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

March 2021

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

My name is Tom Stanton and I am executive director of the Danny Did Foundation, a patient advocacy nonprofit based in Chicago. We hold the mission to prevent deaths caused by seizures. On behalf of Danny Did and the nearly 3.5 Americans who face epilepsy, 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 last year, we learned the heartbreaking news that Halyn, a nine-year-old from Wethersfield, CT, living with epilepsy, passed away two months before her 10th birthday due to Sudden Unexpected Death in Epilepsy (SUDEP). The news of her passing sent shockwaves through the entire epilepsy community. It was another promising life lost 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. We know this story too well, since my nephew, Danny, died tragically from SUDEP in December 2009, just a few months before his 5th birthday.

This legislation before us, Raised Senate Bill 1083, 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 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 were proud to lead passage of another SUDEP law – the Danny Stanton SUDEP Act – in Illinois in 2013.

With SUDEP, we 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



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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.

Thank you for the opportunity to submit testimony on this important legislation. I hope that this committee will support this legislation moving forward. If you have any questions, do not hesitate to reach out.

Sincerely,

Tom Stanton | 773.307.2336

Danny Did Foundation | Executive Director

WORKING TO PROTECT KIDS WITH EPILEPSY

www.dannydid.org

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



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