

Dear Legislators,

I would like to submit testimony in opposition to HB 7015. I am a mother of young children living in Gales Ferry, CT.

Thirteen years ago, our son was born in Evanston Hospital in Evanston, Illinois. He was a 31 week preemie delivered early due to end stage renal failure. At the time of birth and for the first 6 weeks after birth, he was given a less than 5% chance of survival and a zero percent chance of surviving and living a normal life. We were pressured, and cajoled to sign a DNR for this son. Doctors, nurses, even the various therapists who cared for him pressured us to just let him die. We were told his life would be nothing more than, "an untenable burden both financially and emotionally to your family and society at large". Eventually, he was transferred to another hospital, Children's Memorial where the pressure to sign a DNR was increased. Eventually, my son's condition stabilized and he finally made a through a medical shift alive and without requiring resuscitation. Instead of celebrating this milestone, his charge nurse screamed at me that, "you are stuck with him now." She was very angry that we had chosen to keep alive our child when he was not going to be healthy. This child is now almost 14. He has undergone two kidney transplants and some very painful trauma in his life. But he is cognitively normal. He currently participates actively in our local Sea Cadet Group in Groton as a Petty Officer. This is not a child who is an untenable burden to society. Yet, had I listened to the overwhelming coercion of the medical staff who was tasked with keeping him alive, Joshua would have died 13 years ago.

At the time that we were being emotionally pressured into ending our child's life in order to prevent him and ourselves from suffering so much, the doctor said to us that he would only allow us to continue medical treatment because we had good insurance and we were well educated. I have always wondered what that meant for anyone who was poor or uneducated. Did that doctor make decisions for those families? Were they given the same opportunities to keep their children alive?

My concern with this bill is that it will eventually be used to codify legally what is already happening in America's pediatric hospitals. A few years ago, we had another child who required a serious surgery immediately after birth at Boston Children's Hospital. Her condition required just one surgery to resolve the problem permanently but she had to stay in the NICU for a week. As I was talking to other parents' with children in the NICU, I heard stories remarkably similar to mine: the pressure, the coercion, the blaming by the hospital staff. If this bill becomes law, I fear for children with chronic medical conditions from birth on. Who is going to protect them from hospital staff who firmly believe that the kid is going to grow up and suffer too much? I can guarantee that many chronic medical children, particularly poor children or those with parents' who are not scientifically literate, will have their lives cut short.

Even though my son is clearly capable of living an independent life with a career, I have heard comments from individuals about was it really worth it to spend all that money on one life. These are people who know my family and my son. If you give insurance companies the opportunity to avoid paying expensive treatment for a person who will always require care, what motivation is there for them to continue paying for treatment? If you give hospitals that are overfilled and understaffed the opportunity to get rid of that chronic patient who is always in and out of the hospital, do you really not think they won't be forced financially into suggesting suicide as an option? If you give society at large, the chance to decrease it's tax

burden by eliminating the most expensive citizens, are they not going to jump at the chance? When it came to my son's life, the hospitals might have saved his life but they did so reluctantly. I can only imagine what the doctors and nurses would have said to me if legally there had been an option for physician assisted suicide. The fact that codified into law, was the option to end life, would have only given them more justification to add more pressure to force us to end his life. The hospital couldn't do it back then without our consent because we were lucky and had good insurance that willing paid our bills. I am fearful for those disabled who chronically end up in the hospital and have poor insurance, once this bill is passed. What protection will they have?

Sincerely,

Holly Opalenik