

Lisa Rana
Westbrook, CT
6Mar2014
Bill # 200

Testimony in Support of SB 200

*S.B. No. 200 (RAISED) AN ACT EXPANDING HEALTH INSURANCE COVERAGE FOR SPECIALIZED FORMULA.

Insurance and Real Estate Committee

March 6, 2014

Thank you for the opportunity to testify in support of Senate Bill 200 to expand coverage of specialized formula for children with Eosinophilic Gastro-Intestinal Disease.

My name is Lisa Rana, and I am a mom of a child with EGID, his name is Ehsan Rana and he is 8 yo and has struggled with his disease since he was 1 yr old. My son was in the NICU for about 1 month after he was born for feeding reasons. Once we finally were able to bring him home, we thought he was through the worst of it, unfortunately that was only the beginning. Then began our real struggle, we had no idea how our lives would be changed forever. Ehsan was not on the growth chart, he vomited daily multiple times, and never wanted to eat. This was his new normal. I am here to tell our story in hopes of changing the outdated CT law, as well as increasing awareness of this very important health issue.

When Ehsan was diagnosed with EGID we really had no idea of what it meant, all we knew is that we struggled daily multiple times a day to try and get our son to eat and pray he would hold in what we fed him. Since he had severe food allergies on top of his EGID, we were very limited to what we could feed Ehsan. We went to a GI MDs at CCMC here in Hartford and they recommended that he needed an amino acid based medical food (Elecare), so we tried to get him the formula. I was denied by the insurance company and then appealed the decision. My goal was to get him to drink his medical food at an early age so he would get used to it (the formula is very unpalatable and has a severe aftertaste) then maybe he would not have to have surgery and a G-tube placed.

The appeal process took many months of constant documenting and contacting people at the insurance company. Each day that passed was a day that Ehsan was losing weight, and getting sicker. I was informed that I was denied and that his formula would not be covered despite all my efforts. In the same conversation as I pleaded with the woman, she stated this to me 'Maam if you just put a G-tube in your son the medical food (Elecare) would be covered' These are words I will never ever forget. I thought how unethical, so why is it that I need to have my son go through another life threatening major surgery, (he had other surgeries related to his EGID) as well as the cost of all the associated medical supplies, tubes, pumps, syringes, and tubing needed for the feeds, not to mention the psychological effects with not being a normal child. How does that make financial sense for an insurance company or families? Well unfortunately despite my daily struggle to get him to eat and hold down anything, it actually became a medical emergency to insert a G- tube into my son. I remember this day vividly, both my husband

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and I cried, this was when we truly accepted that our son has a life threatening disease that he would never outgrow.

So you ask why we are here today? If we can prevent just 1 other family or child from going through what we have for the past 8 yrs then I have been successful in outlining the daily struggles of the children and their families who are affected by this disease.

In closing it is imperative to acknowledge/recognize that EGIDs as a real and growing disease. It is a disease that could be compared with diabetes. If a diabetic child does not get there insulin they would die. Who in this present day would deny a diabetic child their insulin? The answer is no one. The same holds true for EGID and medical food. Medical food is the only treatment for EGID and therefore this should never be denied. Here in CT we are not current in our medical food/specialized formula law. We need to recognize the disease and ensure that these children are taken care of beyond 12 yo, which according to the current CT law is when coverage is no longer mandated. Therefore the age limit for medical food needs to be increased. Would we really deny children the right to live happy and healthy lives? Thank you. I can take questions.

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