

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 Emma Borys, and I am here today to testify in support of Raised Senate Bill 1083, also known as "Halyn's Law."

I was diagnosed with epilepsy when I was 11 years old. My epilepsy has been challenging to control, but I refuse to let that stop me from living my life to the fullest. I am very proud of my involvement with the Epilepsy Foundation of Connecticut, especially when I was selected to represent my home state at the 2019 Teens Speak Up! Public Policy Institute in Washington, DC. During my year of service that followed TSU, I had the opportunity to meet with Senator Haskell to share my story. He has been a wonderful ally.

As a young adult living with epilepsy, the issue of Sudden Unexpected Death in Epilepsy is very near to my heart. The unfortunate occurrence of Sudden Unexpected Death in Epilepsy is a scary reality that everyone in the epilepsy community must not only live with but must confront head-on. That is why I am testifying in front of the Public Health Committee today.

With greater awareness and education in the medical community, SUDEP cases will no longer be underreported. This legislation will help not only to raise much-needed awareness for SUDEP but will also provide researchers with a body of data to help identify the potential risk factors associated with SUDEP.

Every person living with epilepsy deserves to live life to the fullest. My passion for advocacy helps to keep me moving forward and gives me a sense of purpose. Today, I ask that you, please support this relevant legislation created in the memory of Halyn, a nine-year-old girl with epilepsy who tragically passed away in May of 2019. No parent should have to endure the loss of a child, and no one with epilepsy should have to live in fear. It is my responsibility as a young adult living with epilepsy to be a leader and to advocate for those in the epilepsy community whose voices go unheard.

The epilepsy community wants to work together with medical professionals in Connecticut to help combat the tragic occurrence of SUDEP, and this legislation will allow for that to happen.

I would like to personally thank Senator Haskell for advocating for this legislation and for allowing me to testify with him today.

Thank you for the opportunity to testify in support of this critical legislation, and I hope I can count on your support moving forward. Thank you.

-Emma Borys, Westport
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