



**SUMMA HEALTH EPILEPSY CENTER
& EEG LABORATORY
141 N. Forge St. Akron, OH 44304
(330) 375-3000**

October 30, 2023

Re: House Bill 229, the Brenna Brossard SUDEP Awareness Act

Dear Chairman Cutrona, Vice-Chair Gross, Ranking Member Somani, and members of the Health Provider Services Committee,

Thank you for the opportunity to contribute to testifying on behalf of House Bill 229, the Brenna Brossard SUDEP Awareness Act.

I am a board certified epileptologist who has practiced for over 25-years working with individuals living with seizure-related disorders. I spent the majority of my career in Chicago at RUSH University Medical Center as a surgical epilepsy neurologist. I recently relocated to NE Ohio to establish and direct the Summa Health Comprehensive Epilepsy Center in Akron, Ohio.

I have devoted my career to treating children and adults living with epilepsy-related challenges. My interests included establishing a rural health initiative that for 20 years devoted resources toward facilitating wraparound community services. Funding targeted the underserved and underinsured in NE Illinois and, now, NE Ohio. My path included serving as the inaugural Medical Director and consultant for the Danny Did Foundation founded in 2010 by the Stanton family. Like the Brossard family, the Stanton's child, Danny, had been diagnosed with epilepsy. Like Brenna, Danny lost his life to sudden unexpected death due to epilepsy (SUDEP). Identical to Brenna's parents, the Stanton family were not made aware of SUDEP following Danny's diagnosis of epilepsy.

My experience, unfortunately, has included talking with many coroners over my career who reached out to me on behalf of those children and adults who had gone to sleep never to awaken due to cardiopulmonary collapse implicated in SUDEP.

Unfortunately, a significant knowledge gap remains surrounding SUDEP for both patients and healthcare providers. For example, although not always correlated, the likelihood of experiencing SUDEP is markedly increased in those living with uncontrolled seizures. This also means one can experience SUDEP even during an occasional breakthrough convulsion also known as a generalized seizure.

~~It was only about six years ago, in 2017, when guidelines were created and adopted by the American Academy of Neurology regarding how to address and educate providers, patients, and caregivers~~

~~struggling with epilepsy about the risks associated with SUDEP.~~ It is crucial that healthcare providers, including primary care providers, general neurologists, and epileptologists alike, discuss the risks of SUDEP with their patients, family, and primary caregivers.

Our Comprehensive Epilepsy Center at Summa Health requires the provider include at least one discussion when establishing care with the patient and caregiver regarding the risks of SUDEP in clear, simplified terms with both the negative (e.g., risk of SUDEP) and positive outcomes (e.g., risk of not being affected by SUDEP) to maximize their understanding.

For example, individuals experiencing three or more generalized tonic-clonic seizures also known as grand mal seizures or convulsive seizures annually are at a 15-fold higher risk of SUDEP. The continued attempts at improving seizure control through research and innovative technologies such as wearable devices are needed. It is possible that by reducing frequency of generalized convulsive seizures will positively benefit effect on risk of SUDEP.

I must emphasize, even with the gains I've outlined, to this day a significant knowledge gap of SUDEP exists with healthcare providers and all who struggle with epilepsy-related challenges.

At best, seizure freedom is the most significant modifiable risk factor in preventing SUDEP, particularly convulsive seizures. Other modifiable risk factors include adherence to prescribed anti-seizure medications, continuing to pursue further epilepsy control-related treatments, and avoiding known seizure triggers, including getting enough sleep and minimizing alcohol intake.

To ensure that SUDEP gets the public awareness it deserves in Ohio, House Bill 229 has an opportunity to act as a dominant conduit through which SUDEP awareness, prevention, and research can be guided. Such legislation can meaningfully guide advocacy for other families toward both understanding the risks and potentially preventing the unbearable loss of a child or adult to SUDEP.

Sincerely,

A handwritten signature in black ink, appearing to read "Marvin A. Rossi". The signature is fluid and cursive, with a large initial "M" and "R".

Marvin A. Rossi, MD, PhD, FAES
Medical Director, Summa Health Comprehensive Epilepsy Center