



**TESTIMONY OF
CONNECTICUT HOSPITAL ASSOCIATION
SUBMITTED TO THE
PUBLIC HEALTH COMMITTEE
Monday, February 25, 2019**

SB 396, An Act Concerning Sudden, Unexpected Death In Epilepsy

The Connecticut Hospital Association (CHA) appreciates this opportunity to submit testimony concerning **SB 396, An Act Concerning Sudden, Unexpected Death In Epilepsy**.

Before commenting on the bill, it's important to point out that Connecticut hospitals and health systems provide high quality care for everyone, regardless of their ability to pay. By investing in the future of Connecticut's hospitals, we will strengthen our healthcare system and our economy, put communities to work, and deliver affordable care that Connecticut families deserve.

SB 396 would require the medical examiner, when conducting an autopsy on a person who had been diagnosed with epilepsy or with a history of seizures, to note on the death certificate whether the person suffered a sudden, unexpected death in epilepsy and file the death certificate with the North American SUDEP Registry. The bill appears to apply only to autopsies conducted by the medical examiner's office.

CHA has two major concerns with the bill. First, the North American SUDEP Registry is a private research organization. It is not a government entity or an official repository of medical data. Thousands of research organizations do important work, including the North American SUDEP Registry. But mandating that Connecticut utilize core government resources to collect and provide specific data for the purpose of reporting it to private research organizations raises significant concerns.

Researchers have the ability to access death certificate information through proper channels. Existing statutory parameters apply to release of death certificates, including researchers.

Second, under the bill, the medical examiner would be required to assess every autopsied decedent's case based on a history of seizures, not just epilepsy. Seizure activity can be temporary and is not uncommon. It is unclear what steps the medical examiner's office would be required to undertake to make these screenings for seizure activity, or to assess for a conclusion of sudden, unexpected death in epilepsy.

We appreciate the role that researchers play, but caution against a process that statutorily selects one private organization over others, particularly when a pathway already exists for researchers to obtain the information on a level playing field with other organizations.

Thank you for your consideration of our position. For additional information, contact CHA Government Relations at (203) 294-7310.