



The Honorable Senator Abrams and Representative Steinberg
Co-Chairs, Public Health Committee
300 Capitol Ave, Legislative Office Building
Hartford, CT 06106

Dear Senator Abrams, Representative Steinberg and Members of the Public Health Committee,

My name is Michael Finley and I am the Government Relations Advocate for the Epilepsy Foundation of Connecticut. On behalf of the Epilepsy Foundation of Connecticut and the more than 36,000 individuals living with epilepsy in Connecticut, we urge you to **SUPPORT Raised S.B. 1083 “AN ACT CONCERNING VARIOUS REVISIONS TO THE PUBLIC HEALTH STATUTES.”, also known as “Halyn’s Law”.**

In May of 2019, I received the most heartbreaking news of my professional career. Halyn, a nine-year-old from Wethersfield living with epilepsy, passed away two months before her tenth birthday due to Sudden Unexpected Death in Epilepsy (SUDEP). The news of her passing sent shockwaves through the entire epilepsy community in Connecticut. The epilepsy community in the state had to come to terms with the fact that we lost another promising life far too soon to epilepsy. Raised Senate Bill 1083, also known as “Halyn’s Law, is being pursued to honor her legacy and to bring forth a possible pathway to ending instances of SUDEP. One life lost to SUDEP is one too many.

This legislation before us, Raised Senate Bill 1083, which emphasizes education amongst the medical examiner’s office, will lead to more accurate and uniform reporting of potential SUDEP cases amongst the epilepsy community. This will result in the collection of a critical body of data to help identify the causes and potential risk factors associated with SUDEP. Our ultimate goal is to make this data readily available to research institutions like the North American SUDEP Registry (NASR) to help significantly lower the instances of the SUDEP amongst the over 36,000 individuals living with epilepsy in Connecticut.

We like to draw a comparison to Sudden Infant Death Syndrome (SIDS). Sudden infant death syndrome (SIDS) rates declined considerably from 130.3 deaths per 100,000 live births in 1990 to 38.0 deaths per 100,000 live births in 2016. SIDS rate declined considerably following the release of the American Academy of Pediatrics safe sleep recommendations in 1992, the initiation of the Back to Sleep campaign in 1994, and the release of the Sudden Unexplained Infant Death Investigation Reporting Form in 1996.¹ This data shows how effective reporting can lead to identifying risk factors which, as a result, leads to lower mortality rates for certain causes of death. It’s imperative that SUDEP follow a similar path to SIDS moving forward.

¹ Data and Statistics For Sids and Suid. <https://www.cdc.gov/sids/data.htm>

I have had the pleasure of working closely with the Chief Medical Examiner over the past couple of years to collaborate on this important issue. We look forward to continuing working with OCME on this important topic to help end the leading the cause of death amongst the epilepsy community.

Thank you for the opportunity to submit testimony on this important legislation and I hope that this committee will support this legislation moving forward. If you have any questions, please contact me at 860-346-1924 or michael@epilepsyct.com .