rules and (B) donate his or her brain for research purposes ([P.L. 2013, c.91](#)).

That law was repealed in 2018 as part of a larger bill making several changes to the state medical examiner laws ([P.L. 2018, c. 62](#)). Regarding SUDEP, the 2018 law instead requires the chief state medical examiner to establish a Research Oversight Committee to assist in developing and reviewing research protocols into specific causes of death and sudden death, including SIDS and SUDEP ([N.J. Stat. § 26:6B-14](#)).

Under this new law, among other things:

1. the research protocols must authorize medical examiners to take and transfer tissue samples to approved research projects before obtaining the ordinary consent needed for these transfers, but the research project must not use the tissue before obtaining appropriate consent;
2. the protocols must prohibit tissue samples from being taken if the deceased person objected before death, or the parent or legal guardian of a deceased minor objects, to an autopsy because it is against the deceased person's religious beliefs;
3. the protocols must meet various other requirements relating to approving research projects, obtaining consent for using the decedent's tissue and other identifying information, and restricting the tissue samples and information to approved research purposes only without disclosing the person's identity, among other things; and
4. the chief state medical examiner, as appropriate, must establish awareness programs to educate medical examiners about various types of death, including SIDS and SUDEP (the prior law contained a similar requirement).

North Carolina. In North Carolina, county medical examiners' continuing education must include training regarding SUDEP ([N.C. Gen. Stat. § 130A-382](#)).

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