

11/14/2023

Chairman Cutrona, Vice-Chair Gross, Ranking Member Somani, and members of the Health Provider Services Committee, thank you for the opportunity to testify on behalf of House Bill 229 – the Brenna Brossard SUDEP Awareness Act.

Like you, I am also a legislator, as the President of City Council in North Olmsted. With over 14 years of experience at the municipal level, I understand and take very seriously the legislative process that you are embarking on today.

But today I am here before you as a parent, and as an advocate for all epilepsy patients regarding SUDEP awareness – with SUDEP meaning the “Sudden Unexpected Death in Epilepsy”.

On January 30th of 2022, our lives were forever devastated when our healthy, physically fit, active and thriving 25 year old daughter Brenna passed away without warning from SUDEP during a middle-of-the-night epileptic seizure.

What do I mean when I say “without warning”?

Our epilepsy journey as a family began in 1996 when our son Nicholas began having grand mal seizures at the age of 4 years old. Fast forward to 2012, when Brenna was 15 years old she too began having grand mal seizures and was diagnosed with epilepsy.

So at the time of Brenna’s passing, we had been seeing neurologists and epileptologists for 26 years. Please let that sink in ... 26 years of epilepsy caregiver appointments, from 1996 to 2022.

Not once during those 26 years of doctor visits were we ever informed about this horrible event called “SUDEP” and it’s risk factors. So many opportunities to inform us, that were not taken.

Our family only learned about SUDEP by chance, during a meeting with the Epilepsy Association of Cleveland a week after Brenna’s funeral.

It was stunning to us that we were hearing about this for the very first time. Further, we were incredulous when we learned that the majority of epilepsy caregivers choose to not inform their patients about the possibility of SUDEP.

This is unacceptable, as every epilepsy patient and their family deserves to be informed.

It should be noted that when Nick and Brenna’s seizures occurred, they were always nocturnal in nature, meaning they only occurred during the night while sleeping.

Why is this significant? Because the vast majority of SUDEP deaths occur at night during sleep, when the event is not witnessed and potential life-saving care cannot be given.

Most national epilepsy organizations indicate that there are a handful of steps that you can take to mitigate the risk of SUDEP occurring.

Ironically, Brenna was 100% compliant with two of the main suggestions: be compliant with your prescribed medication, and see your epilepsy caregiver on a regular basis.

But because we were never informed by her caregivers about SUDEP and the steps that can be taken to minimize the chance of it occurring, we were unaware that there are seizure detection and alert devices available.

One such device is a sophisticated detection and alert watch that is worn during sleep. When seizure activity is detected, the Empatica Embrace 2 device will instantly call 3 designated phone numbers and alerts the recipients.

In that scenario, potential life-saving care becomes immediately available to the patient.

I try not to live in a world of “what if” – but when Brenna passed away from SUDEP, she was living on the first floor of a Lakewood duplex home with her two best friends since grade school. Their bedrooms were situated side-by-side-by-side.

Again, because we weren’t informed about SUDEP, nor about this seizure alert device that is FDA approved and only available when prescribed by her doctor - Brenna’s two best friends slept through her death and are forever scarred by what could have been done had they been alerted.

Our son Nicholas now has this same device, and we have test-simulated a seizure on several occasions, and it works instantly and effectively each time.

Please believe me when I tell you that I am not here today to assess blame to the medical community, far from it.

I am here today because with this proposed legislation, we now have an opportunity before us that is simplistic in nature, one that most certainly will result in the lives of Ohioans being saved.

Knowledge becomes this powerful awareness, and this awareness will surely result in prevention.

In the 20 months since we lost Brenna, my wife Joni and I have become actively involved with a number of reputable, national epilepsy organizations. And what we have learned is that in most states, SUDEP awareness is not being offered voluntarily by the medical community.

With House Bill 229, Ohio has an opportunity to be a leader in SUDEP awareness and prevention, so that other families don’t have to experience the traumatic loss of a child that could have potentially been prevented.

Thank you so much for your time and for your consideration. Can I answer any questions?

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