



Hello! My name is Sydney Idleman, I am 27, and I am a special needs mom. My journey began with a healthy pregnancy and many beautiful and flawless sonograms. I believed by doing everything right -- eating healthy, getting regular exercise, and reducing my stress levels -- that I could protect my baby and give her the best possible start of life.

On 4-25-14, my water broke at 36.5 weeks. My labor was quick, a mere 5 hours. I didn't know that would be last, easiest 5 hours of my life. Scarlett was born on 4-26-14 at 2 am, a perfect 5lbs and 15oz bundle; however, she was gray and not breathing. The hardest 6 min of my life followed as they resuscitated her. She began to breathe and then began seizing. She suffered from HIE (Hypoxic Ischemic Encephalopathy) or "lack of oxygen". Doctors called it a fluke and said she wouldn't be able to eat by mouth and may be blind, deaf, or worse. They said the seizures might go away and they might not.

The seizures went away for a few short months. Around 6 months of age, they returned with a vengeance and continue to afflict her daily at the age of 4. We see between 10-30 seizures a day despite medical intervention. It's our normal. It shouldn't be.

My daughter is on Keppra, Clonazepam, Vimpat and Baclofen multiple times a day. She began the Ketogenic diet at age 3, and she also just received VNS surgery August of 2018 at age 4. We have exhausted our options over 4 short years.

My goal now is what it has always been: To protect my child no matter what length I must go to or what walls I must tear down for her. I, along with many other parents here today, are here knowing that we will outlive our children. This is a fear many will never know. Today is a new day for all of our children to get the much deserved chance to improve their quality of life – Claire & Lola's Law (HB 2244). We pray that this law will allow our children to experience many more years ahead. We want our children to not just live, but we want them to prosper and continue to touch the world around them in the most amazing ways that only they can. Thank you for your support of this very important bill.



Top picture: 4-26-14 ~ Scarlett & Mom
Bottom picture: Scarlett ~ Age 3