

HB606

5/10/2022

To enact Sarah's Law for seizure safe schools

Proponent

Chairwoman Manning, Vice Chair Bird, Ranking Member Robinson and members of the House Primary and Secondary Education Committee.

Good afternoon, my name is Sharon DeVore I am the mother of a child who has died from epilepsy, the mother of a child who has epilepsy and the grandmother of an autistic grandchild who has a seizure disorder. This bill is named after my daughter Sarah Elizabeth Linardos.

Sarah began having seizures at the age of 15 years old. It effected many parts of her life over the years, as well as ours- one of those being going to school- Sarah had nocturnal seizures all her life, but her doctors always said seizures are very uncertain. She could have them at any time.

Sending her to school every day not knowing what the day would bring, was scary as parents- not knowing if and when she had a seizure, would someone know what to do? Witnessing a seizure for the first time and not being prepared renders you very helpless.

Sarah graduated High school at the top of her class and continued on to graduate from The Ohio State University Fisher College of Business in 2014. She went on to start a career in Human Resources, all the while having seizures, which for the most part was controlled by her medication. In the Fall of 2017, she began having break through seizures and on Father's Day June 17, 2018, Sarah passed away from SUDEP (Sudden Unexpected Death in Epilepsy). She was 26 years old.

Sarah had so much more left to give this world. It has broken our hearts and changed our family's lives forever. No family should ever have to go through this. We have done things to honor her life and love for education by starting an educational scholarship in her name, as well as being part of this bill to honor her life as well as those children living with epilepsy.

One of Sarah's friends at her funeral wrote a letter stating, "when you were Sarah's friend you were Sarah's friend for life." I would like to think of all of the children here in Ohio with Epilepsy and seizure disorders as being Sarah's friends. I would also like to think that if someday my grandson would ever have a seizure at school, someone would know what to do.

I would like to close by reading a poem that I wrote for Sarah:

SUDEP

SUDEP steals away our shining light

And nothing again will ever seem right

This child I love has gone away

We never got another day

SUDEP steals a parent's heart

I knew that from the very start

My world was shattered apart that day

There just were no words to say

SUDEP has changed the family we know

It was hard for us to let you go

The memories and the photos in a frame

Are all we have left, life will never be the same

SUDEP steals a family's soul

Sometimes life can be so very cruel

This child had so much left to do

And in the blink of an eye her life was through

SUDEP why did you take my baby away

It breaks my heart every single day

The tears I cry for you my love

Are because you are in heaven above

SUDEP please I beg you to go away

So another family will never feel this way

I hope there is a cure to be

So there will be no more loss to see

SUDEP Angel up above

Just know that you are very loved

So shine your bright light the whole night through

And know I will always love and think about you

For my daughter Sarah Elizabeth Linardos

Lost to SUDEP on Father's Day June 17, 2018

Forever Loving and Missing My Angel, Love Mom

Written by Sharon DeVore, 9/11/19