

Mia Matthews, The CHAN's Promise Foundation
3/10/2020 Support for SB 0733 (Channing's Law)

Thank you Legislatures for allowing me to share my story in support of Senate Bill 0733
Public Health - Care of Medically Fragile Individuals, Channing's law.

Our story starts on August 12, 2015 when my daughter Channing came into this world. Shortly after Channing was born, she was immediately taken to the NICU and intubated. Soon we discovered that Channing's mouth could open only a few centimeters and she had a cleft palate. Channing was transferred from GBMC to Johns Hopkins Children's NICU where she stayed for 9 months. During the time she was hospitalized, Channing endured multiple procedures including surgeries to place a trach, gtube and jaw surgery to open her mouth. Also, Channing was diagnosed with chronic lung disease that caused her to use a ventilator 24 hours a day.

Despite Channing's medical challenges, she was known for her resilience. She was a sassy, fashionista that managed to captivate the attention and love of everyone she encountered from nurses to doctors and family members.

Once the time arrived for Channing to come home, my husband and I received extensive training to strengthen our trach care skills and demonstrate our ability to properly care for Channing during medical emergencies.

Channing had home nursing care during the day to allow my husband and I to work and an overnight nurse since she required 24 hour monitoring. While home nursing was an enormous benefit to our family, there were times when we noticed the nurses did not follow protocols or missed important checks when experiencing an issue with the trach or vent.

One time, Channing's trach came out of her stoma and she was losing oxygen. Her nurse called me downstairs and said Channing was in distress. I came downstairs, assessed Channing and I could hear the air escaping from somewhere, quickly I checked the vent which had all the connections intact then I tried to suction Channing and noticed the trach was out of the stoma on her neck. Thankfully, I was home and could fix the issue quickly. This particular time the nurse gathered her things before I could place Channing's trach back in and left because her shift was coming to an end.

On another occurrence, I was called from work to come home because Channing was desatting, which means she was actively losing oxygen and would turn blue in the face. The nurse couldn't figure out why since Channing was on oxygen. I rushed home from work to find that she didn't have the oxygen cord connected to the ventilator. A simple check of the vent and cords would have avoided Channing desatting and loss of oxygen.

We would always educate our home nurses on best practices we learned while Channing was hospitalized so they could be equally prepared to care for her medical needs. This included performing chest compressions and giving her breaths from an

ambu bag because she was experiencing a drop in heart rate or a large mucus plug, until EMT's arrived. Mount Washington and Hopkins trained us on all the possible medical emergencies before we came home as they were inevitable.

Unfortunately, on April 13, 2018 Channing went into distress and this time it was fatal. The nurse, who was assigned to Channing for over a year, called to tell me Channing was in distress, I asked her to suction and turn on the oxygen and I let her know I was headed home. I also asked for Channing's numbers on the pulse ox and she said 4 meaning she was no longer breathing. I immediately told her to call 911. By the time Channing's dad made it home, who she also called while Channing was declining, he noticed the nurse failed to act on lifesaving measures, like connecting the oxygen to the ambu bag and changing the trach. Her ambu bag wasn't hooked to oxygen.

Since this heartbreaking, life shattering situation happened, we've been advocating for home health nurses to receive special education and training beyond what they learn in nursing school so they are better equipped to care for kids with complex medical needs. Looking back, its heartbreaking to think our nurses lacked the proper qualifications when my husband and I had to prove we had certain skills, such as changing the trach, performing chest compressions and understanding the vent alarms before Channing could come home. We did these things over and over again, and we were supervised and assessed by staff at Mount Washington to prove we were capable of caring for Channing. Why aren't LPN's required to perform or demonstrate the same level of care especially as a nursing professional? With an increased push for home care, why hasn't the conditions of care been revised to hold nurses accountable? Why aren't they put through emergency situations similar to the NICU.

Kids with complex medical needs, especially those with trachs need skilled nurses inside the home. They're at a higher risk and vulnerable. I find it unsettling that the nurses are training at the discretion of the residential service agency, their employers, instead of showing is no annual skills test witnessed by the state of Maryland.

My story is just one of countless deadly mistakes made by home health nurses. Our kids who need lifesaving equipment to survive are sent home with less resources than available at the hospitals and nurses who lack the skills to respond to medical emergencies. I am asking the state to provide more oversight in the form of a training program for nurses who want to care for medically fragile children inside of their home.

If the proper training was in place Channing would've still been here with us to celebrate her 3rd birthday, the holidays and spend quality time her family who misses her greatly. I ask you today, please support SB 0733 to ensure the safety and proper care of children like Channing.

I am also in support for SB 716 Maryland Council on Health in All Policies – Establishment. I am in support of the Maryland Council on Health in All Policies to make recommendations to units of the state and local government on laws and policies to implement and positively impact the health of residents of the state. I have a personal connection to the gaps in the laws and policies that are put in place to protect

vulnerable citizens of Maryland. Please pass SB 716 so the members of this council can use the health in all policies framework to make recommendations to improve the quality of life in any capacity (public safety, housing, employment opportunities) for the citizens of Maryland.