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Written Testimony
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Seymour, WI
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Hello,

First, I would like to thank you all for having me and my family here today. I am so humbled to be able to speak to you. My name is Chelsey Schaumberg, and I am from Seymour, WI, which is near Green Bay. I am many things, including a daughter, a wife, a teacher, a mother, and an advocate. The reason I am here today is to speak about the importance of protecting the pre-existing conditions clause in the ACA. This brings me to my daughter, Zoe. Zoe is my oldest, and she would tell you she is 5 ½ years old, adores the color red, loves to dance and play soccer, and is so excited about starting Kindergarten. When my husband and I found out we were pregnant with Zoe, we were thrilled! I started reading all the books, following all the rules about what I could and couldn't eat and drink. My husband and I were so excited to start our family. Everything was going according to plan. However, when I was 24 weeks pregnant, I had an ultrasound and got the news that our daughter would be born with a congenital heart defect (CHD), Transposition of the Great Arteries. Her pulmonary artery and aorta were flipped, creating a blood flow where oxygenated blood would never reach her body. Without surgical intervention, she would die. We found out we would have to deliver her at Children's Hospital of Wisconsin in Milwaukee, two hours away from our home. The hospital told us to prepare to be in the hospital for a month. This heart defect required her to have open heart surgery immediately after birth. To say we were devastated would be an understatement. All the dreams I had suddenly vanished because I didn't know if we'd be bringing her home. My normal pregnancy was gone. I had so many doctor appointments that required us to travel to Milwaukee over and over again, and I cried every time we had to go, knowing what she faced as soon as she was born. Finally, we packed up and headed down to be induced in December.

Zoe was born in December of 2012. She was rushed to the NICU immediately after delivery and was eventually transferred to the cardiac ICU. It was so hard to look at this tiny baby knowing that soon she'd be in surgery. At five days old she had her open heart surgery. It lasted about 10 hours and she fought for her life. Our surgeon, Dr. Mitchell, was amazing. I wasn't able to hold her until about five days after surgery, and that day I got her back in my arms was one of the best days of my life. We were lucky—Zoe bounced back from surgery quickly, but we saw others who were not so lucky and had to say goodbye to their babies. The doctors said Zoe was on "the fast track" and we were home after 2 ½ weeks. She had weekly appointments after we brought her home, which turned into bi weekly, then monthly, and eventually every 6 months. Now we are at yearly appointments. She will have to be monitored for the rest of her life by a cardiologist. So far, she's doing amazingly, but there are some concerns they are watching including a leaky valve and narrowing pulmonary artery. She may need future surgeries or she may not. Only time will tell.

Before Zoe—I will be honest—I never paid much attention to the availability of health care, or the concept of a “pre-existing condition”. After Zoe was born I became aware. Knowing she was protected gave me hope for her future. We were lucky—she would be able to get the health care she needed. While Zoe’s condition is rare, congenital heart defects affect about 1 out of every 100 children. It is the number one birth defect. Some of our close friends also have children with heart defects that required surgery, and these kids would also be labeled as having a pre-existing condition, just like Zoe. Taking away the pre-existing protection clause of the Affordable Care Act would devastating to us and to so many other families in this country. This protection safeguards my daughter. It allows and will allow her to have access to health insurance, to not be denied or go broke trying to get coverage. She can’t help that she was born with a heart defect. We can’t get life insurance for her so we know how that denial feels.

During your lifetime you get asked the question, “What do you want to be when your grow up?” Zoe would tell you right now that she wants to do hair, and be a doctor, and a teacher. The American Dream tells us we can be whatever we want to be. I tell Zoe she can do whatever she sets her mind to, and hope she does whatever brings her joy. I don’t want to tell her, “You can do whatever you want, as long as it’s a job that will give you health insurance because you’ll never be able to get it or afford it on your own.” As a mother, I’m pleading with you to fight to keep the pre-existing protections in the Affordable Care Act. The people who are protected by this are some of the ones who need health coverage the most. We are counting on you to safeguard that right and protect the American Dream for Zoe, and for the thousands of other people like her. Thank you.