

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,

Thank you for the opportunity to submit testimony in **support of Raised S.B. 1083 “AN ACT CONCERNING VARIOUS REVISIONS TO THE PUBLIC HEALTH STATUTES”, also known as “Halyn’s Law”**.

My name is Chris Murtha, and along with my wife, Dr. Victoria Murtha and our sons Dylan and Gavin, we are the family of Halyn Murtha, residents of Wethersfield, CT. Our beautiful little girl died from SUDEP (Sudden Unexpected Death in Epilepsy) on May 25, 2019 just 2 months shy of her 10<sup>th</sup> birthday.

Halyn was diagnosed with epilepsy when she was just 1 year old. She endured thousands of seizures in her short life, multiple combinations of medications and many hospital visits where she was hooked up to EEG monitoring equipment for days trying to find a cure for her epilepsy. Along her journey, she was additionally challenged with learning delays and autism. Her life was challenging, but she was happy and had a way of spreading her unique spirit with the world.

Our daughter’s name was inspired by the rock band, Van Halen. She loved music, playing my guitar while saying, “Rock On!”, dancing around with her brothers, playing with her toys and talking to her stuffed animals. She would say “Hi” to everyone she saw, and ask them, “What’s your name?”. In most cases, she would end her conversations with, “I love you”, which certainly brought a smile to these random strangers. Her pronouncements of love weren’t limited to humans – she would say “I love you” to animals and even inanimate objects.

Her love of everything inspired us to coin the phrase, “Love like Halyn.” If the world would just spread love and kindness to their own family and friends, and inspire them to do the same, we’d live in a much better place. It has become our motto, and we encourage you to tell the people most important in your lives how much they mean to you.

Like all parents, we want to see our children grow up to be healthy and happy, to protect them from harm, and to be a positive contributor to society. Halyn doesn’t have that chance to grow up and we couldn’t protect her from epilepsy. But she was happy, and this bill is one of the ways she can make a lasting contribution to society.

Supporting the Chief Medical Examiner’s Office will help to provide appropriate training and support to their wonderful staff. We appreciate their willingness to support Raised S.B. 1083.

Your support of Raised S.B. 1083 will help to find a cure and will save lives.

SUDEP is the sudden, unexpected death of someone with epilepsy, who was otherwise healthy. In SUDEP cases, no other cause of death is found when an autopsy is done. Each year, more than

1 in 1,000 people with epilepsy die from SUDEP. This is the leading cause of death in people with uncontrolled seizures.<sup>1</sup>

This legislation, which emphasizes education amongst the medical examiner's community, will lead to more accurate and uniform reporting of potential SUDEP cases amongst the epilepsy community. This will result in the collection of critical data to help identify the causes and potential risk factors associated with SUDEP. Our ultimate goal is to make this data 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.

Thank you again for the opportunity to submit testimony in support of S.B. 1083. On behalf of Halyn and our family, we hope that this committee will support this legislation.

Sincerely,

Christopher & Victoria Murtha  
Wethersfield, CT

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<sup>1</sup> SUDEP. Epilepsy Foundation SUDEP Institute - <https://www.epilepsy.com/learn/early-death-and-sudep/sudep>